SAVING ZACHARY: The Death and Rebirth of a Family Coping With Autism

by: Jeanne A. Brohart
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Dedication:

This book is dedicated to my son Zachary, born August 12th, 1997. On April 3rd, 2000, a pediatrician confirmed our fears. Zachary exhibited many signs of autism. It is also dedicated to my wonderful 8-year-old daughter, Anika, and my husband, Fred, who have both been God-sends throughout this ordeal. Finally, it is also dedicated to my mother, who passed away five years ago and whose words provided guidance in the treatment of a grandson she never knew. One year and a half ago, Zachary could barely utter five words, yet, today, at the age of four and three months, he loves learning on the computer, can count to 100, can read at least most words as long as he knows the phonics for each word, knows his colors and shapes (including octagon, hexagon, pentagon and trapezoid) and is beginning to speak in with basic commands and a few sentences. More importantly**,** I now knew exactly how to turn my son's frustration on and off, like a switch! As a family, we now know that Zachary will be one of the lucky ones to escape the grasp of autism and, therefore, I wanted to share our family's journey with other families who are facing this foe as well as with those in the scientific community who devote themselves to finding answers to the multi-faceted puzzle of autism.

Disclaimer:

I am not a physician, nor do I have experience in the field of medicine at all. I am simply a mother with a story to tell. Everything in this book is based on my experiences with my autistic son, Zachary. This book is not meant to be a substitute for individualized medical evaluation, advice, care, or recommended treatment from a qualified, licensed health professional. I do not recommend taking supplements, medications or implementing dietary changes without first consulting your personal physician. Each child is different and family medical history has a bearing on the care any child receives. I know my son, but I do not know my readers' children. Parents are strongly urged to consult with their child's physician prior to adopting anything suggested in this book or drawing cause/effect conclusions or inferences from it. The author, and any subsequent publisher (not yet in print via a publisher) disclaim any liability arising directly or indirectly from the use of this book, or any of the products or treatments within it. Statements made by the author about products, processes, treatment methods represent the views and opinions of the author only and in no way do they constitute a recommendation or endorsement of any product or treatment by any subsequent publisher. The author has no financial, business or personal affiliation or relationship of any kind with any of the companies mentioned in this book, but rather is a customer only, like any other. This book provides several web sites that may be of further interest to readers. The author and any subsequent publisher make no representation or warranty as to the value, accuracy or completeness of the information these sites contain, and therefore, specifically disclaim any liability for any information contained on, or omission from such referenced web sites. References to these web sites in this book are not to be viewed in any way as an endorsement of these web sites, or of the information they contain, by either the author or any subsequent publisher.

TABLE OF CONTENTS

CHAPTER 1

A Shattered Family

Two years ago, December 31st, 1999, my husband, Fred, and myself worked at Ameritech (now SBC) in the suburbs of Chicago. I oversaw three key computer applications for Ameritech's business division. As I rang in the new millennium in the basement of our suburban home, working past midnight to ensure all my areas of responsibility at work were Y2K ok, I had no idea what awaited my family in the New Year…our own personal Y2K meltdown. That February, we would experience the complete shattering of our household and the sudden death of what we had known to be our family, and with that, all our hopes and dreams…gone!

Both Fred and I held an M.A. in Finance and worked at Ameritech, the largest local telephone provider in the Midwest. Fred had been there seven years and I had been there for six. The company was undergoing massive reorganizations as it had recently been bought out by SBC. We now numbered over 200,000 employees. Impressive.

We were both doing quite well in our positions, but, ever since my mother had died of ovarian cancer three years earlier, we had made the decision that we wanted out of corporate life. Each day, we realized more and more the need to spend more time as a family. By the turn of the millennium, we had two children, Anika, age seven, and Zachary, age two. Little did we know that the preparations we were making to leave corporate life would prove so valuable to our family.

Fred worked as a product manager in Consumer Services and I worked as a manager overseeing three key computer applications in the business division of the company. Although, at first, I made more than Fred did, he moved up the corporate ladder rather quickly. He always joked about the fact that "as you get higher in corporate life, you get paid more for doing less grunt work". My workload was horrible, often requiring long evening and weekend hours. I worked with a dozen programmers and/or consultants on a daily basis. The hours were long and the headaches numerous, but I actually enjoyed what I did, tremendously, and herein lies what would become my biggest source of guilt. I was the one who loved my job. I was so wrapped up in my work, I was missing what, in retrospect, should have been so obvious.

Ameritech was a great company to work for. I cannot say anything against a company that was so good to my family and me. After all, it was because of people at Ameritech that I had been allowed to completely do my work from Canada for close to a month as I also cared for my dying mother. My work was such that I could do it at any time of the day or night, and from almost anywhere in the world, provided I had access to a phone line and a modem for my computer.

I am eternally grateful to the people at Ameritech for having had the flexibility and compassion that allowed me to be there for my bed-ridden mother when she needed me most, until she took her last breath. Granted, I did not have a backup and my job impacted payroll for sales. But, still, as I say, though it is a sad reality, "Presidents get assassinated and life goes on". Ameritech would have managed without me somehow. They were under no obligation to allow me to do my work from another country for a month. So, for what they allowed me to do, I thank them from the bottom of my heart.

Ameritech was not the problem. It was corporate America, in general, and the fact that it can and will consume your life. By the time you were home, you were lucky to see your children for an hour or two before they went to bed. When I worked in downtown Chicago, I did not even see my children in the morning since I was on a train by 6:45 a.m., before they were even up. If the day went well, I was back at 6:20 p.m. At some time during my last year at Ameritech, Fred had been kind enough to once calculate for me that I spent six weeks of my life commuting, each year. My typical commute took close to three hours out of each and every workday.

Fred's computation solidified my commitment to a lifestyle change. It prompted me to convince my immediate supervisor and my General Manager to allow me to do the same job from an Ameritech facility where Fred also worked, just fifteen minutes from home. I also pushed for more work-at-home. In the last six months I worked for Ameritech, I probably worked at home two days a week. Fred also worked at home a couple of days a week. He had been lucky enough to do that for a few years and it really helped out with the children. When I also started to work at home, the extra computers and phone lines we purchased quickly paid for themselves. Between the two of us, we came to need very little help from our old babysitter, Jennifer, who lived just four doors down. We would go to the office for important meetings only, when we "had" to be there. The problem with more work-at-home and being "out of your supervisor's view", however, was that we felt an internal pressure to "prove" we were working and therefore, did even more to maintain our work-at-home privileges. So, although I often worked at home, now, I frequently started at 6:00 a.m. and went straight into the evening hours. In spite of it all, I felt I was "there" for my children, but, I was so exhausted…and so was Fred.

Although work-at-home had seemed to be the answer to our prayers, in looking back, I can see that we only worked harder, became more tired, and spent less quality time with our children. We were in a whirlwind situation, constantly on the go. We had five phone lines on eight various jack combinations to allow for the most flexibility possible in our home office. I could be working up to three computers at once, reading email on one, testing applications on another and looking up data for sales or customers on yet a third... all while on a conference call... never taking a minute to look at what was staring us in the face. For the most part, while we worked, Zachary was the perfect two year old, playing quietly by himself.

With no debts and enough saved up to hold us over for some time because we had saved every bonus and as much of our salaries as possible for six to seven years, Fred and I realized we were exhausted and had to pull the plug on corporate life to maintain our own sanity. We figured we could invest wisely and go from there. Little did we realize that the time was ripe for another member of our family as well. We both held an M.A. in Finance and I knew corporate America would always be around should things not work out and we had to go back.

In our minds, however, there would be no going back. Fred and I were very similar in that when we made a decision, we went with it, and moved fast. That was one thing we had absolutely hated about corporate America. It took forever for people to make a decision. It got to be the very reason I decided to quit. I hated what I had to put programmers through. Often, they had to work sixteen-hour days, for day after day after day. They had it worse than I did, but I was one of the people who had to "beat up" on them to get things done.

On January 27th, Fred and I made the decision to leave the company. It would be in the next month or two. We were not sure of the exact date, but we would start to prepare for it, looking into obtaining private health insurance, arranging for the transfer of our IRAs, etc.

With Ameritech's purchase by SBC, all business units were being reorganized. My group was already overworked, and still more was being poured on. I was in our basement when another "just do it" memo came through from my General Manager. As it was, I supported hundreds of salespeople, each of whom could come to me directly for answers to their questions, as well as several key groups within the company. I worked with Finance, Marketing, Sales and I/T on a daily basis. Fifty to one hundred incoming emails and thirty or so phone calls a day was not unusual for me. And, for most of these, I had some kind of "to do" or "investigate". I had become an "efficiency expert". I also had four people reporting to me directly and trained them constantly. One day, I had about ten minutes left before going home and I felt totally drained. I commented to my co-worker of four years that "these days were just too much". We began talking about our positions and the fact that no sane person would ever want our jobs. For fun, I counted the number of emails I had personally sent out that day...eighty-eight...and that had not included the research I had to do, meetings I had attended, calls or the emails I had received. It was just too much!

Two key persons who reported to me had been informed of my desire to leave the company about one month prior to my actual leaving. I wanted them to understand why it was so important they had a grasp of all areas of my responsibility as well as their own. In addition, I had advised my key programmers approximately one month prior to my departure that I was on my way out. When yet another "just do it" memo from my General Manager came in that morning, on Friday, March 17th, 2000, I had had enough. This particular task/request clearly belonged in another group. The VP needed the information in less than a week. I was an excellent worker and even I knew that to do this well, run the necessary reports, etc. would take closer to a month. This was a critical initiative with huge legal implications and I was no fool. In the past, I had been given tasks even my division President and VP were deathly afraid to see go wrong, the implications for the company being so huge. That was it! I had had enough of corporate life. I went straight upstairs and informed Fred that I was going in that very morning to submit my resignation. We had both prepared for a long time, cleaning up most of our issues at work, just in case, but now, it was time, at least for me, to pull the plug. I wanted a lifestyle change and I wanted it now.

Knowing there was no going back, I finished cleaning up my affairs in the morning, and wrote my final memo at 12:15 p.m. My boss got it at the same time everyone else did. It simply stated that effective March 17th, 2000 (today), at 12:00 p.m., I was resigning from my position at Ameritech. I stated I would miss those I supported, but it was clearly time for me to move on. There would be no going back, no second thoughts, no persuasion to stay for more money or more help. I had sent that memo out to over one hundred people at the same time – my decision was final. “It was time for me to move on”...I had no idea how true those words would be even a week from then. Looking back, I had often told Fred that it was as though I was somehow being “pushed” by an invisible hand to quit, right then and there. After all, I had always been such a “good employee” and this was so “unlike me”. I had always planned on giving notice when I left and at times planned to give over one month, but, that particular morning, it was like there was an overwhelming force within me to quit that very day. I felt no guilt though. Those who most needed to prepare for my departure had had over a month to do so. I had cleaned up everything on my desk. It was not as if I had left the company with a mess on its hands. I had been much more responsible than most would ever be. The force within me that morning, I cannot explain, but I did it… I quit! Had I gone just one more week in that position, my life would have been very different. More than likely, I would have remained with Ameritech until “retirement”. But that was not to be, something inside told me to quit that day!

Over the weekend, Fred and I discussed our life and where we wanted it to go. He went in that Monday and submitted his resignation. He had also prepared for well over a month, cleaning up all he could prior to leaving. I think both of our bosses must have had near coronaries. This was so “unexpected” from both of us. We had both been such “good employees”. We had jobs many would have envied. There was no going back for either of us. We were spending entirely too much of our lives working and our children were not getting the attention we believed we owed them. We worked long hours for “our children”, to give them the best of everything, but we were not giving them our time and that was what they truly needed. It was not Ameritech, but rather the slow stealing of one’s life by corporate America in general, that we could no longer take. Ameritech had actually been a fantastic company to work for and I was very thankful for everything that company had done for me, such as allowing me to work from Canada for three weeks while I also tended to my mother who was terminally ill with cancer. I will never forget that. Not many companies would have done the same. We knew all corporations today demanded more and more from their employees though. We wanted a life style change, one that involved more time with our children and with each other. We had always looked at corporate America as a stepping stone, and now, it was time to take that next step and leave it all behind. I remembered writing in a small journal I kept, March 17th, 2000, I quit, March 20th, 2000, Fred quits, March 21st, 2000, new life begins. Once again, I had no idea, how true those words would soon become.

Just before quitting, in late February, Fred and I had taken a quick trip to Canada to visit family and friends. We knew we were getting close to pulling the plug on corporate America and needed some time to think. It was during that visit that my sister-in-law, Christine, took aside her brother and told him she thought our son, Zachary, showed some of the same signs her son, Andrew, had shown when he was young. Andrew had been diagnosed with Pervasive Developmental Disorder (PDD) after a long period of previous misdiagnoses. She had mentioned that Pervasive Developmental Disorder was on the same spectrum as autism. I did not know of this conversation until after we had returned home and quit our jobs. I do not know if Fred was "in denial", did not want to change our plans or if he just did not want to alarm me, but it would be March 22nd before he revealed to me this conversation had taken place.

That night, March 22nd, 2000, was a night I would never forget. The very thought that Fred saw something to what his sister was saying ignited within me a desire to prove to him and to myself that there was nothing wrong with our son.

I rarely logged onto the Internet to research anything, but that night, I did. I typed the word "autism" and got numerous "hits". I visited some of the web pages and researched the topic. I read from 8:00 p.m. until about 3:00 a.m. One site I found was that of the Defeat Autism Now (DAN) conference of 1999. I printed an article from the site, as I had done with so many others, and put it in the stack to be read later that evening. That particular article was the first one I read. As I went through the pages of this DAN article, Fred sat nearby. "Oh, my God!", I said, "Fred, a lot of the behaviors Zachary has are classic signs of autism!" I began circling those behaviors I had seen in my son… behaviors that, in the past, had been so simple to explain away. There, in front of my eyes now slowly filling with huge tears, messaging in black and white to my brain which could no longer be incredulous, were words describing symptoms and behaviors I knew to be those of my son, words that made my heart bulge so that it felt as though it was about to burst within my chest. How could this be? How could I not have seen this sooner?

We had for a year or so thought Zachary was not developing as quickly verbally as his sister had, however, we had been "reassured" by our pediatrician that boys were usually "just a little slower". We had raised our concerns on several visits to the pediatrician. He finally agreed to have Zachary undergo a hearing test, a test he passed with flying colors on October 20th, 1999. A notation from the clinic indicated the child was in a bilingual home (I was French Canadian) and that he had had several ear infections in the past. I had brushed it off. Maybe they were right; maybe he was just a little slower. I spoke to my children only in French; my husband spoke to them in English. Maybe Zachary was a little more confused with that than Anika had been. She had had numerous ear infections also, and she had turned out ok. We just needed to give Zachary a little more time - that was all. Time would prove Zachary was ok. How easy it was to have brushed it all off! Perhaps it was a subconscious defense mechanism, that mechanism of denial that so readily lurks within all of us when there was that first hint of something wrong.

But, the signs I so readily ignored, in retrospect, were clearly there. I just did not see them! I had not recognized them! Bits and pieces of the puzzle started to flow to my brain, and soon, the memories of all the signs I had discounted came together like a deluge, filling my brain and triggering now unstoppable neural activity from the constant flow of small memories I now recognized to be pieces of a larger puzzle. How could I have missed all this? How could I not have put all this together? Just in this quick reading of the DAN article, I had circled at least ten to twelve behaviors Zachary was exhibiting. Large tears flowed incessantly down my cheeks. I could barely breathe. My heart shattered into a thousand pieces.

As I continued to read further, everything made sense now...the pieces of the puzzle were there. The constant spinning of wheels or other circular objects and the staring at ceiling fans I had so easily discounted to Zachary's fascination with mechanics. The gazing at ceiling lights I had brushed off to human love of lights, which of course, went hand in hand with his constant waking, two or three times at night due to what I believed was his fear of the darkness and need to be hugged by his mother. His never-ending energy that manifested itself in constant running back and forth from one end of the house to the other, I had attributed to his being in the house most of the day. After all, our neighbors had pit bulls and rotweilers and I could not leave him outside without supervision, he was only two…. and I had to work during the day. As I continued to read, signs I would not have recognized as symptoms of autism now jumped out at me. I was overwhelmed with more emotions than I could handle - disbelief, fear, anger, distress, guilt, anxiety... hopelessness. It was now about 3:00 a.m. I had read all I could take for now. I went to bed, physically and emotionally drained and cried myself to sleep.

When I awoke in the morning, Fred was not next to me. This did not alarm me nor did I find it unusual since his farm background had never left him and he was usually up by 5:00 a.m. anyway. As I lay there in bed, I asked myself: "Was this just one of these bad dreams that seem so real? Did I just dream that Zachary had autism?" As I continued to lay there for another fifteen seconds or so, the atrophying reality set in, I had not dreamed it…my son had autism! I could not move a single muscle. Only my shattered heart pounded within my chest. The function was there but its life had been sucked out of my body. I was but a shell... a body without life. All the hopes, the dreams, for my son, for my family, for myself…gone! The person I was yesterday died and this hopeless, joyless person had taken her place. The tears flowed, again.

Anika entered the room and saw that I was crying. In her sweet voice, she asked me what was wrong. I told her that her brother was very ill. She looked at me, perplexed and said that she had just seen him upstairs, playing in his bed and that he must be ok now. I tried to explain to her that this was a sickness that was hard to see; after all, I myself had not seen it until just now.

Fred and I took the following week or so to read all we could about autism, discuss what to do, and to grieve. I got dressed that first morning and went to the nearest pharmacy. One of the articles I had read the night before stated that cod liver oil was supposed to help autistic children because it contains natural vitamin A. The article stated that natural vitamin A helped reduce "side glances" so often exhibited by autistic children, a symptom Zachary exhibited, a sign I had failed to recognize for what it truly was. As I sat in my car, waiting for the pharmacy to open, I cried. Ten minutes later, I went in, got the cod liver oil and went back home. I lived only two blocks away but it was difficult for me to drive the short distance, my mind so obviously not on driving; I unintentionally cut off another driver, my eyes were so filled with tears that I had not seen him. Although I had died inside, I had to do what I could for my son, and I had to start right away. I painfully felt my internal death, my shattered heart and cried each and every day and night for the next ninety days. As much as I wanted to be strong in front of my daughter, it just was not within me. I could not hold back the tears. My daughter tried to console me. Fred cried in private. He wanted to appear strong not only for me, but for our daughter also. There were many, many times though, I saw he, too, had been crying.

We told Anika that Zachary had something called autism. It was difficult for her to understand. To her, Zachary was the same he had always been. I began to explain that autism was something not easy to see, that it could take years before you realized someone had it. She asked whether or not you could "get rid of it". I explained how a few children seemed to "get saved" but that it was very rare and that many children with autism were possibly "mentally retarded" as well, meaning that they had a very low intelligence or ability to learn.

As soon as Anika learned that some children do "get saved" she told me that she would help me "save Zachary". It was then and there that I decided this would be true for our Zachary. We would do all we could to "save him" from the clutches of this terrible monster.

A week went by. We were waiting for our personal medical insurance application to be approved. We had been informed by the insurance provider that applications usually only took two weeks for approval. Fred had sent our request in quite a while ago, much longer than two weeks and we had yet to hear back from them.

It was now March 30th, 2000. Still there had been no answer from the insurance company. I could not wait any longer. We were on COBRA, a temporary health insurance. I knew Zachary's visit would be covered through that. I got up, called the pediatrician's office and asked to schedule an appointment with a new pediatrician. I requested a visit with a new, young woman pediatrician, Dr. Johnson, since the pediatrician I had had in the past had recently moved to another clinic. I informed the nurse of my suspicions and stated that I did not want one of those five or ten-minute visits, but rather thirty to forty-five minutes to discuss my son's situation. The visit was scheduled for April 3rd, 2000.

CHAPTER 2

The Confirmed Diagnosis

That week, on March 28th, 2000, Zachary had returned my butterfly kisses as I changed his diaper. He found this very funny. I recalled a class I had taken over fifteen years ago - Abnormal Psychology. At that time, autism was attributed to the lack of bonding between a mother and a child, the old "cold mother" syndrome. I remembered, back then, being appalled by the fact that a mother could be so cold to her child that the child could spend hours in a corner just "rocking" himself/herself. I had found the whole subject repulsive. It was as though I did not even want to hear about something so horrible. I remembered sitting in that class and thinking that would be something I would never live through. I would love my children. Yet, here I was, years later, facing this very disorder. The difference was that this **<u>was happening to me</u>** and I knew I loved my son, as much as I loved my daughter and that the "cold mother" syndrome was a bunch of crap. Those butterfly kisses he had found so funny told me there was still a little person within him, a little person who loved me as much as I loved him. My heart clung to those little butterfly kisses...within these kisses was my ever so tiny and fragile glimmer of hope. I had not lost him, not yet!

As we prepared to meet with the pediatrician, Fred and I intensely researched autism. From 7:00 a.m. to 3:00 a.m., almost every day for the next two weeks, we read absolutely all we could on autism. We ordered books via the Internet, to be delivered overnight, and devoured them the next day as we sought to satiate ourselves with knowledge about this disorder. Between the two of us, we had read over twelve books by the time we were ready to meet with Dr. Johnson and had poured over countless articles on the Internet.

Many articles we had read as well as a most valuable book, **<u>Unraveling the Mysteries of Autism and Pervasive Developmental Disorder</u>**, by Karyn Seroussi, published in March of 2000 (talk about timing) indicated what appeared to be a strong link between autism and diet.

I spent the better part of the evening on March 29th at a health food store in the suburbs of Chicago. Author after author seemed to believe that autistic children could not digest gluten and dairy proteins. I have to be honest, I had never heard the words "gluten" or "casein" before I began researching autism and I considered myself to be a very well educated person, having two undergraduate degrees (one in Psychology and one in Finance) as well as a Masters of Arts in Finance. I had also taken close to two years of graduate work in Psychology and Business Writing. So, with close to ten years of university, how could it be that I had never even heard of these things called "gluten" and "casein"? Fred had heard of them though. He had a background in agriculture.

At first, it seemed simple enough; "gluten" was something in almost every grain, wheat, barley, oats, etc. OK, I could deal with that…. so he could not have "gluten"... and "casein" was a "dairy protein". I would just go to this special food store and buy foods that did not contain these things and go from there.

As things would go, it would not be that simple. I spent over four hours in the store reading labels only to find out that the great majority of foods, he could **<u>not</u>** have. Almost everything contained dairy or a gluten containing grain he could not eat. In researching autism there were names of products I had learned needed to be avoided. These were words like: **<u>Wheat, Oats, Barley, any "gluten containing product", Casein (another word for "dairy protein"), Whey (the liquid part of milk), Malt, Lactose, Milk Solids (or any product with the word "milk" in it). Artificial Flavorings and Food Colorings or Preservatives (nitrates and nitrites, etc.) were also to be avoided</u>**. And then, there was this thing with phenols Karyn Seroussi had also mentioned in her book. I had found that section too short when I first read it. As I scanned parts of her book as I prepared to write this book, I noticed she had mentioned one example, in particular, where a little girl had eaten bananas and had had a very adverse reaction. **<u>Foods high in phenols included bananas, apples, tomatoes and raisins</u>**.

For now, I knew for a fact the main things were the dairy and the gluten. I would avoid the high phenol foods also. As I very slowly worked my way through the aisles of the store, I very quickly came to realize just how hard this diet thing was going to be.

I came out of the store with a few things I knew Zachary could eat: rice products, organic French fries, uncured meats, etc. I had enough to meet his nutritional needs for that week. I would work more on Zachary's diet in a week or so. The food was one thing, but, before my battle could really begin, I had to gather as much data as possible to plan my strategy. I began with the visit to the pediatrician on April 3r^{d,} 2000. First, I had to confirm my suspicions. Armed with my DAN article that outlined many of the symptoms of autism, most of which I had circled in red because Zachary displayed these behaviors, I entered the doctor's office. The article I had found on autism was approximately twelve pages long. I went through all of the pages with the pediatrician, showing her the circled items. She sat there, taking notes, inputting them into Zachary's file, every once in a while, looking at Zachary who was busy spinning a toy on the floor and basically kept to himself and never looked our way. As I finished going through the article, I again, broke out in tears and said in a quivering voice: "So, do I have a reason to be concerned"? "Yes", she answered in a soft, gentle voice, "you do". There was that inner feeling of death again, only this time, there was also anger that my previous pediatrician had missed this. Had **<u>he</u>** not notice that Zachary's ears and cheeks were always red? Fred and I did not realize these were signs of food intolerances, but should **<u>he</u>** not have known? Should **<u>he</u>** not have mentioned something? Perhaps I was looking for someone to blame, someone other than myself because I missed so many signs. Blaming someone else was not going to change the situation but I felt betrayed by the medical profession. After all, I basically had to diagnose my own child. How long would Zachary's problem have gone "unnoticed" had Fred and I not figured it out for ourselves? Along with the anger, there was also relief in knowing that my suspicions had been confirmed by a medical professional, that someone finally saw what Fred and I saw. I could now plan my attack on this disorder. I needed to focus on **"saving Zachary",** a phrase/task that would become paramount in our home.

By the end of April, Fred and I spent literally hundreds of hours researching the subject of autism. It was all we did, day and night… read, read, read. Forget the housework and other trivial matters. We were starting the battle to save the life of our son and time was of the essence. Reading breaks were spent hugging Anika and Zachary and caring for their basic needs. I hugged my children differently now. I cherished each of Anika's sweet gazes and wondered what would become of my son.

Zachary had always been the "perfect baby", he "never cried"… words I had written in my journal soon after he was born, words I once treasured as sweet memories of my perfect baby now haunted me to the deepest of my inner being. My perfect baby had been replaced by a very vulnerable, and sick child. How could this have happened? I thought back, looking for answers.

CHAPTER 3

Zachary's Birth

Zachary was my second child and his birth was a very fast one. As his birth neared, I limited myself to work-at-home. I was not going to take any chance of going into labor on some commuter train. I was on a conference call with approximately ten other people on August 12, 1997. The call lasted from 8:00 to 9:40 am. During the call, I experienced a very slight amount of back pain, but nothing worse than sitting in a bad position would do to anyone. When the call ended, I got up to go to the bathroom across the hall. As soon as I got up, I felt a little bit of "leakage" and wondered if my water bag had burst or if I was simply losing control of my bodily functions. With my first child, the water bag had been "broken" by the doctor and so I never really knew what it felt like to have it break naturally. I had heard the stories of women having a lot of water flow embarrassingly down their legs but what I felt was no more than a couple of tablespoons of liquid and hence, I really did not think my water bag had burst. I would later learn that it had, but that Zachary's head held back all of the fluid. As I took my first few steps toward the bathroom, I felt intense contractions. Fred had stayed home that day. I called for him and we both agreed I should go to the hospital.

Given the intensity of my contractions, we left the house by 10:30 a.m. and were in the emergency room by 10:50 a.m. I had never seen Fred drive like such a maniac. The hospital was a good fifteen minutes away and I was sure he thought I was going to have the baby in the car. When we got to the hospital, he left our car right in front of the emergency entrance. He wanted to go back and move it but I insisted he would miss the birth of his child if he went to move the car. We lived in the suburbs of Chicago and there were about ten women in labor in that hospital on that morning. A large white board in the hallway informed doctors of the "stages" the various women were in. On the board was the patients' last names, room numbers, stages, etc. The woman farthest along in her labor was at the top of the list. When I was admitted, my name was placed at the bottom of the board. Within a few minutes, I had jumped to second place, then to first and the nurse was frantically calling for a doctor who was, it seemed to me, nowhere to be found.

With my first child, I had been much better at dealing with the pain. This time, I felt like a "pain wimp". I had wanted drugs to ease my discomfort. Unfortunately, I was already fully dilated and ready to push, and therefore, could not be given any medication. The doctor finally arrived. A few minutes into my pushing, the nurse came up to me and said, "Honey, you're going to have to push harder now". Her tone did not relay any sense of urgency, but Fred would later tell me he was getting a little worried that the baby was not coming out as quickly as he perceived the doctor would have liked. Zachary had very large shoulders and it was very difficult for me to give birth to him. He was finally born at 11:11 a.m., a beautiful 9-pound boy. I was stunned. I was so sure this one was going to be a girl, too. I think I had even convinced Fred of that also…after all, a woman can often "sense" these things, right? Fred and I looked at each other in disbelief, almost confusion, when we saw it was a boy, but, we were very happy at the surprise…it just took us a minute or two to get over the fact that this baby was not another girl. With our daughter, Anika, the first question I asked after she was born was “when do I eat?” with Zachary, I was so tired, it was, “when can I get some sleep?”

Soon, I was in my room. The nurse came in and asked if they could give Zachary some formula of some kind since he was a little low on sugar, at least that was what I thought she had said. Anyway, I did not recall much of what happened for the next two hours, I was out cold. I awoke to the tapping on my arm by a nurse who said to me: “You’re going to have to take your son now, he’s been screaming for two hours straight and we can not take it anymore”.

I gladly took my new baby. My room was dark. I kissed him a few times. He fell asleep within what seemed to be less than two minutes. I kept Zachary with me almost the entire time until my release from the hospital. He cried a little, but, for the most part, he was a perfect baby. Had there been signs of Zachary’s problem since day one? I wondered?

CHAPTER 4

Our "New" Health Insurance

Shortly after our visit of April 3rd to discuss Zachary's condition with a new pediatrician, we received a call from the health insurance company that had been sitting on our application. They were asking what the April 3rd visit had been about. I answered, honestly, that I suspected Zachary had autism and that I needed to discuss it with a pediatrician. Later, they called again and stated there was "a problem"... that they could not cover Zachary but that they would be willing to cover Fred, Anika and I. The representative stated that they "would not touch Zachary for fifteen years!" We inquired about coverage with a $5,000.00 deductible for Zachary...just looking to cover "catastrophic" losses like a transplant or something. Little did we realize how even $5,000.00 goes nowhere in today's medical "machine". Still, they refused to cover Zachary at all!

I could not believe it...but then I did. After all, insurance companies were in the business to make money. When you wanted the real answer to something, unfortunately, in today's society, look no further than the all mighty dollar! Fred and I decided that if this company refused to cover Zachary, the entire family would no longer require its services. The appalling thing was that later, this same company would again solicit our business... that was, everyone except Zachary. Sure, "we will insure you", I thought to myself, "as long as you were young AND healthy!". Again, we informed them we were not interested in their services. In our hearts, we could not ethically pay premiums to a company that refused to insure our son. Like so many American families, we decided to go without insurance. Sure, we had had "insurance" in the past, but, you get what you pay for...a small co-payment of $10.00 buys you exactly that... a $10.00 visit...with "care" worth about the same. After all, Zachary had been to the clinic or to immediate care on numerous occasions, yet, all the signs were "missed"...how could that be?

CHAPTER 5

Doubts....

Having outlined the signs my own son exhibited, and reading through my son's medical files as I prepared to write this book, I now looked back and wondered…how could so many signs have been missed…and by so many?

Interestingly, Fred had told me that about a year earlier, when he had suspected something was wrong with Zachary, he had actually mentioned the word "autism" during a couple of visits to the pediatrician, visits I had not gone to since I worked in downtown Chicago and the pediatrician was only a block or so from Fred's work location. He told me how on one occasion, the pediatrician just gave him a funny look and just kept talking, as if the "word" had not even been mentioned. He did not acknowledge the word "autism" had even been uttered, did not go into any conversation about autism, did not come out and say: "what makes you think he is autistic?"... nor did he say: "no, he does not show any signs of autism from what I can see in his chart" – nothing, not a word!!! On another visit, again Fred had raised concerns. He was "reassured" that "boys were slower" and that there probably was nothing to worry about. I requested a copy of Zachary's medical records. NOWHERE in Zachary's entire medical file was the term "autism" noted. I would think that any COMPETENT doctor would have made a notation to that effect if a parent even suggested a possibility of autism existed. But, no....NOTHING!!!... and Zachary's FIRST BLOOD TEST (the one taken at his birth) WASN'T THERE EITHER!!!

Sadly, I truly wondered whether Zachary's clinic suspected autism but wanted to force our family to go somewhere else because we were "costing them too much money". After all, they were part of this PPO/HMO program and only made so much money per child each year, regardless of whether or not they saw the child. The fewer times they saw a child, the less testing needed, the more profitable that child was for the clinic. Zachary was always there. Had they seen the problem but just never admitted it? I truly wondered. Fred was probably right. When you wanted the "real answer", look for how the "almighty buck" fit in and you would probably find it. That, in too many situations in life, was what it usually boiled down to. Doctors were expected to turn a profit… their employers have stockholders and kids like Zachary did not bring in the bucks, they just showed up on the expense side of the balance sheet.

The fact was that Zachary's chart, when taken altogether, screamed of signs of autism. Instead, the pediatrician successfully lulled Fred and me into thinking there was nothing wrong, that boys were often just slower. You would think that any competent doctor would have at least documented the fact that a parent suspected autism and requested screening for autism be done. After all, there was a developmental test that could be given to eighteen month olds to screen for such problems.

Yet, that screening was not offered... nor was it even mentioned. Special tests and "all that good stuff" would obviously have further diminished clinic profits. I only learned about that test after **we** had figured out Zachary was autistic and we researched autism on our own.

As we began to question things, our suspicions were further aroused. Certain things in both Zachary and Anika's medical records confused both Fred and me as we read their files. And, why had it taken three weeks to get a copy of our children's records? The clinic's answer to us when questioned about this was that they were "understaffed", yet, when we offered to come in and photocopy the records ourselves, they said that was not allowed. Why not? They were my children's records. I had a right to see them. And if they were so understaffed, why could I not come and copy them myself?

Although I had no way of proving this, it was my suspicion that the reason it took three weeks to obtain Zachary's file was because the clinic went through the file before it was released to a parent to remove any "damaging" information or "white wash" the file as I called it. When we received the file, nowhere in it was there any mention of Fred using the word "autism" in his questioning the pediatrician. There was one comment in the file that Fred and I both caught and neither of us remembered such a discussion even taking place. It was a comment to the effect that the pediatrician had asked us to "count" Zachary's words and get back to him in a few weeks. Later in the file, there was a comment that we "never got back to the pediatrician" with the count. Fred and I absolutely did not ever remember such a conversation...and, had one occurred, why would the pediatrician not have brought it up again and again with each passing visit? "Patient File White-Washing" was the only answer I could come up with. That conversation never took place. Given our concerns, we certainly would have remembered it!

But again, how could I prove any of this? I could not, nor did I have the time or the energy to do that. Looking to blame someone, to scream "incompetence" or to yell to the pediatricians "you knew it all along" was not going to change my situation. I had to focus on Zachary. I learned from this experience though. In the future, I would NEVER take it for granted that my children's medical records accurately reflected my concerns. **I would request copies of records whenever something critical came up.** That is the lesson to all parents here.

If a doctor were not willing to provide my child's file within a few days, I would go with another doctor. It did not take three weeks to run off a file copy…not unless someone had to "review it" prior to sending it on to a parent!

As I researched autism on the Internet, I found more stories of parents who discovered the same situation for their children when it came to the notation of parents' concerns in a child's records. Parents whose healthy children had died within ten to thirty six hours of receiving vaccinations, for example, were told there was no connection and nothing had been recorded about the parents' suspicions of a "link" in the child's records. Parents whose children seemed to suffer all kinds of adverse effects after vaccinations were told that there was no connection. Parents whose perfectly healthy children had died up to ten days after receiving vaccinations and who had seen rashes on their children shortly after the shots were told by medical examiners their children died from "undetermined causes". Parents whose child had died at nine weeks of age received autopsy reports showing their child to be only five weeks of age (thus, the child would have received fewer vaccinations, at least in theory). Parents whose children had died from what they believed were causes related to vaccinations who were told their children had died from SIDS. The Internet was polluted with such tragic stories.

Of those parents whose children were diagnosed with autism, many felt that the symptoms surfaced right around the time of vaccinations, some within days, others within a week or two. I had never believed that vaccinations were the actual cause of Zachary's autism, but perhaps, for some of these children, they were. I had always believed Zachary must have had a genetic predisposition to autism, but I certainly understood the suspicions of other parents.

I did more reading on vaccinations, in general, and I found something very troubling. **The "rubella" part of the MMR2 (Measles, Mumps, Rubella) vaccine a child received around the age of eighteen months was made from the cells of an aborted fetus, a strain of cells that had been kept alive in labs for over thirty five years.** The child from whom the cells were taken to produce the "rubella" vaccine had been aborted in 1964. I could not believe what I was reading. No one had EVER informed me of this. Did people even realize this?

I called the manufacturer of the MMR2 vaccine at their National Service Center (800-672-6372) on November 29th, 2001 and asked them to confirm this information... Merck's Service Center did that...they confirmed this was indeed true. I asked that the information on the MMR2 (the current vaccine given to children) be sent to me in writing. In addition, I asked how long this particular vaccine had been in production. **The representative stated that MMR1 (the first form of the vaccine) had stopped being produced in 1981, twenty years ago!** The second, MMR2 had come out after that. It was recommended the vaccine be given to children ages twelve to fifteen months and again prior to entering elementary school. I asked if the **vaccine was available in "single doses"** so that parents did not have to give all three (measles, mumps and rubella) to their child at once. I was informed that the vaccines could be given in single doses but that currently, those supplies had been depleted and had to be re-stocked. The representative could not tell me when the "single dose" would again be available nor could he tell me why doctors did not even mention the vaccine was available in three doses. When I inquired as to what had changed in the list of ingredients between the MMR1 and MMR2, nothing was mentioned about the "human cell" factor of the "rubella" part of the MMR2. Yet, on the Internet I found several references to the fact that the MMR vaccine (including the "rubella part") had previously been made from chicken cells. I asked for a list of ingredients for the old MMR vaccine but was told that it had been out of production for so long, that the list was no longer available!

Interestingly, the new **smallpox vaccine, made by another company, was also now made from an aborted human child (it used to be made from calf cells)... and the government was planning on possibly making it mandatory (they are still debating that)**! It was also my understanding from having researched this also on the Internet that little research on humans had been done with regard to the new smallpox vaccine. There was recently talk of having a smallpox vaccine made of non-human cells. **If two versions of the smallpox vaccine were eventually made, one would have to know to ask for either the "human cell based" or "non-human cell based" (if available) vaccine**. Morally, I must admit that I had a big issue with not being told that a vaccine came from the cells of an aborted fetus. I guess it was like everything else... “buyer beware”!

For those who cared to read more about the subject of vaccinations, their unproven effectiveness, etc., a valuable book on the subject was that of Dr. Neil Z. Miller, *Vaccines: Are they Really Safe and Effective?* New Atlantean Press, P.O. Box 9638, Santa Fe, NM 87504.

Needless to say, there were literally hundreds of web sites on the subjects of autism, learning difficulties and vaccinations on the Internet.

My intent in this book was not to go into every theory as to the causes of autism, but rather, to make people aware of some of the very critical issues surrounding this illness.

CHAPTER 6

Signs So Easily Missed Or Dismissed...

Having researched autism intensely, Fred and I saw that there was a great deal of debate as to what actually caused autism. Everything from vaccinations to genetic predisposition and neural abnormalities had been hypothesized. It was not the intent of this book to debate this issue but rather to simply help parents spot possible warning signs, help further scientific study and give an account of how one family dealt with this disorder.

As each day passed and we learned to deal with the upheaval autism can bring to a family, I looked back and realized that the difficulty in diagnosing autism in its earliest stages lied in the fact that **many signs of this disorder were so easily missed or dismissed** by parents, family, friends, and healthcare professionals rather than seen for what they truly were, early warnings of a deep, underlying problem.

The rest of this chapter provides an account of the various behaviors that were exhibited by our son, Zachary. Although this list is in no way to be considered all-inclusive of all possible signs/symptoms of autism, it does provide some key signs. Parents need to learn to trust their judgment. If something in your child's behavior "looks odd", take a closer look, do not be lulled into a false sense of security. If only I had known what to look for.

Constant Crying Under The Nursery Heat Lamps

My nap of two hours after Zachary's birth was brought to a rather unusual end. I awoke to a nurse tapping on my arm and saying, "you're going to have to take your son now, he's been screaming for two hours straight and we can not take it anymore". My first thought was, "you idiot, why did you let him cry that long, you should have come and woke me right away", but I did not say anything, not wanting to upset the person who cared for my son while he was in the nursery. As soon as I took Zachary into my dark room, he fell asleep within a couple of minutes. I kept him with me pretty well until I was discharged the next day. He slept almost the entire time, although looking back, I can recall that after feedings, he had a hard time actually falling asleep and I had to walk around with him to calm him down.

Perhaps the first indication we should have had that something was not right was the fact that **for the first two hours after his birth, Zachary cried non-stop**. Looking back, I guess that should have been a sign to any parent or healthcare professional that something was wrong. Did not the fact that a newborn cried for two hours non-stop in itself seem very abnormal? Almost every newborn I had ever seen just slept in the first few hours after birth. Given that so many autistic children have hypersensitive senses, I have often wondered if it was the heat lamps he was placed under at birth in order to regulate his body temperature that caused him to cry incessantly the first two hours of his life. After all, he did fall asleep right away when he was brought into my room, a dark, nice, cozy place to sleep. Of course, at the time, who would have thought there was anything wrong? Who would want to even think there was anything wrong with such a beautiful baby boy? Certainly, not his parents! I was so tired from the whole birth itself I did not even think about such possibilities. Even as I look back today, how could I have seen that Zachary was hypersensitive to the heat or light from the heat lamps? A parent suggesting such a thing, even today, would surely be viewed as "over-reacting" or "crazy".

The Perfect/Horrible Baby Syndrome

In the journal I kept of my children as they grew up, words I once wrote as cherished memories now came back to haunt me. "Zachary is the perfect baby", I once wrote. He never cried, never complained, loved to play by himself. I remembered when he was first born, how I would always say to myself, "he must be up from his nap by now", and I would have to go check to see if he was up because he never cried out for me to come and get him. Whenever he awoke, he just stayed in his bed, perfectly content to be alone. When I returned to work, five months after he was born, Zachary went to the babysitter's, Jennifer, for the first time. Even she stated that Zachary was such a good baby, the easiest she had ever cared for, that he was always content to just play by himself in the crib. Little did either of us realize that this was one of the first signs of autism manifesting itself.

Although Zachary was the "perfect baby" I have come to learn that the opposite can also be true, that a child can be an "absolute monster" also. It just depended "which one" you got. Of course, maybe the "absolute monster" was just a manifestation of a more severe case of autism. Who knows? This, like the "heat lamps" was obviously, again, not something I could easily prove or disprove…and who complains to a pediatrician about a "perfect baby", anyway?

The Loner Syndrome/Lack of Social Skills

Children who suffered from developmental disabilities such as autism, I had read, often appeared to be "loners". They preferred staying in their own private space by themselves to interacting with other family members or other children. I remembered how Zachary used to stay in his own corner in our basement, "playing" with a few things, quietly, while Fred, Anika and I watched television after a long day. I did not ever remember him jumping up on us like Anika used to do. He just seemed to always be **"busy", by himself**. He never showed much interest in anyone. Of course, Fred and I were always so exhausted from the demands of corporate life that, again, we did not question this behavior. After all, he was such a "perfect child". Another behavior so easily missed or dismissed.

Does not Like to Look At Self In Mirror

Not only did Zachary not show interest in those around him, he also showed no interest in himself. On several occasions, I had tried to show him his reflection in the mirror and he had simply turned away. If I tried to prompt him to look, he would resist even more. He did not want to see himself nor did he show that amazement children have when they first realize "that is me" in the mirror. I just thought he was "afraid" of it and still too young to understand that was him looking back. I had completely forgotten about this particular behavior. It was only as I began to write this book that I remembered this "problem with a mirror". I had not tried to make him look at himself for a long time. I had, again, overlooked what may have been one of the first signs of autism.

Inappropriate Play

It was now so easy to see that Zachary had so many symptoms of autism. He used to "play" by himself, or at least that was what we had convinced ourselves he was doing. He used to love tipping his cars and trucks over to spin the wheels. He could do that for a couple of hours at a time, placing an object in the center of the wheels and spinning them until the objects went flying off. He found that absolutely fascinating. He found ways of spinning almost anything. We used to joke that he would one day become a mechanical engineer. He was "just interested in mechanics or physics", we thought. Of course, in retrospect, that again was a symptom easily explained away, one of those, "he will grow out of it" behaviors. Fred's sister had a son, now eleven, who used to love to play with vacuum cleaners. He would spend hours playing with the apparatus. I remembered how she joked with us when he was just two or three that he would grow up to be a vacuum salesman.

Now, I knew that something as simple as finding yourself joking about a child's potential future occupation could be a hint of a bigger underlying problem...that it could be more than simple fascination!

Zachary played for hours if we let him, doing basically the same thing over and over but we did not know to question these behaviors. In looking back, even attempts at distracting him and making him do something else were rejected. He always wanted to go back to his intriguing activity.

Zachary's attraction to his toys was not a normal one. He was not pushing his cars/trucks around. He just tipped them over to look at their spinning wheels. His play was not "appropriate" for most toys. Zachary had **never had any attachment to a stuffed animal of any kind and neither did he have a favorite blanket as so many normal children did**. I once had a parent in a playground tell me that his child used to take plastic lids off containers and just fling them with his wrist and make them come rolling back toward him along the floor, and that he could do this for hours. As I spoke to this parent in the park, Zachary was playing in the sand, filling a bucket and dumping it out, filling and dumping out, filling and dumping out…never really doing anything else. I went over to show him how to let the grains of sand run between his fingers and fall to the ground. That just gave him one more fascinating behavior to use for hours on end. In the bathtub, Zachary performed the same behavior with water, taking some water in his hands and then letting it flow through his fingers, over and over. I remembered how, before we realized what was really wrong with Zachary, Fred told me he read somewhere that on average a child may spend up to forty-five hours experimenting with "volume or water displacement". That may be so, but if Zachary was allowed to, he could do all that "experimenting" in a matter of a few days.

The Tumbleweed

Zachary loved to roll or rock on the floor, so much so that Fred affectionately called him his little "tumbleweed". In looking back, I wondered if this rocking motion and the "vertigo" sensation it surely created was another early sign of autism. This, too - just another suspicion I had as I tried to piece together the puzzle of autism.

Focus

Zachary's focus on a particular activity was amazing. He could be "entertained" by one activity for a long time, hours actually. Of course, I had read that ability to stay focused was a sign of higher intelligence…so, let him focus on what he was doing, right? Wrong! Most young children get bored rather quickly by the same activity and want to move on. Again, we had "explained it away"…he was just "really focused, really intelligent".

A World of "Order"

To Zachary, all **things had their specific place and there had to be order in his world**. Anything out of order was not tolerated. Furthermore, things had to be done his way or not at all. A simple thing such as stacking blocks had to be "just so" or the blocks would go flying as he burst violently out of control and swung his arms to scatter the blocks. Zachary took crayons and lined them up perfectly, one next to the other, the tips and bottoms perfectly aligned with one another. If the crayons were of different sizes, he would attempt first to align them at the tips, then, seeing that the bottoms were not aligned, he tried to align them at the bottom. Seeing that the tips were then "out of place" would spark the frustration and violent outbursts. It just got worse the more he tried. He would never attempt to draw with the crayons, just line them up. If lining them up tip-to-tip or bottom-to-bottom did not work, he lined them up in a long line, the tip of one touching the bottom of the previous crayon, until there were none left.

He did the same activity with other toys as well, lining up cars, trucks, Lego blocks, food cans, etc. The rolling of up to twenty side by side food cans across my kitchen floor and living room was a regular occurrence. Zachary would peel the labels off food cans if given the opportunity. After the removal of about twenty-five food can labels in one sitting, I ended up putting a hook on the pantry door so that he could not get to the cans. The days were long enough without having to guess what was for dinner and the putting of cat food cans into the pantry was no longer allowed. Feeding the cat was Anika's job, and the whole idea of opening one of those cans by mistake while attempting to gather something up for dinner grossed me out completely. I basically wanted nothing to do with any "pet duties". Anika wanted the animals (we later got a dog as well), and any new food cans were immediately marked with a big black permanent marker "x" on the top of the can and placed into a special storage area immediately upon coming into the house.

For Zachary, labels were not "part" of the can; someone had put them there, so he took them off. It was the same thing for the labels on the crayons. He peeled those off too. He removed the labels on my computer diskettes, the inventory tag on my computer, etc. Anything that "did not belong", any sticker, any label, on a toy, on an appliance, on anything, was promptly removed. In addition to peeling labels and stickers off, Zachary was a master stacker. He stacked blocks, cans, puzzle pieces, videos, CDs, plastic containers, etc. and the stacks had to be perfectly aligned. To Zachary, the world always had to be in a specific, and perfect order. If he hurt himself on the finger, for example, and a scab formed as the skin tried to heal itself, Zachary would incessantly "pick at it" and make it much worse since to him, the scab "did not belong there", nor did a bandage. It made healing any injury, no matter how trivial, much more difficult. I applied ointments at night, as he slept. This need for order made most simple household tasks difficult. To Zachary, all clothes belonged in the same laundry basket. So, if a basket of clean clothes and a basket of dirty clothes were both in the house, he retrieved them and "put the clothes together". When I did laundry, he dragged clean clothes out and attempted to toss them in the washing machine along with the dirty clothes. Likewise, all dishes belonged in the dishwasher (clean and dirty alike). If "perfect order did not reign" in his world, if I tried to prevent him from putting clean clothes in the washing machine, if the stack of blocks, or cans, or videos got too high, and tipped over, or could not be perfectly aligned, he got very upset and would throw himself back on the floor, often hitting his head. That was the most troubling behavior to deal with.

Tantrums/Violent Outbursts

Zachary's focus on any activity was intense and any disruption or change in what he was doing that was initiated by another person, a pet or by the laws of physics would set him off into a violent outburst of frustration. Most times, those outbursts involved his throwing himself back on the floor (or the ground if we were outside) and kicking his legs or flinging his arms hard onto the floor. Having earned a degree in Psychology and done some M.A. work in Psychology also prior to switching my area of study to Finance, I knew that tantrums were a behavior that could not be rewarded. Whenever Zachary would throw himself back, even if he looked like he "hit hard", I would keep my cool and just walk over and past him, not giving him any attention for what he had done…and let me tell you, at times, that was very tough. Like any parent, it was instinct to want to see if Zachary had hurt himself badly, and ignoring this behavior was a very difficult thing to do. Yet, I knew rewarding such behavior by giving him attention would only make it much worse. I did not show any concern, frustration or anxiety on my part when he did this. As I continued this practice, over time, I found his tantrums to last less than five to ten seconds. He still had his outbursts, but, due to the lack of reward or attention, they continued to be very short. It was difficult at times, especially, for example, when we were shopping or visiting someone. People tended to look at me as though I was a freak because I was not "tending to my distressed child" or they wanted to help by comforting Zachary and I found myself in the middle of the dog food aisle at Wal-Mart barking out to a perfect stranger "do not give him any attention, I do not want you rewarding that behavior". I was often too tired to go into even a simple explanation to a stranger. As any parent of a temperamental two-year old child knows, a "difficult child" drains all your energy. I chose to focus on what I considered important, and having to account for my actions to every stranger around was never high on the priority list. It would take me a lot longer to shop if I had to explain my actions to everyone given the fact that something as simple as changing direction when in the middle of aisle could set Zachary off. I dealt with my temperamental child my own way, as any parent would. And, like any parent going through the "terrible twos", I could not wait for it to end. The "terrible twos"…I had explained away the tantrums and violent outbursts. Another sign so easily dismissed.

Arching of Back

Since I usually did not pay much attention to Zachary's tantrums and did not speak to him until he "calmed down", and I say that "relatively", of course, I really did not notice the fact that he sometimes arched his back when we tried to pick him up. It was only after I realized he was autistic that I paid more attention to his every move and truly noticed this additional characteristic/trait often seen in such children in my own son. I would not say it was something he did frequently, but it was there.

Screaming

One thing that I did remember quite vividly was the fact that Zachary screamed constantly. Over one hundred times per day, he emitted these very high-pitched, drawn out screeches. They were unbearable for both Fred and me. For a while, we ignored them, but as they became more frequent, each and every scream somehow just drained our energy. They exhausted us. We just thought it was the "terrible twos" and hoped for the day they would suddenly end, but that was not to be the case. The screams just got worse and more frequent.

Not yet suspecting autism, I thought this was a condition Anika's pediatrician had once mentioned to us when Anika was first learning to speak. With Anika, she had not screamed, she pulled her hair out. From the front, her hair looked fine. If you drew a line from one ear, across the top of her head to the other ear, however, from there on, down back to the neckline, she looked practically bald. She used to twirl her hair with her fingers and pull it out. The hairs on the entire back half of her head were no longer than maybe 1/3 of an inch or so, basically, just the "new growth" was there, everything else, she had pulled off. We were concerned about this and decided to take her to see her pediatrician. She was seventeen months old at the time. In accordance with the doctor's suggestion, I simply cut Anika's hair so short that she could no longer grasp it. Once I did that, the hair pulling completely stopped for good. The doctor had informed us that there was actually a medical term for this condition, and that it was the result of a child experiencing frustration because they are trying to communicate but are yet unable, and so, this was how they vented that frustration. I remembered how he mentioned that children who experienced this extreme frustration when unable to communicate either pull their hair or screamed.

I asked Jennifer, my babysitter, if Zachary screamed a lot at her house. She stated that he did not. When I mentioned this to the pediatrician, during one of Zachary's visits, he stated that was quite normal, that a child may only express such behaviors where he felt most comfortable. So, I figured I had had one child who pulled her hair and that I was now experiencing the other aspect of the condition, the screaming. Had I just been "lulled" back into not seeing what was truly there? Another symptom missed or dismissed.

Lack of Flexibility

I usually sat Zachary in the child seating area of the shopping cart whenever we went to the store. At times, if I took just even one step back, instead of continuing forward, that could set him off screaming. I found his lack of flexibility in changing direction impacted everything I did. Something as simple as rewinding a videotape in the VCR with the story going "backwards" on the television set caused him extreme stress. A three point turn in a car was a nightmare…and, if in a really tight spot and more than a three point turn was necessary to maneuver the vehicle, the screams in the background were deafening. At no time did this manifest itself more than when we attempted to travel to Canada to visit family. We took a looping on-ramp onto the highway. Zachary perceived it as a change in direction. He calmed down after a while, but then we had to stop for gas...another change in direction. We had to go under the highway to get to the gas station. Zachary could not take it. He screamed and screamed and simply would not stop. We had actually driven seven hours of what was normally a twelve-hour trip. Zachary had screamed for approximately three hours straight. Fred and I could no longer take it either. We turned around and went back home. What a disaster that trip had been. Funny thing though, almost as soon as we had turned around, Zachary stopped crying. He did not cry again. We made it home without so much as a whimper.

Routines

Shortly after, we tried again - we made yet another trip to Canada. It proved difficult as well. This time, we were determined to make it there, and we did without much incident. We were to stay there for about ten days. Zachary ate very little the entire week. I practically had to force feed him every day. Another horrible "vacation"! I was so glad to get back home. Upon arriving, he began eating normally by the next day. This was one of the only times I really recalled a change in routine being a problem. I did not find routine changes particularly impacted Zachary. I felt most times, he strived on change. That puzzled me since almost every book I had read on autism stated routines were necessary for these children. I really had not found that to be true for Zachary.

Staring at Lights, Ceiling Fans, Anything that Spun or Turned

Shopping was also often complicated by the fact that Zachary had an intense attraction to ceiling fans and lights. Zachary loved to look at anything that spun or turned…and ceiling fans fit the bill perfectly. He also loved to look directly at lights, almost putting himself into a trance as he glared into them. As I learned more about autism, I came to realize just how much Zachary loved to stare at lights. He would bring whatever light he could, right up to his eye. A red light seemed especially pleasing, maybe just because it was so different than the others. It was almost as though he was purposely activating specific areas of his brain, almost getting a high from the light, or at least intensely enjoying the experience it seemed to create in his brain. Not all lights were pleasing to him, however. If the sun was particularly bright on some days, that bothered him. He would squint a lot. I even purchased a small pair of sunglasses when he was three in an attempt to lessen his discomfort. I did not realize how intensely Zachary enjoyed most types of lights until after I knew he had autism and read in a Defeat Autism Now (DAN) article that autistic children often liked to stare at lights. Prior to that, I thought all children stared at ceiling fans and lights. Signs, again, so easily missed or dismissed.

Looking back, I saw how Zachary had an intense love of anything that shined, turned or spun. If we were traveling and he began to fuss, all I had to do was position the vehicle next to a huge truck and let Zachary look at the wheels turn. Since we lived in the suburbs or Chicago and almost every road had two lanes going one way, this was always an easy enough thing to do and it calmed him right down. If I then passed the truck or fell back behind it, then the trouble started again. If trucks were not available, I saw him extending his little neck to see the wheels of cars that were nearby. It took me quite a while to even realize that during travel times, he had this need to see spinning wheels. Of course, at first, like everything else, I thought nothing about it, just that he was fascinated by the "mechanics" of it all. This sign was easy to miss for a long time, after all, you look forward when you are driving, and the position of his car seat in the vehicle did not allow me to see him that well in the rear view mirror. Another sign, missed for a very long time. It was only after I realized Zachary had problems that I began to piece all these little things together.

Fascination with Captions/Credits

Zachary also preferred to see the scrolling of the captions at the end of a movie/video to the actual movie itself. He would go right up to the screen and look intensely as the captions/credits scrolled by. This was something he had not particularly done prior to being diagnosed, but it became more noticeable later.

Sideway Glances

Visual self-stimulation took on many forms for Zachary. Another way by which he seemed to almost be able to self-stimulate his brain for a "high" was through the use of "sideway glances". It was almost as if he would focus his eyes on a single object, keep them on that target and then quickly move his head as far in the opposite direction as possible without losing sight of the original target object. This appeared to give him a vertigo sensation and he loved it. When I think back, he actually did this fairly often, but, I really had not noticed the frequency until I read about "sideway glances" in a Defeat Autism Now (DAN) article on the internet after I truly realized there was "something" wrong with Zachary. Of course, prior to reading that article, I just thought he loved vertigo as much as Anika did. She would always ask her father for a "zoom-ride" as we came to call it. A "zoom-ride" simply consisted of Fred taking Anika into his arms, holding her in a position that was basically parallel to the floor and spinning her as fast as he could or as long as she could take it. It was great fun for both father and daughter. I had seen Zachary's sideway glances as a "zoom-ride" substitute. Again, I had "explained" away another symptom. These glances disappeared within a couple of weeks of being put on cod liver or flax seed oil.

Lack of Eye Contact

Lack of eye contact was perhaps one of the easiest signs to explain away. Zachary was just a very shy child, taking after his father who was also very shy when he was young. . I played with him and tried to force him to look at me, in the eyes, and at times, he did, for maybe up to 30 seconds. Over time, the glances into my eyes or anyone else's would become shorter and shorter, almost non-existent. Often, when I had thought he was looking at me, upon closer examination, I came to see that more often, he was looking at my mouth move. Once more, it was not until after I realized Zachary exhibited signs of autism that I came to view this as a symptom of a bigger, underlying problem.

Looking Through You

Not only did Zachary not like to give eye contact, but when he did, more and more it appeared to me that he was looking "**through me**" instead of at me. Normal eye contact usually involved some kind of movement of the eye, be it ever so subtle. Zachary's stares were just blank stares with, it now seemed, no movement whatsoever, just a type of fixated, focused stare. As I read more and more on autism, I came to see this as yet another symptom in my son which got worse with time...another one I had missed completely.

Sensitive Hearing/Chronic Ear Aches

Zachary had chronic ear problems as an infant/young child, so, the fact that he tugged at his ears a lot did not alarm me. I was constantly calling the pediatrician about "possible ear aches". Many times, he did have one, but many times, I would take him to the doctor's office and his ears were fine. It was always difficult to determine whether or not I should take him in, most times I did, preferring to "make sure" he was ok. Looking back in his medical records, I now saw the pattern, suspect ear ache, up at night, earache after earache after earache…up at night, up at night, up at night. It was everywhere in the medical records. The doctors should have seen this was something more than just ear aches given we were often told his ears were ok. I was sure his pediatrician and immediate care must have thought we were overly anxious parents, but I did not care. I always insisted on taking him in if I suspected he had any ear problems. Zachary never seemed to develop much of a fever when he did have earaches, so, it was very difficult for us as parents. We often just went with our "gut feeling" that something was wrong with his ears. I now wish I had known that chronic ear infections paired with doses of antibiotics were common in children with autism. I wish I had known to look for "something else" when I suspected something was wrong with his ears but that they checked out fine. Why had the doctors not figured it out? Again, perhaps they had but simply refused to admit it. A child like Zachary can be very expensive for a clinic that was part of an HMO/PPO. They had to have been losing a lot of money with him. He was constantly there.

It was only after I determined Zachary had autism that I figured out his hearing itself was somehow being impacted by his condition. I first came to that conclusion one afternoon when trying to put him down for a nap. We were lying on my bed, as we often did. I was hugging him and trying to get him to settle down and go to sleep. We lived about one half hour from O'Hare Airport. We heard jets often, but not so low that they really bothered us…at least that was what I had thought. As I laid there quietly with Zachary, he all of a sudden put both hands over his ears and looked terrified. I had never seen him do this before. About thirty seconds later, his eyes, now focused on the ceiling just above us, went from that point and followed across the entire ceiling as the jet made its way over our house. I was amazed. It was as if Zachary had heard the jet close to 30 seconds before I had and this one really bothered him. I did not know if it was due to the engine type of this particular plane, the particular sound waves it emitted, or what. I just knew this one really impacted him. That was when I truly saw how sensitive his hearing was.

I then began to notice that the sound of almost any small motor frightened him. Taking him for his first haircut was a real treat. That was just after we had figured out he had autism. Fred and I decided we would let "father" go first to show his son that getting a haircut did not hurt. As soon as the barber's clippers went on when Fred was in the chair, Zachary went into a screaming fit. I had to take him outside for a walk to calm him down. When I came back in for "his turn", I explained to the barber that Zachary had autism and told this barber who had about 30 years experience cutting hair that he had two minutes to get the job done while I held Zachary tightly between my arms. The barber completed the task in the allotted time. That was the first and last time I took my son for a professional haircut.

Nothing Hurt

The whole thing with Zachary's ears was really confusing. It was almost as if he was more sensitive to certain frequencies of sound than to the pain of infections within the ear itself. One time, the doctor told us he had a very bad infection and had actually punctured his eardrum because of it. Zachary had cried a little and was somewhat crabby but he did not appear in any pain. The only reason we even realized he had an earache was because we found a fair amount of fluid in his crib and saw it was also coming out of his ear that he was slightly tugging when he woke up one morning. How could he have such a bad infection and yet show so little discomfort? He was only ten months old. You would have thought the pain would have bothered him tremendously. We felt like horrible parents for having missed such a bad infection and were extremely concerned about permanent damage. Things were always so difficult with diagnosing earaches...when we took him in, we were told often there was none, when we did not take him in because he did not complain, that was when it had been the worse, actually puncturing his eardrum.

There were a few other things that I now looked back on and saw were also related to his autism and this characteristic of "not feeling pain" exhibited by many of these children. For example, during one of his visits to the pediatrician Zachary received three needles (vaccinations) in addition to the oral polio. When the pediatrician gave him his first needle, there was no crying. Second needle, still no crying. Third needle, still no crying. Although I was hugging and kissing him between each needle and the doctor and I joked about what a "good baby" he was, I now looked back and saw that this too was quite abnormal. At the time, though, it was so easy to explain away and have pride in our "good little man" who could tolerate pain so well. Who would have thought that this manifestation of being such a "good boy" was actually a sign of a deep underlying problem? Of course, a child **should** cry when he gets three needles in a row…what a fool I had been to have not seen this…but the doctor had not seen it either. Would not any professional consider this lack of crying when needles are given "abnormal" for such a young child?

The "nothing hurt" symptom also manifested itself while we were on a trip visiting my in-laws in Canada. Ever since I had had my children, I had never cooked using the two front burners of my stove, just as a precaution for the children. I had always said the "be careful, it was hot", like every other parent would say to warn them of the possible danger. We had a gas stove. My mother-in-law had one of the new electric stoves that had a smooth glass surface under which the elements were located. To Zachary, the difference in the appearance of the stove must have sparked his curiosity. Unfortunately, my mother-in-law, not having small children around all the time, cooked using front burners as well. Zachary went up to the stove and touched the "red light". The burners of these new stoves looked like bright, attractive, red, circular lights. Anyway, I was too far away to stop him and my mother-in-law was at the sink and had not even realized Zachary was near her. He just went up there and put his hand on the element for what seemed to me like a long time as I yelled at him from across the room. It all happened so fast. Zachary looked at his finger but he did not cry.

Again, what a "good little man" he was for "taking the pain". I quickly put his hand under cold water to stop the action of the heat from further damaging his skin. He seemed ok though, so, at the time, we did not think much about it. Zachary always appeared to be so tough. Even when he played or banged himself up, he never cried. All of these things, his insensitivity to pain, I now saw where part of his condition, yet, as a parent, it was easier and more preferable to think I had such a "tough little guy", right? The punctured eardrum, the three vaccination needles and the burned hand had happened over a long period of time and so, the sign of insensitivity to pain was easily missed or dismissed...again.

No Fear of Danger

Zachary showed basically no fear of danger. He was not afraid of water, cars, dogs, falling off of furniture, not anything. That, too, I would later read was often seen in children with autism. Again, I had not made the "connection" of this particular symptom until after his diagnosis. Another sign...completely missed.

Waking Up At Night

Although I had been easily able to nurse our daughter Anika for five months, with Zachary, it was different. It took me everything to nurse him for just three weeks. He was up practically every hour of the night for the first three weeks. I thought it was just the normal need to feed infants have every couple of hours when they are first born, but with Zachary, it was **every** hour. After three weeks I was suffering from complete exhaustion. I kept telling Fred that I just did not seem to have enough milk to ever satisfy him. Fred suggested I stop nursing. I was devastated both physically and emotionally. Why could I not do for Zachary what I had been so easily able to do for Anika? I had tried so hard and I loved him so much. What was wrong with me? I went through such an ordeal psychologically, I had such a feeling of ineptness as a mother. I now know that perhaps the problem was not with me, but with Zachary himself, even at such a young age. The problem was not simply an insatiable hunger.

After about six weeks, he slept more because I had given him a few spoonfuls of rice cereal to fill him up. During a visit to the pediatrician, I explain to the doctor that I could never satisfy his hunger and that I gave him a little rice cereal. I had given him the cereal from September 29th to October 18th. Zachary was born on August 12th, so from week six to week nine of his life. Although the portions were quite small, and he had been eating the rice cereal fine for almost three weeks, the doctor said it was too early and so I took him off the cereal until he is five months old. From week six on, Zachary slept about six hours per night. Around one and a half to two years of age, however, his sleep patterns changed drastically. He was up almost each and every night, at least once, if not twice and usually, he woke up screaming. We never knew why. It might take just a few minutes to put him back down, or it could take several hours. What I did know was that Fred and I were walking "zombies" during the day and we were totally exhausted by Zachary's, and our, abnormal sleep patterns. This lasted until Zachary was about thirty four months old. I often tried to rock him back to sleep, but, for the most part, he ended up in bed with us.

A Heightened Sense of Touch

In looking back, I would not say that Zachary hated to be touched since he did like to hug us in bed, but he definitely had problems with certain sensations on his skin. He limited the type of clothing he wore and when very stressed out, he often said, “clothes off”. I often found Zachary’s skin to be quite dry. One time, I tried to put Shepherd’s Cream on his arms and legs. This was a very gentle cream and I thought it would help moisturize him a little. He was probably about two and a half years old at the time. It was right after we had found out he had autism. All he had on was a diaper as he lay on his back on the bed in my bedroom. No sooner had I put the cream on his arms and legs that all his limbs went up in the air and just stiffened. It was as if he had rigor mortis, except that unlike a corpse, he just screamed. Fred was upstairs with Anika watching television. I yelled at him to pour a bath for Zachary right away, that I had to remove all the cream I had just put on him to settle him down. As soon as he sat in the bath and I rubbed all the cream away, he was fine. Other than that, the only other odd thing about Zachary’s sense of touch was that he seemed very cautious about touching anything new or different...that went for objects as well as food. He always approached things that were new by slightly touching them with just one finger first or by turning his entire body away from the object and refusing to touch it altogether. His problems with the sense of touch were difficult for me to understand. How can a child be in some situations so cautious about touching a new object, be so sensitive to the application of a cream on his limbs, but yet not cry after receiving three vaccination needles, or burning his hand on a hot stove? I just did not understand until I remembered the “opiate effect” of casein and gluten.

Having now read a great deal about autism, and knowing just how sensitive some children were to the sense of touch, many preferring not to be touched at all, I found myself truly blessed in the fact that my child, for the most part at least, did not mind being hugged or kissed. I knew I would have found that extremely hard to deal with and my heart went out to parents who had to deal with this heart-wrenching situation.

Lack of Pointing With Finger

Although I did not realize this until after Zachary was diagnosed as having a problem, he never pointed to anything with his fingers. I now know this to be another characteristic of autistic children, however, I completely missed this one in my own child until reading about it.

Walking on Toes

Related somewhat to Zachary’s sense of touch was the fact that he did walk on his toes. At first, it was not that obvious, but with time this symptom manifested itself more and more. It was only after he was diagnosed as having a problem that I truly noticed it.

Constant Running Back and Forth

Perhaps one of the reasons I did not see Zachary walking on his toes so much was due to the fact that he **always** seemed to be running back and forth. He did it at our house as well as at the babysitter's. I thought it was his way of burning the huge amount of energy he had and probably did not get rid of during the day. We had one huge room in our basement, forty feet long. Zachary would run from one end to the other, on and on. If he was not spinning something, he was probably running. It got to be quite frustrating for us after a long day dealing with corporate America. We did not understand where he got so much energy.

For a long time, we attributed it to the fact that he was just a busy, energetic two-year old. When Fred and I talked to people at work about it, most of them said boys were harder to raise, climbing on things, jumping all over, etc. I guess we did not think much of it because other people reassured us their kids were too energetic also.

Jumping Down the Stairs

For a while, Zachary had mastered going down stairs as one normally did, the first foot hitting the first stair, the second foot hitting the second stair and so on. As time went by, however, he lost that ability to go down stairs normally and started to jump down each stair using both feet. Gone was use of "alternate feet and alternate stair". I did not notice the "proper" behavior had disappeared until well after Zachary had been diagnosed as having a developmental problem.

Hand Flapping/Leg Banging/Body Shaking/Seizures

At first, Zachary did not exhibit much hand flapping although this was quite common in autistic children. There was some, but it was so minor, that again, it was not something I would have considered bothersome or really noticeable. When I did notice hand flapping, it was more at night, as he laid in bed. Perhaps, that is why it did not stand out so much in my mind. When it came to manual movements, he was more of a finger person during the day, than a hand flapper. He would use one finger to spin everything. If he could not spin something, he would use his finger "**as if**" he was spinning something. For example, he would take his finger and run it up and down your cheek, very fast, from the top of your cheek to the bottom and do it repetitively, "as if" he was spinning or turning something on your face. Or, he would do that same motion on your forehead, or on his own forehead, or even in the air.

This was perhaps the one motion he did the most, using one finger to "spin" or "pseudo-spin" as I called it. He also developed a sort of need to bang his legs on the bed before going to sleep. He laid there on the bed and started banging one leg after the other, up, down, up, down, hitting the bed with each leg as hard and as quickly as he could. I later wondered if perhaps those were seizures, but I did not think so, his legs went up and down quite high. I knew, however, that at puberty, many autistic children developed seizures. Zachary could do the "leg banging thing" for quite a while (at times for a half hour or so). Or, he would shake his entire body on the bed. Again, it was almost his way of releasing energy before going down for the night. I knew autistic children could have seizure. I can not say 100% that this was what he was going through. I just did not know at that time. I let him do it simply because I knew it helped to calm him down. These particular increased body movements only manifested themselves after we discovered Zachary was autistic, whereas the "finger" thing was there from probably around eighteen months of age and intensified over time. We just did not know what to make of it.

Pushing Forehead Along The Floor

The one thing we did see but really could never explain was the fact that Zachary often put his forehead on the carpet and while on his knees with butt in the air he pushed his forehead along the floor for quite some distance. Again, we did not know what to make of this particular behavior. Did he simply like to look between his legs at the far wall getting further and further away? Was his forehead itchy and that was some weird way of scratching it? We had no clue! This behavior occurred about once a week or so and was odd and bewildering to us.

Head Banging/Self Mutilation

Pushing his forehead along the floor was probably related to the head banging Zachary periodically engaged in. At first, it did not seem to be that frequent, or was seen as more of an “accident”, the result of his two-year old tantrums. But, as time went on, he engaged in this a little more. The other way I noticed Zachary hurting himself was by biting himself on the arms or knees. I never reinforced that behavior with any attention and the biting subsided as time went on. If I found the head banging to be particularly bad, I would put his bicycle helmet on in the house. It covered the entire back of his head and since he did not like having it on, it reduced the frequency and intensity of this behavior. Of course, any jolt or blow to the head was one too many and this was a behavior we found extremely stressful. Every once in a while when he gets frustrated and “goes down”, he still hits his head hard enough that it continues to be upsetting for everyone. Pushing himself back often happened so fast when he was frustrated it was difficult to stop.

As time went on, Zachary started to punch himself in the face or on the head with both fists. He could do this quite hard. It looked like this “motion” provided a stress relief for him. Usually, this behavior did not last very long, a few hits and it was over. I quickly learned to say “gently” instead of an outright “no” since “no” just made him want to do it more. With “gently” he could still have “the motion” and he learned to “tap” himself lightly instead of giving himself a full force blow to the head. This was not a frequent behavior, but it was there.

Limited Food Choices

When Zachary was small, he used to eat pretty well anything we gave him. As he grew older though, his eating habits changed a great deal. He completely stopped eating certain foods. Even my babysitter complained that all she could ever get him to eat were toast, ravioli or macaroni and cheese, and applesauce. He loved macaroni and cheese so much that he would literally eat it by the handfuls and seemed to never get enough. He never wanted to eat any of the meats or soups I would send over for him. Drinking milk was never a problem. He did love milk. Water and juices were completely out. If we ate at the restaurant, he always ate mashed potatoes with gravy and ham. I could never get him to eat any other vegetables or any fruits. He wanted nothing to do with them. Meats, for the most part, were never a problem. He liked most of them. Again, we joked about what a "true little man" he was…just a "meat and potatoes" kind of guy. It was only after we figured out that Zachary had autism that we took a very close look at what he was eating. Healthy foods were given, but usually not touched. Over time, he limited himself to certain things. Fred and I never seemed to like the same foods and so we often cooked more than one thing or, more often, just did the "drive-thru" thing where you go to all your favorite restaurants or delis and get the various foods "to go", take them back home, and then, everyone eats…basically each of us had a different meal. In today's society, it was not unusual…and with both Fred and I having good corporate jobs, it just made life a lot easier. It was not that we ate mainly "junk food"...not at all. Chicago and its suburbs provided ample healthy eating it you wanted it. We bought expensive meals all the time. Why make lasagna, salads, Chinese etc., when the restaurants down the street made them much better and faster than you ever could.

I was not much of a cook anyway…not that I did not make good food, I just did not enjoy cooking. Fred knew that before he married me and I used to chuckle whenever he went back home because his mother was a pretty good cook and he would just "chow down" back on the farm where he had been raised. So, fine, I was not a person who liked to cook. I could still give my children a balanced diet that included all food groups. The fact that I had a two year old who did not like fruits and vegetables did not seem that unusual to me. I had heard a lot of parents tell me their children were the same. Anika loved fruits and vegetables, but even for her, that came with age. I figured Zachary would probably be the same and start to like them also around the age of three or four. It was only after Zachary was diagnosed that I realized just how much he did limit himself to certain foods. This, I would learn, was very typical in children with autism.

Red Cheeks, Red Ears or Bags Under the Eyes and Over-eating

Having never been closely exposed to a child with food allergies I did not know that red cheeks and /or ears and/or bags under the eyes were more often than not, a sign of some kind of food intolerance. I had no idea at all that this was the case and many, many parents to whom I spoke were also not aware of this.

Zachary often had either very red ears or very red cheeks. I also found he had bags under the eyes, but given his poor sleep patterns, I thought those were due more to a lack of proper sleep. Zachary had been on formula since he was three weeks old. Looking back at his pictures even that young, he always seemed to have red cheeks and ears – from a few weeks of age until well past two and a half. Yet, his doctor never brought it to my attention...and I never knew to ask. At his six week checkup, the doctor and I discussed how his feedings had to be slowed down…he was drinking too much milk. I recalled telling the doctor how he was always hungry. At six weeks, he was already well off the 100th percentile on the growth chart. I remembered Fred telling me how there were pretty tall men in his family and that Zachary would most likely take after some of his uncles or cousins. I slowed feedings down, but at ten weeks, Zachary checked in again, at the 100th percentile on the growth chart. So, again, we discussed slowing down feedings. Looking back, I wondered, why had the discussion been limited to "slowing down feedings"? Why had we not discussed **the reason** Zachary was eating so much in the first place? After all, was it not true that newborns, whether human or animal, eat only as much as necessary to fill themselves. Yet, Zachary was always wanting to drink milk. He was insatiable. I now understood why that was. He craved the "high"!

As he continued to drink, his cheeks continued to turn red. But, back then, I did not recognize this for what it was. A sign of a food intolerance. He was just two and a half months old; I figured his skin would get better with time and that his skin was this color because he was a newborn child. After all, he did have a big red birthmark right in the center of the forehead down to the bridge of his nose; so, I thought that red skin was a "normal" skin tone for him. Then came the "teething period" and the "it was probably just his teeth excuse". Of course, looking back now, I realized Anika never had a problem with her cheeks being red...or her ears. Zachary's skin was very dry too. On November 29th, after Zachary got up from a nap, I noticed the skin on his cheeks seemed "bumpy" and "cracked" and that slightly yellowish fluid was oozing out of his skin. His "normally" red cheeks had gotten much worse in one day.

Very concerned by the sudden change in his skin, I called the pediatrician's office at 4:38 p.m. …no one called back. I called my father who was a practicing physician. He felt I should take him in. According to my father, you always had to take a skin rash seriously and have it looked at. The pediatrician's office still had not called back by 6:00 p.m. (I had call waiting as well as voicemail, so I knew they had not) …so; I placed a second call to the pediatrician's office. Since it was now past regular business hours, I went to the answering service. Of course, HMOs/PPOs screened calls and they usually preferred to have you come in the next day...at least that had been my experience. I emphasized the fact that I had spoken to my father, who was a practicing physician in another state and who stated I should have him looked at. I insisted on a referral by the on-call physician to have Zachary looked at that night. I stated I was taking him in to "immediate care", the after-hours facility, and that they better make sure the referral was there by the time I arrived. By 7:00 p.m. or so, Zachary was looked at. First, the doctor came, looked at Zachary, asked me a couple of questions and went out. Then he came back in with another doctor. The other doctor looked at Zachary's face and then the two of them went out of the room together. Shortly after, the first physician came back in, alone. He stated: "Well, I've consulted with another physician, and we both agree that your son is a direct admin to emergency". "WHAT?" I said. "What for? What's wrong with him?" He has what appears to be "Facial Cellulitis", a staph infection. "How serious is this?" I said. He replied: "Well, it can be very serious if it gets to his brain". I could barely swallow. I started to cry.

The doctor gave me a piece of paper and told me to go straight to emergency at the hospital down the street and have him admitted. He stated Zachary would probably have to be on a pretty strong dose of antibiotics. He would call ahead to let them know I was coming. I took Zachary, put his coat on quickly, picked him up in my arms and hurried off. I was a ball of nerves. As I made my way through the parking lot with Zachary in my arms, I placed a call on my cellular to my father and told him what had just happened. I asked him what he thought and whether Zachary could die from this. He stated: "It depends on how bad the infection is"…that was as good as a "yes" in my book. I was devastated. I rushed to emergency. It only took me about five minutes to get there. By then, I had now placed a call to Fred and told him about the doctor's visit and about the conversation with my father. Fred and Anika came to meet me at the hospital. By the time they got there, Zachary was finally asleep.

I had also had the opportunity to speak with another physician who examined him in emergency upon his admission. This physician did not feel that a strong treatment of antibiotics would be necessary. He felt he could go with something a little less strong. The doctors at the hospital seemed to believe the rash on his face might be due to eczema. Zachary was put on an ointment called Bactroban, which would be applied three times daily for fourteen days. I was to take him in for a follow-up visit in two or three days to see how that was working. On January 2nd, I took him in to see his regular pediatrician. He thought the rash looked as though it was "resolving". I was to come back after the fourteen days of treatment. Zachary already had an appointment scheduled for the 18th of January for his routing six-month examination and the doctor felt he could look at his cheeks then.

On January 15th, I was out of Bactroban and by 6:00 pm on January 16th, I noticed his cheeks were red again. I was totally stressed out over that. I decided to call the doctor again. Of course, I went to the answering service and once more, had to insist on having my son seen that night. I thought how they must just hate parents like me, those who would not wait until morning. Anyway, having gone through what I had in late November, I was not messing around… he was going in to "immediate care" to be looked at once more. I saw yet another physician. This one thought that yes, his cheeks were quite red but that since there was no swelling or tenderness and no "oozing", that it was probably "just the way he was". She explained that some children have redness of the skin, but that they usually outgrow it by the time they are two. She gave me a prescription for an ointment that I was to apply whenever I felt his cheeks were getting too red. She would provide enough for me **for over a year**.

What a relief! All right, I had a prescription for "this condition". For Zachary, Fred, Anika and I, unfortunately, if we had only known...this "prescription" would only serve as a "face mask" hiding a deeper, underlying problem. Did not the fact that a "one year supply" was prescribed for an infant, in and of itself appear rather odd? Looking back, I certainly questioned it! So, there we were. **Another sign missed and dismissed** by both Fred and myself, and, **by all five physicians who had examined his cheeks as well**! Was there a lesson there? You bet there was!

Dislike of Certain Food Textures

Related to the limitation of food selection/choices was the fact that Zachary grew to like only certain food textures. Again, this was something that became more evident to me with the passage of time and only after he was diagnosed as having a problem. Meats were ok, but anything smooth, like Jell-O or pudding, he would seem to "gag" from... slowly pulling his tongue out and letting the food fall onto the floor. By the time he was two and a half even mashed potatoes were out. Crunchy foods were in. Zachary's need for "crunching" brought out behaviors that were troubling, and confusing to watch.

For example, when he was thirty-nine months old, we were playing outside in the sandbox. Zachary took a handful of sand and put it in his mouth. Two days earlier, I had filled the sandbox with new play sand purchased at a local hardware store. Our sandbox had a cover on it, and therefore, I was not particularly worried about the sand containing animal feces. Anyway, I sat there, looking at Zachary, waiting for the inevitable reaction, the spitting out of the sand. It did not happen. Instead, he proceeded to "chew and swallow". I was in total disbelief. I sat there, frozen, totally confused, yet, amazed by this behavior. I just could not believe what I had just seen. He then made a motion to put yet another handful of sand into his mouth. That was when I "snapped back to reality", wiped the sand from his hands and took him back into the house to clean out his mouth. Later, at about age three and a half, Zachary would start eating chalk as well. I could not explain this behavior other than the fact it must somehow have been associated with his desire for very specific food textures.

Gnawing

For a period of about two months, right around the time that Zachary was two and a half, he engaged in another very odd behavior – gnawing. He literally chewed the drywall around the windows of his bedroom and my bedroom down to the metal framing. It did not matter how much we tried to stop this behavior, nothing we did worked. When he got up from a nap, even if he was up just a couple of minutes before we were in the room, he would clamp his teeth into the drywall just underneath a window and take bites out of the drywall, only to spit them out onto the floor. That was shortly after he had been diagnosed.

Diarrhea/Constipation

Zachary had constant bouts of diarrhea. Although I did not realize it at the time, this was one of the most common characteristics in children with autism. He also suffered somewhat from constipation, but the diarrhea was many, many times more frequent and more severe, and it got worse with time. Of course, every parent knew about the BRAT diet to treat diarrhea…bananas, rice, apples, and toast (the B.R.A.T. diet as they called it in medicine). That was what you were told to give your child whenever you called in about diarrhea problems. Sure, it stopped it, for a while. Again, we had simply been "masking" the true problem by following "protocol" for the treatment of diarrhea…we were treating "diarrhea" when we should have been treating "autism" that was manifesting itself through constant bouts of diarrhea. And those things we were told to give him to stop the diarrhea (bananas, apples, and toast, at least) actually only made his condition worse. He could not tolerate the phenols in these foods. Diarrhea, for autistic children such as Zachary, was simply a symptom of a deeper underlying problem and unknowingly, we were simply masking the problem again with B.R.A.T. foods..over and over again. We missed it completely, again!

A Special Note on Diarrhea: When yeast begins to "die off" (a good thing), that usually manifested by massive amounts/big bouts of diarrhea (something to be aware of and to watch for).

Toilet Flushing

Although Zachary was not yet potty trained, he loved to flush the toilet. He could flush it twenty times in a row if I let him. Of course, again, I did not realize this, too, was a sign of autism. Fred, Anika and I had almost trained ourselves to now run to the bathroom upon hearing the first flush. Once, however, even that was not quickly enough. It was not until well after he was diagnosed as having a problem that I actually found Zachary in the bathroom one time with his head actually in the toilet, looking at the swirling action of the water. After that it would be close to one year before I would keep the bathroom doors unlocked.

Yeast Infections/Diaper Rash

Perhaps another of the most easily missed signs of autism was that of yeast infections. To most parents, they probably just look like your simple "diaper rash". But, what exactly was a diaper rash? It was a reaction to what…to the acidity of the urine… to the lack of aeration due to having a diaper on? Or, was it something else? In Zachary's case, it was that something else. It was a yeast infection mistaken for a "simple diaper rash". After all, why get all upset over a diaper rash? We could just buy a cream to simply make it "go away", right? Wrong! Once again, the cream simply masked the problem. The rash got better for a little while, only to come back. It was actually my babysitter, Jennifer, who suggested that maybe he had a yeast infection. As she stated: "I have watched a lot of kids and seen a lot of butts and that would be my guess". I would not even have thought about that possibility. Where would he get a yeast infection? When it came right down to it, I did not know anything about the whole subject of yeast infections... nor on the signs of autism in general. Once again, I requested my son be looked at before day's end. I was at work but called the pediatrician's office from there at 11:20 in the morning. I worked in downtown Chicago but Fred was in the suburbs and he could take him in. I did not get a call back until after close of regular business hours. Once again, Zachary would go to "immediate care. Was I on some "black list" in that clinic that they could never call me back promptly? " Who knows, but, sure enough, just as my babysitter had suspected, it was a yeast infection.
Zachary was just under a year old. Since I did not know that both red cheeks and yeast infections were signs of autism, I did not think anything further of it. Zachary did not have that many diaper rashes after that. I completely missed and dismissed this symptom as well.

A red circle around the anal area was also a sign of a yeast infection. With Zachary, the rash was all over, but over time, the red circle around the anus became more evident and the rest of the bottom cleared up. Every once in a while I still see a circle around his anus and thus, I think yeast infections, unfortunately, are an ongoing battle for these children.

Loss of Language/Labeling/Commands/Non-Sense Language

Zachary had said his first word in triplicate on May 2nd, 1998. Luckily, I kept a journal of these things and so, looking back was much simpler. I remembered the joy I had when he said "mama, mama, mama". I was French Canadian and only spoke to him in French. By eighteen months, he only had about four words. The pediatrician spoke to me about the fact that maybe, because of the two languages, he was just a little slower. Boy, was I a fool for even letting him get that one past me. Anika had developed language just fine in a bilingual home, as have many other children. Fred told me that "his side" spoke quite late, that he was almost four when he said his first words. All right, I would give Zachary more time.

Zachary did develop a little more language, but then, he began to lose it again. It was my babysitter, Jennifer, who then suggested he get a hearing test. So, I called the pediatrician and insisted he get one. Funny thing though, in the medical records, it appeared as though they suggested it - another "odd" notation in Zachary's file. Fred or I never remembered them telling us to "count" Zachary's words and get back to them either, yet that was in there, too. We would certainly have remembered given our concerns. I can assure you they most certainly did not initiate this whole investigation into Zachary's hearing or his delayed language. We practically had to beg to get them to do anything. What they did provide for us was a "consultation" with **final assessment showing by the attending physician: " Rule out hearing loss and speech delay"**.

Fred had waited four hours or so to see this doctor and it turned out to be nothing more than an end of day five-minute consultation. Not a hearing test. Fred was very upset about it. He had spent four hours there thinking Zachary was actually going to get a hearing test, and instead, he was given a "quicky 5:00 p.m., five-minute, make sure there was a tongue in the mouth, a larynx, a nose and an ear on each side of the head consultation" that ruled out speech delay. There was no suggestion at all as to a possible problem...again, nothing! If there had been a tongue or ear missing, I was sure I would have already mentioned that to the regular pediatrician by now. That was on August 16th, 1999. How could Zachary keep seeing doctor after doctor and yet not one of them mentioned a food intolerance? The fact was simply that they were not looking for Zachary's problem or did not want to admit it. All we were getting was the latest "five minute, quick fix visit". When I learned the outcome of this latest particularly useless visit, I was rather upset. I later called to schedule a "real" hearing test. That "test" happened on October 20th, 1999. Again, as I looked back, it was not much of a "test" either. A few words were said and the technician would see if Zachary, as he sat on my lap in the test booth, looked in the direction from where the sound came. I had already told them that he could hear fine when it came to the human voice. She did not tell me anything I did not already know. They tested various sound **frequencies**, but nothing unusual showed up...surprise, surprise! To them, Zachary appeared "normal". Yet, to this day, he was still quite sensitive to various sounds.

So, again, I had been "lulled" into thinking my son was fine. It was just that "boys were slower", as I had so often heard. I would give him more time. After all, Fred had a nephew (his sister's son) who did not speak until he was well over three. Zachary would probably just be the same way. Hearing problems had now been dismissed.

Zachary had actually lost quite a few words he had once used. When he did finally develop language, it was more “labeling” and “commands” than conversation. If I told him the name of an object just once, he knew it. When I said, “what’s that”, he could easily tell me the name of the object. Anything that had to do with labeling things came easily to him. He also learned to speak in “commands”, using small, consistent phrases like “open the door”, “I want ----“. Normal conversation though simply was not there!

Echolia (Repetition of Words)

When Zachary finally did begin to develop more speech, long after he was diagnosed as even having a problem, his speech was primarily a condition known as echolia whereby he simply repeated words. Since by the time he actually said more words we knew there was a problem, I did recognize his speech for what it was when it did come. By the time Zachary knew the alphabet, he could repeat it up to ten times before finally falling asleep. He did repeat everything he heard and he repeated it over and over again. This was a well-known condition in autistic children.

No Response When Called By Name

Zachary also did not respond to his name at all when he was called. It was as though he could not hear me. I had always found this troubling, but always brushed it off to the fact that he was “so interested” in his other activities. No matter what I said to get his attention, it was as though he could not hear me at all. Zachary’s babysitter had commented about that on several occasions. I now know that this, too, was a sign of autism.

Sense of Smell

Zachary’s sense of smell did not seem to be affected, other than his general dislike for any new food. He just had to look at a new food and would turn away. Of course, I had no way of proving whether or not he could smell it from far away and smelling it was why he would run off as opposed to a visual cue of something being new. The one thing about his sense of smell I did notice from quite early on was that he liked to be “sniffed” around the ears, in his hair, on his tummy, and especially, around the neck. Actually, “sniffing” him often served as a method of calming him down. If he got upset, often all I had to do was to start sniffing him around the neck and he would calm right down. This actually also helped him to fall asleep. I never thought much of anything other than the fact that it was kind of “cute”. In fact, he “sniffed” my neck and ears first and that was how I came to recognize and use this behavior to calm him down.

Although I am certain there were many more variations of these behaviors in autistic children, I wanted to provide, best I could remember, all those things I was now convinced were related to Zachary’s condition.

So there they were…the signs...signs so easily missed or dismissed. If only, if only I had known what to look for... or how to put it all together!

CHAPTER 7

Looking for Help

It had been over twelve months since Fred had mentioned the word "autism" in the doctor's office. We had lost over a year! The guilt was horrible. We should have pushed more for an answer to our concerns. Focusing on the "should haves" or on the instinctual desire to "blame someone" or to get depressed as you blame yourself was not going to change matters. Now we knew and we **had** to focus all our energy on "saving Zachary".

Dr. Johnson said that she would get a few telephone numbers to get us get started in finding people who could be of assistance. Zachary was now protected under the Americans with Disabilities Act and was entitled to participate in certain state-funded programs. She also gave me the name and phone numbers of two top behavioral psychology professionals in Chicagoland. I told her I had talked to my father who was a doctor about my suspicions regarding Zachary and that he suggested I also see a neurologist. My father was within a few months of retiring from emergency and, although he continued to practice in his clinic, he readily admitted that he had no idea how to even begin to treat my son for autism. It just was not something he was familiar with. Looking back, he was the only doctor I knew who ever **admitted** "not knowing something".

I knew my father had spent several hours researching autism on the Internet when I informed him of Zachary's condition. I heard the helplessness and sorrow in my father's voice when he mentioned that a man in his town had a daughter, now twenty seven, who had autism and had spent her entire life in a special home, never once saying a word. Although perhaps to a lesser degree, I think he must have felt that feeling of inner death I had felt that first night. Dr. Johnson agreed to provide me with the name and number of a neurologist but she did not have it at the moment. She asked that I call her office the next day and stated she would leave the information with the nurses. As Fred and I left her office, he made a comment to me: "She won't last here". I asked him what he meant by that. "She's too willing to help…to recommend tests and specialists", he said. "She is still too new to the system".

That afternoon, I went home and took out my little "keepsake book" in which I had written so many precious lines about my children as they were growing up. I looked at all the entries for Zachary. Dr. Johnson had stated that I should have as much information on Zachary's development as possible when I spoke to the neurologist. Zachary's Date of Birth, August 12, 1997. First time Zachary rolled over, February 13th, 1998. First word, "mama, mama, mama", May 2nd, 1998. That was now almost two years ago. It was at that moment that I truly saw that Zachary had actually lost words he used to say and that now he only used about five or six words. Again, something so critical, I had brushed off to the fact that boys were "slower" and that he was just a quiet child. How could I have been so blind?

Zachary pulls himself up against furniture, July 31st, 1998. Zachary's first step, September 13th, 1998 - I had waited a long time for that one. Zachary is running well, January 2nd, 1999. These were the basics I needed to be ready to speak with the neurologist.

The next morning I got up and called Dr. Johnson's office as she had instructed me to do. The nurse who answered the phone stated my best route would probably be to go with the behavioral therapist Dr. Johnson had recommended. The nurse had yet to give me the name and telephone number for the neurologist. I felt an anger come over me. How dare this nurse question what I should or should not do for my son. I wanted to see a neurologist and I was going to see one. I knew that HMOs/PPOs limit the seeing of specialists but I was determined to see one and the nurse's medical advice/opinions had not been asked for. She then made another comment to the effect that she thought I really should call the behavioral therapist. I was really getting angry and insisted she give me the name and number I had called for. She provided me with the information and I hung up. It would only be later that I would figure out what she was trying to tell me in her tone of voice, but could not say outright. At the time, I did not see she was actually trying to help me...but soon, I would!

I left a message on the voicemail at the neurologist's office stating that I was interested in getting a preliminary evaluation of my son. The next day, I received a call on my voicemail at home from the neurologist's nurse stating that this neurologist was very experienced with autistic children because he too had an autistic son and that "he could put Zachary on drugs" as necessary. I was appalled by this message. I had inquired only about a **preliminary evaluation** of my son and the first thing out of this office's mouth was that they could provide me with "drugs" to control my son. If that was their first inclination without having even seen Zachary, I was not interested in their services and left them a message exactly to that effect. I now understood what Dr. Johnson's nurse had been trying to tell me all along, what she perhaps knew but could not say outright. After that episode I had completely lost faith in the "medical" community. I would try another avenue.

I then called the office of both behavioral therapists Dr. Johnson had given me numbers for. Both were out of Chicago and Dr. Johnson had told me they were among the best in the nation for the treatment of autism. Fred and I were debt free and could come up with the funds to pay for a good program if we had to. Behavioral programs could cost anywhere from $35,000 to $50,000 a year. Both offices had waiting lists of close to a year or more. Zachary could not wait that long. I could not wait that long. We had already lost enough time! I tried something else.

I called the State of IL to see what was available for Zachary. According to Dr. Johnson, he was now protected under the Americans With Disabilities Act. Well, that sounded great. Surely, I could get him some help through the State. Unfortunately, for children like Zachary, under three years of age, this provided very little...only two hours of speech therapy per week. What was that? Basically nothing! Had he been over three years of age, he could have received up to five hours... maybe... if I fought for it. The assistance provided could vary from state to state…I just knew that for Zachary and for our family, the State was not the answer.

Ever since that night, when I first confirmed for myself what was wrong with my son, I had made it a point to get up very early and be there "in Zachary's face" by the time he woke up. As soon as he awoke, I would try to engage his eyes to look at me. For the most part, he did not.

But, still, before he got up, I would spend time "working with him" for anywhere from fifteen minutes to an hour or so. As I spoke with the State's social worker, I kindly told her: "Thanks, but no thanks. I do more with Zachary before he gets out of bed in the morning than what the State was offering me for an entire week".

Dr. Johnson had also given me the phone number for some type of "outreach" program that could help me with babysitting Zachary for an hour or two if I had to go do errands, etc. Again, for our family, it was not something we were interested in. Fred and I could take turns babysitting when errands had to be done…and anyway, we preferred to do all errands as a family.

So, the neurologist was out, the behavioral psychologists were out, the State was out and we had no family in the area...we were pretty well on our own! I came to that realization very quickly. Sure, I knew if I wanted to I could find another neurologist, perhaps students of behavioral therapy, etc., but, then again, no one knew my son better than I did, and no one would have the patience with him that I did. I did not want to be running from one "professional" to another, professionals who could give me no guarantees, and who quite honestly, had no more answers than I did.

To me, by definition, if the solution offered was just "masking" the problem either with drugs or with constant, drill-like repetitive routines; that was not truly getting at the underlying issue, was it? I went to bed that night, resolved that our family would "save Zachary", no one else could or would do it for us. In my heart, I knew that I did not have to spend tens of thousands to do this. I did not agree with the whole reward-punishment system that was at the very heart of behavior modification techniques. That was fine if it worked for other parents, but it would not be the route we chose to pursue as a family. I, also, could never consent to just putting Zachary on drugs to once again "mask" the problem…forget that! And, anyway, deep down, what could a neurologist tell me anyway? So, he could confirm there was something wrong with the manner in which my son's brain worked. I already knew that. I could not think of anything a neurologist could really do to help in terms of getting "rid" of Zachary's autism. All he could really do, deep down, was offer me a prescription! I already knew that! Autism was still too big an unknown in too many disciplines. No one had any guarantees because no one really 100% knew what caused the problem in the first place.

Although we had consulted with a pediatrician about Zachary's autism, and thereby confirmed our suspicions, we consulted no further with doctors, psychologists (behavioral or otherwise), or other healthcare professional in the treatment our son as their "answers" were too few or too ambiguous or their waiting lists too ridiculously long. We had made a few calls based on the information provided by our pediatrician, but nothing seemed to be a viable option for Zachary.

Like me, all those we had “reached out to” for help would simply be going by trial and error anyway. I was determined. As a family, we could do this…we had no other viable choice. **We were on our own**!

CHAPTER 8

Family and Friends

Fred and I had settled quite a distance away from family due to work. We both held Masters of Arts degrees in Finance and the towns of two to six thousand people where we had grown up, obviously, were quite limited as far as any career advancement in our field. So, we lived in the suburbs of Chicago. With such a “difficult child”, work and family were all we could handle. We had plenty of people we considered acquaintances, but true friends were not something we had much time for.

My babysitter, Jennifer, was probably the person I spoke to the most. Fred had one friend, Kevin, whom he used to do things with once in a while. Kevin was the father of three and truly a good person. He worked like a dog to support his family and when he was not doing that, he was off to the Army Reserve on weekends. So, even though Fred got along with him quite well, we really did not see much of Kevin simply due to his schedule. Fred and I had pretty well been each other’s best friend ever since we had begun to date back in 1983 and married in 1984. Friends, in the usual meaning of the word, were not something either of us missed. Jennifer though truly cared for our children. She had been a wonderful babysitter.

What I admired most about Jennifer, however, was the fact that she was among the first to even begin to suggest to us that there may have been something wrong with Zachary. She, too, felt he had not been developing as quickly as he should have verbally. It was she who actually suggested I have Zachary’s hearing tested. Of course, I knew he could hear well. I had done those little tests parents do, snapping fingers behind the ear to see if there was a reaction, etc. Still, Jennifer along with my sister-in-law, Christine, did put the “bug in our ear” that something was not be right. The week after our trip to Canada in February, just before we quit, Jennifer mentioned to me that she had herself expressed concerns over Zachary to a pediatrician she knew. The pediatrician had seen Zachary while she was on an outing/errand. As Jennifer told me about this encounter, she calmly stated that this pediatrician she knew thought Zachary might have exhibited very mild signs of autism. Looking back, that just made me all the more suspicious about my own pediatrician. How could this man have seen what Zachary’s own doctor had “missed” time after time after time? When Jennifer made that comment to me, I did not take her seriously enough though. Zachary was not autistic. He was just a little slower, that was all...just as his doctor had said.

While we had been in Canada just five days or so prior to this conversation with Jennifer, my sister-in-law, Christine, basically told my husband she thought Zachary had some of the signs her own son, now 11, had shown. Andrew had been diagnosed with Pervasive Developmental Disorder (PDD) when he was around eight. PDD was, in Christine’s words, along the same spectrum as autism. Fred had not mentioned Christine’s conversation to me until March 22nd.

It was because of these two conversations, the one with Jennifer, and shortly later, the one with Christine, that I set out to “prove they were wrong”, but, unfortunately, they were right and less than a month later a new pediatrician would confirm that.

With the confirmed diagnosis came calls to family members we felt should know of Zachary's condition - the grandparents, the aunts and uncles…those people you would call if someone died…and that was just how we felt, we had lived through the death of the son we thought we had and awakened one morning to a very sick child.

Although they meant well, some family members did not seem to accept the diagnosis very well. After all, some books stated that up to 75% of autistic children were mentally retarded and Zachary did seem intelligent enough. Some of it may have been pride, not wanting to believe that one of our family members could possibly have this disorder, or it may simply have been disbelief, denial, or simply the inability to cope with the diagnosis. I just know that we heard a lot of "I do not think he's autistic" from family members who would later "try to see the problem" when Zachary was around. But, then again, this was a disorder whose signs and symptoms were so easily missed or dismissed. We had not seen them for so long. So, it did not surprise me to see they too had difficulty with the diagnosis. Others simply did not want to talk about it, not knowing what to say, they preferred not to say anything.

What did surprise me, however, was the fact that others still had a very different reaction. A couple of them admitted they "suspected" something was wrong with Zachary, yet had never mentioned anything. This was, to me, quite troubling. Upon hearing of Zachary's diagnosis, another family member said: "I knew there was something wrong with that kid!" That hurt. Why had this person not said something? Why had they not approached us with their concerns or suspicions? Not only did I feel betrayed by the medical community, I now felt betrayed by members of my own family. I felt surely I would have said something to them had the situation been reversed. I guess you could not take anything for granted, not even from family. I understood that they did not want to hurt us and probably thought we would see it "in time". What pained me was the fact that for these children, time was of the essence…we only had one chance! I knew Fred and I had missed it for a long time too. Too often, being in the eye of the storm, we failed to see what was all about us. Just getting through the whirlwind of each day was so difficult that we never took that "critical step back" to make sense of the tornado we knew to be our daily lives. None of that mattered now. I felt no bad feelings toward anyone – I had to move on, to once again, focus on Zachary.

I certainly hope my story will help friends and family to talk more openly, to understand that what may be obvious to someone "away from the situation" may not be to the person in the middle of the hurricane and that courage to discuss the issue was perhaps the greatest expression of love you could give to someone dealing with what may appear to be autism or a similar disorder.

CHAPTER 9

Grieve…but not too long! Then, get determined...and stay focused!

I cried each day for close to ninety days after discovering Zachary had autism. I tried very hard not to cry during the day, but often, I could not hold the tears back. Primarily, I cried at night, as I went to sleep. I allowed myself time to grieve the son I had lost...but at the same time, this was no time to get depressed. I had a son who needed me and so quickly, I resolved to get determined and stay focused to best help Zachary. Even though I cried a great deal in those first ninety days, it was also during those days that our family's plan of attack began to take form. Fred and I spent the entire month of April 2000 researching autism…from basically 7:00 am to 2:00 or 3:00 a.m. almost each day. Reading breaks were spent feeding the children or caring for their other most basic needs…a bath (they probably got one a week during that month), some hugging, a little playing, etc.

On March 22nd, 2000, I had confirmed for myself Zachary's problem as I read the DAN article on the Internet, shedding the first of many tears my eyes would shed for him and our family over this condition. Yet, on the following day, on March 23rd, 2000, first thing in the morning, before the pharmacy even opened, I was there, in a parking lot, waiting to buy cod liver oil to help alleviate some of Zachary's sideway glances. I grieved, yes, but I did not let that grief take over me completely. I had a child that needed help, and for that child, I had to be strong. I fought the sense of depression each day. I would not let autism take another member of my family. I started right away to do something to help Zachary...each day . As Zachary began to make progress, losing his sideway glances, sleeping all night, we inched along. This was a very difficult time, but, like so many parents who had gone through this, or through something worse, I had to get through it. I figured I had one shot at my child's future. I was not going to make it a "blank".

For me to defeat my adversary, I needed to be thinking clearly. Depression would not allow me to do that. So, I picked myself up, as did Fred and Anika and we started our plan of attack. I had always told myself during difficult times in my life that, **there was always someone better off than me in life, but there was always someone worse off, too…so, I counted my blessings and went from there!**

CHAPTER 10

What To Do? Where To Start?

If there was one thing I had learned from reading about and living through autism in the last year and a half, it was that autism was not hopeless. I could truly make a difference for my child.

The other thing that I learned was that autism was "big business". I was sure many children have been "saved" due to various techniques such as those of behavior modification, and for those parents, I was extremely happy. However, today, given the well documented fact that autism appears to be linked to a child's inability to process gluten and dairy proteins, I could not help but think that behavior modification techniques simply masked a problem and did not get at the underlying roots. What I found particularly troubling, as I read about autism, was that based on the book I was reading, the "big bucks" sentiment grew more and more within me. For example, if I read a book on autism where the approach was behavior modification, even though that book had been written in the last 3 years, there was little mention of anything having to do with diet. An entire book on behavior modification may have one paragraph stating that "scientists have hypothesized everything from lack of bonding with the mother, diet, genetics, etc. " under the section dealing with what "causes" autism.

I found it truly irresponsible and unethical for some of these so called "professionals" to not go into the research that now clearly showed these children could not digest gluten and dairy products. I was not saying that all behavior therapy books were like that, but many were. I became very suspicious of behavior modification books that did not also suggest a casein and gluten free diet. Behavior therapy programs for autistic children could cost anywhere from $35,000 to $50,000 a year (and those were estimates we had read about in March of 2000, close to two years ago from the time of the writing of this book). I approached all books cautiously. I was critical of everything. I always kept in mind the author, what they were advocating and how they profited financially from their books/suggested therapies. Zachary had already been a victim of the "all mighty buck" as far as I was concerned and I was not about to let that happen again. If drug therapies were suggested, I wanted to see empirical results. How successful had they been? What else was involved? It was sad to say, but given everything we had been through, I trusted very few people with Zachary's care. I would be the one who had to deal with him my entire life if my decision was not the right one for him. And after me, the burden could possibly fall onto Anika and that was something I desperately wanted to avoid.

The fact was, I knew my child best. I knew I would never consider institutionalization. I looked for alternatives that did not mask but rather addressed the underlying problem. We had gone through enough "masking" to last us a lifetime. We were not going to choose the "easiest route short term". We would go with what we honestly felt was in Zachary's best interest long term.

When Fred and I first discovered Zachary had autism, we had immediately asked for the names of well-known behavior therapists in our area. I had read of children being saved by some of these programs although I did not agree with all the techniques used. We most likely would have considered **some** behavior therapy had this option been available to us at the time but both offices had long waiting lists. In addition to having a B.A. and an M.A. in Finance, I also had a B.A. in Psychology and had done enough graduate level work in Psychology (two years in General M.A. program with Psychology, Business Writing and French emphases) to understand behavior therapy quite well. It was during my studies as an undergrad in Psychology that I had also taken a course in neurology. Little did I realize that all of these aspects of my background, together, would later help me understand my son and autism, in general.

Having read everything we did, Fred and I felt Karyn Seroussi's book explained so much of what we saw in Zachary...so many of his symptoms. We pinned our hopes on dietary intervention. If gluten and casein acted like drugs or some other hallucinogen on Zachary's body, I was prepared to do everything to remove those "drugs" from his system. That theory most certainly would explain why these children with autism, like Zachary, acted as though they were in a "drug-induced", almost "trance-like state". That was probably why so many of these children woke up screaming at night, most likely experiencing "bad" hallucinations. It potentially explained why so many children hit themselves on the head, hit their eyes and ears and hated to be touched. Were they trying to do away with what they were "seeing" in their brains, what to them, appeared to be no less than a "demonic reality"? After all, many a person who was high on drugs was afraid to be touched…afraid that the demons they saw in their heads were also those trying to physically grab onto them. Not all "drug trips" were good. It all seemed to make sense now. It was not "lack of bonding" with the mother that was the problem for these children...holding therapy, I thought to myself, would not take away the "demons" these children must see inside their heads. I had to take the "demons" out!

To take the "demons" out, I first had to know how they got there. As I read more, it became clearly evident, that yeast infections or Candida overgrowth was at the root of the problem for most of these children. Many autistic children, just like Zachary, had medical histories outlining occurrence after occurrence of earaches. Unfortunately, in today's society, a parent's first "fix" for earaches, as was mine was, too often to put a child on antibiotics. The broad spectrum antibiotics available today cured the earaches but allowed for the oncoming of autism as the beneficial bacteria of the intestinal walls were killed by the antibiotics used to do away with the earaches. The result was that due to the killing off of beneficial bacteria in the intestinal walls, there was a yeast (often Candida, but may be another strain) overgrowth for many of these children. Yeast overgrowth can be a difficult thing to diagnose. As outlined in Dr. Shaw's book, **Biological Treatments for Autism and PDD**, pages 68-69, when he speaks of diagnosing yeast disorders:

> "Why is Candida such a problem to diagnose? The condition that occurs in most children with autism in not technically an infection, it is really an overgrowth of the intestinal tract. Furthermore, the yeasts do not colonize the intestinal

> Tract in an uniform fashion. Instead, they usually form
> Clusters or nests. Sometimes, they settle in the crypts of the
> Intestine, which are small out of the way "side pockets".
> Therefore, failure to detect these organisms by endoscopy
> Examination (examination with a long tube into the intestinal
> tract) of the intestinal tract does not rule out their presence…
> The real question is not whether or not an individual has Candida,
> but rather how much Candida is there."

Karyn Seroussi's book explained that this yeast overgrowth must somehow "bore holes" in the intestinal walls, allowing the proteins of gluten (found in most grains) and casein (present in dairy) to escape and somehow get to the brain causing the hallucinogenic state and most likely the whole slew of other symptoms associated with autism, symptoms affecting senses (i.e., sight, touch, etc.) and perhaps other areas of the brain associated with socialization, ordering, etc. as well. The fact that we were a society that tended to reach first for antibiotics and ask questions later no doubt had contributed to the fact that today, we saw so many more children with autism. Dr. William Shaw who wrote **Biological Treatments for Autism and PDD**, showed that **in the last twenty years**, the incidence of autism had at least doubled, with boys being affected more often than girls.

Had it only been coincidence that the new MMR2 vaccine that had human cells from an aborted fetus cell line in the "rubella" part of the vaccine had come out in 1981, also 20 years ago? Perhaps. Who could say for sure? I wondered, why boys were more impacted ...then I wondered what the sex of the aborted fetus had been...had it been a female? Thought after thought went through my mind? If cows were getting mad cow disease from eating the parts of other cows, then why would children not get sick from being injected with another human's cells? It was all speculation, of course...absolutely no proof for any link between autism and MMR vaccinations! When faced with an unexplained illness such as autism, I found it was easy to speculate as to the "why"s... but, again, the fact remained that there was no proven "cause/effect" between the MMR2 and autism. All I had were questions...and more questions! What I did know was that yeast overgrowth was a problem in many autistic children. The question for me now became, how do you stop the yeast overgrowth and begin to heal the intestinal wall?

There were several ways to kill Candida or yeast. For example, Nystatin was a prescription drug available to kill yeast overgrowth. Preferring not to put my child on any prescription medication, however, I chose to go with something else. I thought I had read that Nystatin contained all natural products but I could not remember for sure. The fact that it required a prescription did not appeal to me personally. I found that I could use cranberry extract tablets or garlic (Kyolic) to aid in killing yeast naturally. Also, Dr. Doris Rapp, M.D., who wrote "**Is This Your Child?"**, another excellent book, on pages 444 through 450, provides effective ways of dealing with yeast. Natural yeast inhibitors or killers, according to Dr. Rapp, include broccoli, horseradish, kale, turnips, and cabbage. Of course, these were all things Zachary simply refused to eat. Critical in killing yeast was the removal of pretty well all sugars from a child's diet - that included natural and processed sugars, since sugars helped yeast grow.

As we soon discovered, however, dealing with the yeast was just the tip of the iceberg – although a very critical first step. For Zachary, we implemented a complete diet overhaul. If that was what it took to make Zachary well, then so be it!

So, from all this reading and all this research, where was I? I knew for a fact I had a least two enemies – casein and gluten, and possibly a third, phenol, just briefly mentioned in Karyn Seroussi's, "**Unraveling the Mysteries of Autism and Pervasive Developmental Disorder**."

As I read more about autism, I got more discouraged. I discovered gluten was sprayed on a ton of products to stop them from sticking (spices, salt and pepper, French fries, etc.). Within two or three weeks, I had basically figured out that the safest approach was to assume all processed foods were out, and to slowly look for those things Zachary could have. It became very clear to me, very quickly, that 99.9% of what was in a regular food store, Zachary could not eat. Companies that used "trace amounts" of a product, such as gluten, needed not indicate this on their packaging. So, to me, everything, every food was suspect unless I specifically ruled it in and let me assure you that the "ins" were few and far between. Dairy and gluten became my enemies and I was preparing to win the war.

As parents, Fred and I wanted to do everything we could for our son and do it as soon as possible. Therefore, we read constantly during the month of April…getting up at 6:00 a.m. or so and reading almost straight through until 2:00 or even 3:00 am the next morning. All we did for that one month was read…read…read.

In her book on autism, Karyn Seroussi explained how there appeared to be a link between autism and gluten and casein/dairy proteins…that it appeared children with autism usually had a yeast overgrowth in their intestinal wall that eventually allowed "holes" to be bored into the intestinal wall and thus in turn allowed proteins that were not properly broken down in the intestine to pass into the bloodstream. She explained how these proteins seemed to act like a hallucinogen on the brain of these children and that this most likely explained why these children always seemed in a "trance-like" state, in their own world...it was because the effect of these proteins gave them a "high" and thus, it was as if they were "tripping out on drugs".

Of all the explanations for autism, that one was the one that seemed to make the most sense to us given what we were experiencing with Zachary. The more I researched autism and allergies, the more it all made sense to me. Zachary had so many signs I now knew to be signs of a food intolerance….the red ears and cheeks, the red circle around the anus (yeast infection), the constant earaches that resulted from stuffy sinuses caused by foods that produce a great deal of mucus … foods rich in gluten and casein. The pieces of the puzzle were slowly coming together.

It just seemed to make so much sense now - so much seemed to be “explained”. I now understood why Zachary woke up several times during the night and often could not be comforted in spite of hours of rocking. Not all “drug induced” trips were “good” and it was possible he was “seeing” things in his head that scared him. That certainly would explain why so many of these children did not like to be held. Zachary was probably afraid that what he was “seeing” in his head, those “things” were now trying to get a hold of him…even though I was the one physically holding Zachary, some “monster” in his head may have been what Zachary perceived as the “thing” trying to get a hold of him – his reality.

Having taken one class in neurology when I studied psychology as an undergrad, I knew that it was quite likely and credible that these proteins adversely stimulated certain parts of the brain. That could explain a whole slew of symptoms… the need for order in everything, the stacking of objects, the pouring in and out of sand in a sandbox, the “need” to eat sand if the body perceived a deficiency of some type, the hand flapping, the rocking back and forth, the desire to gnaw weird things like the window sills, leg or body shaking, the many over-sensitivities of the senses...so many things now made sense to me. If these proteins stimulated the brain adversely, depending on the area of the brain impacted, it was definitely conceivable that such a wide range of behaviors could be explained. I did not have to know all the mechanics of it for now, that could be left to researchers. As a parent, I saw how this could very well explain so many of Zachary’s behaviors and symptoms. This was one explanation that honestly made sense to Fred and me, and so, that was what we decided to use as the basic underlying assumption for starting to treat Zachary. Gluten, casein, and phenols, things I had not even heard of until just the past few weeks, those three things now became “the enemy” in our family. We resolved to put Zachary on a casein and gluten free diet right away and limit phenols as much as possible as well.

Casein was a milk protein, so, to us, that was the equivalent of “all dairy”. That was easy enough…avoid anything make with milk, milk solids, or those products that specifically said casein. Gluten was a protein found in grains. OK, that seemed simple enough. Little did I know just how difficult it would be to avoid gluten.

Grains containing gluten included wheat, barley, bulgar, kamut, oats, spelt, triticale. That did not seem so bad. Wheat, oats and barley were the only ones Zachary had eaten in the past. I figured I could probably adjust to a diet without those things fairly easily. In researching those things he could eat, I discovered quinoa, amaranth, buckwheat, rice, millet to be ok. Of those, rice and buckwheat were the only two I was familiar with and Zachary really did not eat much of either one. From now on, he would just have to, that was all there was to it.

I could not have been more mistaken as to how difficult a casein and gluten free diet would be...and one low in phenols too! The more I read, the more I learned just what we would be facing as a family. Gluten was the bigger of the two problems….it was on almost everything. Gluten was sprayed on spices to keep them from sticking, it was sprayed on frozen French fries for the same reason. Basically, for any food that went through some type of processing, unless I specifically knew a food was gluten free, I had to assume it contained gluten…down to the salt and pepper. So, trips to the restaurant or eating out of any kind were out. Trips, in general, just got a lot more difficult. All of Zachary's food would have to be packed wherever we went. And worse, all those foods Zachary used to love, the macaroni and cheese, the bread, the crackers, the cookies, the cheese, the milk, the yogurt, the ice cream, the chocolate and countless others, now, were all out.

Once Fred and I resolved to do this, I started to search for a food store where I could find foods he could eat. Luckily, we lived in the suburbs of Chicago at the time and there were quite a few health food stores in the area. (A year later, we moved to the Upper Peninsula of Michigan and even there, we were able to maintain Zachary's diet, so, being in a big city to get some of these products was not a must.). The thing that was nice about having a health food store right there was the ability to read the food labels for myself. That was both a blessing and a curse, if that word can be used. I found a health food store about half hour from where we lived. That store was big and the moment I entered, I thought, "great, I am sure I can find foods for Zachary here". I started down the aisles. Having read a book by Lisa Lewis called **Special Diets for Special Kids**, I had some idea of the products I was looking for...but no idea as to what laid ahead.

As with most food stores, produce came first. Zachary did not like vegetables or fruits very much to start with and to make things worse, Karyn Seroussi's book had made mention that phenols also seemed to affect autistic children. Phenols were very high in apples, bananas, tomatoes and red grapes. Those were pretty well the only "produce" Zachary did like...and now, they were out. Thank goodness, potatoes were ok. Try as I may to learn more about phenols and their effect on the body, I found no books on the subject in the U.S. or Canada. After several hours of research on the Internet, I did find one book on phenols and its possible links to autism, ADD, Alzheimers, and a whole slew of other things….but, it was only available in Australia. The book was by Mary Duncan and was entitled "**Boron, Phenols and Health: Clues to the Mysteries of ADD, Alzheimer's, Asthma"** (ISBN 0-646-26612-8 – not available in the US or Canada). I sent away for it and allowed six weeks for delivery. To obtain a copy of this book, I sent $18.00 US to: Alkimos Australia, 26 Trian Road, Carabooda, Western Australia, Australia 6033. The book finally arrived. I had been so eager to read it and although I was able to get some "bits and pieces" from this book, I found you needed to have a good background in chemistry to thoroughly understand it and that was something I did not have...yet, research did seem to show a link between phenols, boron and ADD/autism. I would later notice that many foods high in boron were also high in phenols. Interesting to say the least!

I had already decided that those foods high in phenols (bananas, apples, tomatoes, red raisins/grapes), as outlined in Karyn Seroussi's book, would also be excluded from Zachary's diet. That did not leave me with much. I picked up a bag of red potatoes and went to the next aisle. That was where the real work began. As I picked up product after product, and read label after label, I very quickly, and sadly, realized just how difficult this was going to be. It seemed everything had either wheat or casein in it in one form or another...even in this store. I spent over four hours in the store and was still only two-thirds done. A young man who stocked the shelves must have seen me there as he went about the store during his shift. He came up to me after the four hours and asked if I needed help finding something. I must have looked either very discouraged or very tired because he had this look on him where you could tell he felt sorry for me… that he knew I or someone in my family must be on a very strict diet by the way I read each and every label. When I first heard his voice saying "Can I help you find something miss" over my left shoulder, I thought, "Great, someone who can help me find some of these items on this list I have".

I had wanted to read all the labels for myself as much as possible to better get familiar with Zachary's new foods, but by now, I was exhausted. Even though I had the names of some of these products, I had no clue as to what some of them looked like, so, an offer of help was most welcomed at this time.

As I turned around to say: "yes, can you ever help me", my eyes fell upon a young man, approximately eighteen years old. His hair was dyed a very bright blond (almost yellow) and it had large green stars dyed in it as well…and it was very "spiky". As my eyes got over the initial shock of the hair, they moved to the neck area. A chain with a padlock just below the Adam's apple adorned his neck. Had I not been so tired, I probably would have laughed a little because this was so unexpected…I was a very conservative person. I was too exhausted even to laugh though, and the circumstances that had brought me to that store in the first place still weighed too heavily upon my heart. The fact was that this young man had offered to help me, and at this point, I really did not care what he looked like. As I showed him my list of items and explained that Zachary had autism and needed to be on a gluten free and casein free diet, he sympathetically looked at me and said: "Oh, I can show you a bunch of products he can have. I am vegan and I use these all the time". "Vegan"?, I said, "what's that?" (yet another new word in the food industry.... where had I been?). "Well, it was kind of like a vegetarian, only stricter…I do not eat anything that comes from an animal", he replied.

Too tired, I did not even bother to comment, but I thought to myself that this was a young man who could eat anything but yet chose to impose upon himself a difficult, very restrictive diet. I did not say anything. My focus had to be Zachary and I was too tired to get into any philosophical discussions at that time. As he said, "Follow me", I turned and noticed the multiple silver earrings in his ears and the one on his tongue. I was raised in a very conservative family, and, it was not my place to judge him...but this was all kind of "new to me". He really was a very nice young man…and best of all, he was willing to help me. I turned to follow him. You could not help but notice the fact that his pants were about two thirds of the way down his butt, and he had boxer shorts with stars on them, to match the hair, I presumed. I guess that was about the "last surprise" for me because I could no longer hold back the little giggle that, by now, managed to surpass even my state of exhaustion. Just how was I supposed to follow this guy without noticing that! As I followed him down the aisles, I felt a little ill at ease, but the feeling of uneasiness quickly passed when I reminded myself that this young man chose to come to work like this...pants barely hanging on and all. So, my thoughts once again came back to Zachary and the reason I had come to this store in the first place.

For the next half hour or so, he spent his time helping me find products for Zachary's new diet. I kept asking if he would get in trouble by spending so much time with one customer, but he insisted he would not. I finally got out of the store (it closed at 11:00 p.m.) and made it back home. It was about 11:30 at night and by then, I was so exhausted I could barely talk. That one trip to the grocery store for Zachary, start to finish, had taken over five hours... and I hated to shop in the first place! The next morning I told Fred about my experience at the store and about the young man who had helped me.

As I described the young man, Fred kind of snickered a little. I told him surely the teenager must have felt a certain "bonding" with me since my hair had been cut very short, was rather "un-kept" that day, and my style probably could have matched his closely…only without the spiking, the dye and the big green stars. My hair used to be quite long and Zachary used to love to "twirl" it as he went to sleep, almost to the point of driving me crazy. After finding out that he was ill, I cut my hair very, very short. I no longer had the time to care for it anymore. Anything that took away from my focus on Zachary had to be minimized. Based on my first trip to the grocery store for Zachary and everything I had learned in just that one event, it truly sank in just how difficult this casein free and gluten free diet was going to be. I did not loose faith, however. I returned to that store almost every week, each time learning a little more as to what Zachary could or could not eat and each time noticing that the kids who worked there were mostly like the first young man I had met. Many of them had chains and padlocks around their necks, earrings and dyed hair…and, they were all so nice and willing to help.

I was starting from next to nothing. As I read more on the Internet, I became more encouraged as I found more and more sites dealing with gluten free and casein free diets. I thanked the Lord each day that I lived in the computer age and that the Internet had such a wealth of information at my fingertips. I did not think I could have handled researching all this in a library. That would have been just too hard! So, that was one blessing. And, along with the Internet, we also had this great company called United Parcel Service (UPS) that delivered pretty well everywhere in the U.S. These two things would help me tremendously in my battle against autism.

CHAPTER 11

Zachary's Supplements

I read somewhere in my hours of research that it took three days for the body to eliminate casein (the dairy protein) and up to ten or eleven months to eliminate gluten from the body. It would actually be closer to twelve months before we saw the really huge improvements in Zachary. This diet was going to be a challenge to say the least.

There were so many things that Zachary could no longer eat that I had to make a huge adjustment psychologically as to how I looked at nutrition. The five food group thing was out. Zachary could not eat most grains and those he could eat, he pretty well disliked all but one or two. The same was true for fruits and vegetables. He had never been big on them to start with and those he did like, he could not have due to the high phenol content. So, my first problem was making sure he got all his necessary vitamins and minerals. I found a company that specialized in dietary supplements (vitamins, minerals, etc.) for autistic children. This company, **Kirkman Labs**, out of Wilsonville, Oregon, became my first tool in Zachary's new diet. All of their products were available without prescription and their salespeople were always willing to take the time to talk to you about the products. From now on, Zachary would get his vitamins and minerals not from foods, but from supplements. "Food" would only be a matter of calories from now on, calories to sustain activity each day. It was very difficult psychologically to make this switch in how I looked at food…it was no longer a means of "nutrition" but rather just one of "caloric intake" to provide energy for the body.

Kirkman Labs was located in Wilsonville, Oregon (97070) and could be reached by phone at 800-245-8282 or 503-694-1600. Their web site was at www.Kirkmanlabs.com. According to their web site, Kirkman Labs has been in business since 1949. Their web site states that they worked in conjunction with Dr. Rimland, the "father of autism research" in coming up with some of the supplements for autistic children. Dr. Rimland had always stated he thought there was a biological link to autism. If they had studied autism and done so much research on these products, I was not about to reinvent the wheel. I was ready to try them. This was the only company I had found that dealt specifically with producing nutritional supplements for children with autism or learning difficulties.

Why Kirkman Labs?

In researching autism, I found that gluten was sprayed on many things…including vitamins/supplements. So, again, I had to assume all store bought vitamins contained gluten. Unless supplements specifically stated on their label that they were "gluten-free" or "casein-free", I had to assume they contained at least "gluten". Karyn Seroussi's book noted that autistic children were affected by gluten and casein AT MOLECULAR LEVEL and so, even a minute amount of these proteins could have an adverse effect on these children. Kirkman Labs' products were gluten and casein free. I found Kirkman Labs to be a "one stop shop" for Zachary's supplements and thus, a tremendous time saver. Also, Kirkman Labs provided an information sheet on pretty well all products they sold. I have replicated some of these below.

Again, I was not looking to reinvent the wheel. This company has been researching supplements and their impacts on autistic children for a few decades now...they knew a lot more about it than I did. My only reason for providing their "information sheet data" was to provide what they had learned as "they state it". The research had already been done on how these products were used and how they helped these children. Including the Kirkman Labs information sheets just made the writing of this particular section on Zachary's diet easier and more efficient. I did contact Kirkman Labs in order to obtain permission to use this information in my book. They focused only on providing products for autistic children and others with learning disabilities and as such, I felt they would have a better understanding of Zachary's needs than would most companies out there...and that saved a lot of valuable time!

In addition to providing the supplements below, I have indicated whether or not the product was maintained at room temperature or refrigerated and have provided an approximate annual cost for each product.

Word of Caution: **I never gave vitamins with animal fats or oil of any type. It just "flushes" the vitamins and wastes money**.

Also, life is not perfect. There were definitely days where I would forget to give Zachary his supplements...not often, but it did happen. When that occurred, I would just get back on track with normal doses. I NEVER "gave more" of a supplement than the recommended dose. Just getting back on track was the best thing to do. At other times, I would purposely choose to give Zachary's system a little break for maybe a week each two or three months.

Finally, I found I HAD to use measuring spoons. Estimating doses was difficult and I found that when I just estimated, I was more than likely "off". All of Zachary's supplements were non-prescription, but still, they did get expensive and so I found it wise to measure accurately.

Super Nu-Thera

This was Zachary's "power-punch" vitamin, available in liquid or powder form. Zachary did not like the taste of the liquid form even though I tried to hide it in foods/drinks. It had always been very difficult to get Zachary to take anything...even fresh orange juice. The powder form available in a capsule worked fine for him. I found it easy enough to hide. It also tasted better to him. Anyway, these vitamins provided high doses of vitamins that were not properly absorbed by autistic children. The chart below was replicated from the back of the Super Nu-Thera 450 gram dietary supplement powder container. Especially noteworthy was the vitamin B-6 dose…it was 25,000% the normal daily value for vitamin B-6. Vitamin B-1 and Vitamin B-2 were also very high doses. Vitamin B was a key factor in neurological development.

With Zachary, we chose to introduce supplements slowly to see how he reacted to each one. For the liquid vitamin, we found he had more difficult a time taking it orally and he seemed to develop more diarrhea than we would have thought. We tried the liquid over and over and it got to the point that even a small amount was not well tolerated by his system. The Super Nu-Thera 450 gram dietary supplement powder (chart below) he did not like due to the taste. When I spoke to a representative at Kirkman Labs about the "taste" issue, she stated most kids were fine with it. Luckily for me, the company had a third product and that one worked well for him…Nu-Thera Hypoallergenic Capsules. I can not explain why that was, I just know that this was what we experienced.

This particular product we kept at room temperature per the manufacturer. We allocated about $70.00 for a one year supply for a child four and under. As Zachary ages, he may require a little more since body weight was a factor when determining proper dose.

Super Nu-Thera 450 gram dietary supplement powder :

Super Nu-Thera Supplement Facts	Serving Size = 5 grams Servings Per Contain = 90	
Amount Per Serving:		
Calories: 6	Calories From Fat: 0	
Sugars: 1.6 grams		
Each Serving Contains:	Amount Per Serving	% Daily Value
Vitamin A (Acetate)	5000 IU	100%
Vitamin D	200 IU	50%
Vitamin C (Ascorbic Acid & Sodium Ascorbate)	500 mg	**833%**
Vitamin B-1 (Thiamine Nitrate)	15 mg	**1000%**
Vitamin B-2 (Riboflavin)	15 mg	**882%**
Vitamin B-6 (Pyridoxine HCL)	500 mg	**25,000%**
Niacinimide	30 mg	150%
Vitamin B-12 (Cyanocobalamin)	10 mcg	166%
Pantothenic Acid (Calcium Pantothenate)	20 mg	200%
Vitamin E	30 IU	100%
Folic Acid	400 mcg	100%
Biotin (d-Biotin)	100 mcg	32%
Magnesium (Magnesium Oxide)	250 mg	62%
Zinc (Zinc Citrate)	10 mg	66%
Manganese (Sulfate)	1500 mcg	42%
Selenium (Chelate)	50 mcg	71%
*Percent Daily Values are based on a 2000 calorie diet		
Other Ingredients: Fructose, Natural Flavor, Natural Sweetener, Natural Orange Flavor, Silicon Dioxide		Does not contain: Sugar, starch, soy, fish oil, acacia, wheat, corn, milk, yeast, casein, gliadin, gluten, or artificial colorings.

As I stated earlier, Zachary did not like the taste of this particular powder, so, we went with the Nu-Thera Hypoallergenic Capsules. I was able to pull the capsules apart and easily hide the supplement in his food/drinks. The label on the back of the capsule product was as follows:

Nu-Thera with P5P
Contains P-5-P the active co-enzyme of vitamin B-6**
Serving Size: 2 capsules

Each Serving Contains	Amount Per Serving	% Daily Value
Vitamin A (Acetate)	2500 IU	50%
Vitamin D	200 IU	50%
Vitamin C (Ascorbic Acid & Sodium Ascorbate)	60 mg	100%
Vitamin B-1 (Mononitrate)	7.5 mg	**500%**
Vitamin B-2 (Riboflavin)	7.5 mg	**441%**
Niacinimide	20 mg	100%
Vitamin B-12	10 mcg	166%
Pantothenic Acid (d-Calcium Pantothenate)	10 mg	100%
Vitamin E (Acetate)	30 IU	100%
Folic Acid	400 mcg	100%
Biotin	200 mcg	66%
Magnesium (Glycinate, Oxide))	100 mg	25%
Zinc (Citrate)	10 mg	66%
Manganese	1500 mcg	42%
Selenium (Chelate)	25 mcg	25%
P-5-P (Pyridoxal 5 Phosphate)**	50 mg	Daily Value not established
*Percent Daily Values are based on a 2000 calorie diet		
Other Ingredients: plant cellulose, magnesium stearate, silica.	Important: The capsule shell is made from plant cellulose; magnesium stearate and silica are added as lubricants.	Does not contain: casein, gluten, sucrose, artificial color, flavorings, preservatives, yeast, soy, corn, wheat, or milk.

The Vitamin B-6 was provided in the form one would have if it was already digested, as P-5-P, the active co-enzyme of vitamin B-6, and that was why it was not listed under "B-2" in the above label….so, Vitamin B-6 was still present in this product, it just appeared in a different form.

KIRKMAN LAB INFORMATION SHEET ON NU-THERA HYPOALLERGENIC CAPSULES STATED:

> "Nu-Thera Hypoallergenic Formula is a condensed version of Super Nu-Thera which contains no fillers, sweeteners, flavorings or allergens. This product is formulated for those individuals who are sensitive or have allergies to ingredients commonly used in the dietary supplement industry. Individuals who are unable to use other Super Nu-Thera products due to sensitivities or reactions to certain ingredients will now have a suitable product to use to get the nutritional benefits without the fear of a reaction to ingredients. Nu-Thera Hypoallergenic capsules have the following features:
>
> *Capsule shell is made from plant cellulose, not animal gelatin like other products
> *No fillers are used
> *No flavorings are used
> *No sweeteners are used
> *No preservatives are added
> *No colorings are present
> *Only vegetable grade magnesium stearate is used as a lubricant
>
> This product contains 50 mg. Of Pyridoxal 5 Phosphatet (P5P) and 100 mg. Of Magnesium from a glycinate-oxide blend. In addition it contains condensed potencies of all of the other nutrients present in other Nu-Thera products. The condensation of some of the potencies was required so as to fit all the nutrients in the small easy to swallow capsule.
>
> The Vitamin C content of the Nu-Thera Hypoallergenic formula is less than recommended levels for autistic children, and it is therefore advised that additional supplementation be given. Kirkman offers Vitamin C 250 mg. In the hypoallergenic line, plus a chewable Vitamin C product. Other nutrients which have been reduced can also be supplemented such as Magnesium or Vitamin E if necessary, but even the condensed potencies are substantial enough for most individuals except for the Vitamin C. When hyperactivity is a concern extra Magnesium supplementation could be necessary and when immune weakness is apparent, extra Vitamin E supplementation would be warranted. Kirkman has both of these products in the hypoallergenic line as well".

This product worked very well for Zachary. It was important to note, however, that although I had not given him the powdered form (first of the two labels above) in several months, I recently tried it again (on November 13th, 2001) and he took it just fine. So, as with everything, it was often trial and error several times before Zachary accepted something new. If there was one thing I had learned about being the parent of an autistic child it was that I became very "in tuned" with everything about my child's behavior, down to very minute details that provided hints as to when I might be able to try again (i.e., change in texture preferences, etc. in other foods). Since Zachary was put on Nu-Thera capsules, per the manufacturer's recommendation, I also supplemented with Vitamin C and Magnesium.

Buffered Vitamin C Powder

Vitamin C helped the immune system. Again, this product was one that remained at room temperature. Zachary only needed to get ¼ teaspoon of this per day (powdered form was what I used) and it came in a 7 oz jar. Kirkman Labs had capsules also for Vitamin C. We allowed $25.00 or so for a one year supply.

KIRKMAN LAB INFORMATION SHEET ON VITAMIN C STATED:

> “Many physicians are recommending very high doses of vitamin C for autistic patients especially those undergoing heavy metal detoxification. Up to now Kirkman has offered two forms of vitamin C, chewable tablets and Hypoallergenic capsules both of them dosed at 250 mg. With doctors now suggesting from one to three grams daily, the 250 mg dosage forms may not be convenient or practical.
>
> Kirkman has therefore developed a buffered vitamin C powder which is very easy to administer and is great tasting. Vitamin C is formulated with sodium, potassium and magnesium ascorbates to produce a buffered product which is very gentle on the stomach because the normal high acidity of ascorbic acid is counteracted by the ascorbates. A small amount of sucralose and natural passion fruit is added to make the product taste great when dissolved in water or juice. One quarter of a teaspoon supplies 1100 mg of vitamin C.
>
> Vitamin C is the most popular vitamin supplement in the country. The list of health conditions where Vitamin C has shown to be of value is indeed very long. Vitamin C has some specific roles in autism, however, making it a necessary supplement in the nutritional treatment of autistic children. Some of its key roles include:
>
> *Vitamin C boosts the immune system
> *Vitamin C inhibits Candida growth
> *Vitamin C promotes wound healing and gut healing
> *Vitamin C protects against toxins and allergens
> *Vitamin C inhibits certain viral activity”

Magnesium

Again, per the recommendation of the manufacturer of Super Nu-Thera, I did put Zachary on a magnesium supplement because he was quite “hyper” at times. It did seem to help him although he still had “his days”, but then again, all children did.
This was another product that came in capsules and was maintained at room temperature. We allowed $20.00 for a one year supply. Like the vitamins, this product was not given with animal fats or any oils as that just “flushes” them from the system.

KIRKMAN LAB INFORMATION SHEET ON MAGNESIUM STATED:

> “Magnesium is an essential mineral that is involved in many body functions as well as being a constituent of bones and teeth. It is essential for element of cellular metabolism and is an enzyme activator. Magnesium is extremely important in autism and other developmental disorders for the following reasons:
>
> *Magnesium counteracts the side effects of high B-6 therapy
> *Magnesium helps curb hyperactivity
> *Magnesium relaxes nerve impulses and muscle contractions
> *Magnesium helps prevent muscle spasms such as tremors or twitching
>
> Dr. Bernard Rimland is the leader of Vitamin B-6 therapy in treating autism. Dr. Rimland has concluded that supplementation with Magnesium along with the B-6 administration gave improved results. Side effects of the B-6 such as irritability, sound sensitivity, hyperactivity, and bed wetting stopped when Magnesium was included.
>
> Dimethylglycine (DMG) and Trimethylglycine (TMG) are often used in helping to treat autism. These compounds can cause hyperactivity in some individuals. Magnesium can be helpful in this situation along with folic acid.
>
> Signs and symptoms of magnesium deficiency include fatigue, mental confusion, heart disturbances, irritability, weakness, muscle spasms, loss of appetitie, insomnia, and a feeling of weakness. Cardiovascular disease can be triggered by inadequate magnesium. Cardiac arrhythmias are often benefited by this mineral.
>
> Kirkman’s Super Nu-Thera products contain Magnesium in the correct ratio to Vitamin B-6 for most individuals. Some users have found that additional magnesium is necessary to curb hyperactivity and help in normal sleep patterns”.

TMG (Trimethyglycine) Liquid with Folic Acid and Vitamin B-12

Again, in researching autism, I found that Dr. Rimland and Kirkman Labs were very excited about this particular supplement. It seemed to somehow help trigger language in autistic children. I thought to myself, fine, I'll try it. I had nothing to lose. Zachary had lost language and was now down to less than five words. If this could somehow help to get him talking again, it was worth a try. Again, I was not out to reinvent the wheel. I figured if they got anything positive in autistic children from any of these supplements, I would give them a try.

This was another product that we kept at room temperature. It was available in liquid, powder or capsule form. We went with the liquid for Zachary. We allowed approximately $60.00 for a one year supply.

KIRKMAN LAB INFORMATION SHEET ON TMG WITH FOLIC ACID AND B-12 STATED:

> "TMG is DMG with one more methyl group. TMG stands for Trimethyl-glycine while DMG stands for Dimethylglycine.
>
> DMG is well known in the autistic community. For many, it improves speech, behavior and energy. Not many people however know about its "Big Brother" TMG. In short, TMG provides several remarkable benefits and then becomes DMG!
>
> TMG donates one methyl group (it has 3 methyl groups while DMG has 2) that reduces harmful homocysteins and increases beneficial seratonin by stimulating the production of a precursor called SAMe, which acts as a natural antidepressant by increasing the level of seratonin. The remaining two methyl are DMG. The liquid has a pleasant sweet taste and includes Folic Acid and Vitamin B12.
>
> *All the advantages of DMG and more
> *Increased seratonin levels
> *Folic Acid and Vitamin B-12 included
> *Casein and Gluten Free"

Another information sheet from Kirkman Labs provides more information on TMG. It stated:

Trimethyglycine
(TMG)
DMG's big brother that does so much more….

How is TMG Different from DMG?

In simple terms TMG is DMG with one more methyl group. TMG stands for Trimethyglycine while DMG stands for Dimethyglycine.

Dimethyglycine (DMG) is well known in the autistic community. …Not many people however know about its "Big Brother", Trimethyglycine (TMG). In short, TMG provides several remarkable benefits and then becomes DMG.

TMG donates one methyl group (it has 3 while DMG has 2) that reduces harmful homocysteins and increases beneficial seratonin by stimulating the production of a precursor called SAMe. The remaining two methyl are DMG!!! The formula is 250 mg of TMG will result in 125 mg of DMG.

What is Trimethyglycine (TMG)?

TMG is a naturally found chemical compound found in some foods. It can be extracted from sugar beets in a very concentrated form. The result is a 99% pure white crystallized powder with a distinctive taste. It is mildly sweet with a mild aftertaste.

TMG is also known as glycine betaine.

What is the Benefit of TMG?

TMG is the newest and most effective methylation-enhancing compound. Methylation is a natural process that makes new cells, creates natural antioxidants and breaks down harmful chemicals.

TMG converts one of these harmful chemicals, toxic homocysteine into methionine. It also boosts the level of beneficial SAMe and then becomes DMG (Dimethyglycine). It takes approximately 250 mg of TMG to naturally produce 125 mg of DMG.

This methylation of TMG produces the following benefits:

1. TMG methylation lowers dangerous homocysteine levels, thus lowering the risk of heart disease and stroke. Methylation is the primary process by which homocysteine is transformed into nontoxic compounds such as SAMe.
2. TMG methylation produces SAMe, which may have potent anti-aging effects, and has been shown to alleviate depression, remylenate nerve cells, improve Alzheimer's and Parkinson's disease patients, and protect against alcohol-induced liver injury.
3. Methylation protects DNA".

I never used DMG at all since TMG was available by the time we figured out what was wrong with Zachary. He has done well on TMG and takes it easily.

Folic Acid With B-12

The liquid folic acid needed to be refrigerated so we always had to keep that in mind when traveling. We simply packed it on ice. The dose was only ¼ teaspoon per day. We allowed about $25.00 per year.

KIRKMAN LAB INFORMATION SHEET ON FOLIC ACID WITH B-12 STATED:

> "Folic acid is a vital nutrient for all individuals and has recently been recognized by the US government as a necessary supplement to be included in everyone's daily diet. For children with autism this can be especially important because of their very often limited diets. For those using DMG, Folic Acid is even more necessary because DMG can reduce the amount of folic acid in our body.
>
> To offset the reduced folic acid Kirkman Labs has developed a pleasant tasting liquid combining Folic Acid and vitamin B12. In most cases this will prevent or eliminate hyperactivity which is one symptom of folic acid deficiency. Because folic acid can sometimes mask a vitamin B12 deficiency, vitamin B12 has been added to the product as well.
>
> *A fundamental nutrient required for good health
> *Casein and gluten free
> *Can eliminate hyperactivity created by the use of DMG
> *Pleasant tasting liquid can be used alone or with other beverages"

and still another Kirkman Lab fact sheet on Folic Acid and B12 stated:

> "Folic Acid With B-12
> *A common B vitamin with amazing results for autistic children…now in a new liquid*
>
> Why Folic Acid is Important?
>
> Folic acid produces many health benefits. One of the most important to autistic children is the reduction in mitochondrial stress, common in these children.
>
> Folic acid helps protect the chromosomes, is needed for the utilization of sugan and amino acids, promotes healthier skin, and helps protect against intestinal parasites and food poisoning.
>
> What is Folic Acid?
>
> Folic acid (also called folic acid or folacin) is a vitamin in the B group. Foods rich in folic acid include grains, green vegetables (spinach, broccoli), meat (liver) and legumes (lentils and kidney beans).
>
> Folic acid acts as a coenzyme (with vitamin B-12). It also stimulates the formation of digestive acids.
>
> Why Did not We Get Enough Folic Acid?

Although present in these foods, it is often difficult to obtain enough folic acid from diet alone. Some 80 percent of Americans, especially children, are not getting enough.

What are we doing wrong? For one thing, we aren't eating enough vegetables. In fact, if current USDA data is to be believed, the average American is lucky to get one serving of folic acid-rich fuits or vegetables a day.

Does Folic Acid Effect Emotional Health?

Our nervous system is very active and as the activity in the central nervous system increases the needs for folic acid increases.

Studies have linked low levels of folic acid with disturbances in behavior and other problems with nervous system functions.

In a review of folic acid in psychiatric disorders studies published between 1967 and 1992, the researchers concluded that low levels of folic acid is very common among individuals admitted to hospital for emotional behavior.

In the studies it was concluded that the mental problems improved with folic acid supplementation.

In a recent study patients that had low levels of folic acid had the lowest scores for cognitive functions and when given supplements of folic acid greatly improved their scores in memory tests.

A recent study published in Medscape, Dr. Jonathan E. Alpert, MD, PhD, a medical researcher from the Harvard Medical School, discussed the relationship between folic acid and mental health. He says in part:

> 'A relationship between folic acid and neuropsychiatric disorders has been inferred from clinical observation and from the enhanced understanding of the role of folic acid in critical brain metabolic pathways. Depressive symptoms are the most common Neuropsychiatric manifestation of folic acid deficiency. Conversely, borderline low or deficient serum or red Blood cell folic acid levels have been detected in 15% to 38% of adults diagnosed with depressive disorders. Recently, low folic acid levels have been linked to Poorer antidepressant response to selective seratonin Reuptake inhibitors. Factors contributing to low serum folic acid levels among depressed patients as well as the circumstances under which folic acid and its derivatives may have a role in antidepressant pharmacotherapy must be further clarified.
> [Medscape Mental Health 2(1), 1997. ^{c} 1997 Medscape, Inc.]

Is It Better to Get Folic Acid From Food or Supplements?

Folic Acid is one of the few nutrients that are better absorbed in its synthetic form. The reason? Dietary folic acid is a complicated molecule that must be broken down by enzymes in the gastrointestinal tract. Anything that interferes with those enzymes; whether it is age, illness, or the action of other nutrients; can interfere with folic acid absorption.

Why You Should Take B-12 if you are Taking Large Doses of Folic Acid?

Folic acid should be taken with Vitamin B12 to prevent the folic acid from masking a B12 deficiency.

Calcium Supplement With Vitamin D

Since autistic children can not tolerate casein, found in cow's milk, I put Zachary on a calcium supplement, again, developed by Kirkman Labs specifically for children like Zachary just to make sure his bones were getting enough of it. This product was kept at room temperature. We allowed approximately $30.00 for an annual supply.

KIRKMAN LAB INFORMATION SHEET ON CALCIUM POWDER WITH VITAMIN D STATED:

> "Many individuals with autism do not get enough calcium in their diet. This is especially true if they are on a dairy free diet. This shortage of calcium is a problem because calcium is essential for good health.
>
> Apart from being a major constituent of bones and teeth, calcium is crucial for nerve conduction, muscle contraction, heartbeat, blood coagulation, and the production of energy and maintenance of immune function.
>
> Calcium deficiency in children can cause rickets, bone deformities and growth retardation. Low calcium intake also contributes to high blood pressure, osteoporosis and colon cancer.
>
> Kirkman's Calcium with vitamin D is available in a pleasant tasting powder that is partially absorbed in the mouth (the mouth contains many small blood vessels close to the surface and calcium is absorbed directly into the blood stream) as well as in the small intestine. The great taste of Kirkman's Calcium Powder with Vitamin D is a result of using the calcium carbonate form of calcium. No other form of calcium is as good tasting and easy for children to accept.
>
> Kirkman's Calcium with vitamin D can also be used in cooking and baking. It has been successfully incorporated into cookies, pancakes, muffins and other baked goods."

Yet another information sheet from Kirkman Labs stated:

> "Why is Calcium Important?
>
> Many individuals with autism do not get enough calcium in their diet. This is especially true if they are on a dairy free diet (gluten and casein free). This shortage in calcium is a problem because it is essential to our health.
>
> It is the most abundant mineral in the body. It makes up 1.5 to 2 percent of the total body weight. Our bones contain 99% of the body weight of calcium.
>
> Our Body Will Take the Calcium it Needs by "Eating Our Bones"
>
> When dietary calcium is insufficient or serum calcium levels drop, the body takes calcium from bones. That can leave them weak and prone to fracture. "Eating our bones" as a source of calcium, rather than getting it from the diet can have devastating consequences. Once bone loss has occurred it cannot be restored. Prevention is the key.
>
> Typical American Diet Causes Calcium Deficiency
>
> The typical American diet consists of processed foods, carbonated soft drinks, caffeine, high protein, sugar and excessive salt consumption. This interferes with calcium and can result in very low calcium levels in the body.
>
> How Much Calcium is Necessary for Us to Take?
>
> Many researchers suggest that to stay healthy the average body, before the age of 24 (man or woman), needs up to 1200 mg of calcium daily.
>
> It is very difficult to get enough calcium in a normal diet. This is especially true if the person is cutting down on the consumption of dairy products, which is the best source of calcium. In order to get enough calcium you would need to drink 3-4 glasses of milk a day or eat four pounds of broccoli a day. Below is a table of the calcium content of popular foods. (milligram abbreviated is mg)

Food Type	Serving	Calcium (mg)
Milk	8 oz glass	302
Orange Juice	8 oz glass	300
Cheese	1 oz slice	174
Broccoli	4 oz serving	108
Potato	8 oz serving	30
Bread	One slice	20
Tomato	One	5
Rice	8 oz serving	2

What is In Kirkman's Calcium?

Kirkman's Calcium is a blend of:
*Calcium Citrate – very easily absorbed
*Calcium Carbonate – very easily absorbed
*Vitamin D – essential for calcium to absorb
*Only natural sweeteners and natural flavors

What is NOT in Kirkman's Calcium?

Kirkman's Calcium DOES NOT contain any:

Sugar, starch, soy, fish oil, acacia, wheat, corn, milk, yeast, casein, gliadin, gluten, or artificial flavorings or dyes

What is the Best Form of Calcium to Take?

Kirkman's Calcium Powder with Vitamin D is available in a great tasting powder that is partially absorbed in the mouth (the mouth contains many small blood vessels close to the surface and the calcium is absorbed directly in the blood stream) as well as in the small intestine. It is very easy to absorb. Vitamin D is added to help the calcium absorb better.

The good news is that you can cook with this calcium. Neither heat nor cold affects Kirkman's Powder. The taste will disappear in most foods"

Super Cranberry Extract ™

Cranberry juice, garlic and oil of oregano have all been proven to be beneficial in controlling candida (yeast found in most autistic children's intestine). I decided to go with this particular cranberry extract for several reasons. First, gluten-free garlic in pill form was difficult to obtain. Even when I did find some, and tried to hide it in French fries, or some other food. Zachary usually detected it and spit out whatever I was feeding him…and of course, due to the taste and his young age, he absolutely refused to eat any fresh garlic. As far as oil of oregano, I did find organic oil of oregano through a health food store. My sister-in-law who had a child of eleven that was diagnosed with PDD swears by it. One or two drops on the tongue was supposed to be fantastic in helping to control yeast. Christine had done a lot of research on healthy alternatives to treating her son and so, when she suggested it, I decided I would give it a try.

Well, even one or two drops was still too much for Zachary... he would spit it out and wipe his tongue on his shirt for about two minutes. Oil of oregano has a very strong taste…even for adults. It got to be that Zachary would "see me coming" with the stuff and run off as fast as he could. Giving him oil of oregano was very difficult to say the least and I did not want a battle on my hands each time I tried to give him a supplement. Some parents use Nystatin to treat yeast infections, but that was something for which they needed a prescription (even though I believe it was a completely natural product – not sure on that though) and I knew there were still differing opinions on its use. I was not interested in putting Zachary on any long-term prescription of any kind (anything over thirty days) and I had read somewhere that you often "go off, then back on" Nystatin. So, that left me with cranberry extract, a product for which I did not need a prescription and a product I knew was safe.

Super Cranberry Extract ™ was kept at room temperature. The recommended dosage was for three tablets per day...I usually gave him two. This product was rather expensive, costing approximately $350.00 per year. It was an excellent product, however. I still tried to supplement somewhat with my "crushed garlic tablets", but not always. I used organic garlic tablets since anything else most likely had gluten on it. Fresh garlic would have been great but Zachary refused to take it – of course – one clove a day was needed as daily intake to control yeast. There was no way I could ever get Zachary to go with that! Oil of oregano had a very strong taste. I doubt most children would take it although I know some who do. It was also quite expensive ($28.00 for a 10 ml bottle – basically 2 teaspoons). The cranberry product was a good one and along with other supplements, I hoped that would be all I needed to help control Zachary's yeast. Every once in a while I still saw a red circle around his anal area though so I felt the "yeast battle" was probably not completely won...I found it tended to be a recurring thing.

There was always the Nystatin option. Again, that required a prescription. I am not aware of the cost, but getting Nystatin to do the initial "kill" of the yeast and then putting Zachary on cranberry extracts and other products as shown below was certainly an option too. We chose not to go with Nystatin but just with the non-prescription items. I do not recall Nystatin's side effects but if I ever I decided to go that route that would certainly be something else I would need to discuss with a doctor...in addition to "how long" Zachary might need to be on it. But, I am not convinced I want to go that route yet. If I recall, children usually went "on and off" this product.

KIRKMAN LAB INFORMATION SHEET ON SUPER CRANBERRY EXTRACT^{TM} STATED:

> "Kirkman's Super Cranberry Extract^{TM} is a new patented form of cranberry extract that is 64 times more potent than any other cranberry extract on the market. <u>Each tablet is equal to about 10 gallons of cranberry juice!</u>
>
> Kirkman's Super Cranberry Extract^{TM} is an active nutraceutical concentrate prepared from cranberries by a proprietary resin-based process. This unique process yields a concentrated extract, which possesses far superior antibacterial properties, antioxidant properties and anthocyanin content than those usually associated with cranberry juice.
>
> Kirkman's Super Cranberry Extract^{TM} has been shown in vitro to completely inhibit the growth of the following bacteria:
>
> *E.coli
> *Staphylococcus aureus
> *Staph epidennidis
> *Bacillus subtilis
> *Yersinia enterocolitica
> *Serratia marcescens
> *Salmonella typhimurium
> *Pseudomonas aeruginosa
> *Pseudomonas fluorescens
> *Garderella vaginalis
>
> Kirkman's Super Cranberry Extract^{TM} has also been tested in vitro on Candida yeast strains and has exhibited the ability to kill or deactivate the yeast cells.
>
> Kirkman's Super Cranberry Extract^{TM} does not affect acid based friendly bacteria! It is all natural and has no side effects. It is very safe: in fact, the joint Food and Agriculture Organization/World Health Organization Expert Committee on Food Additives established an allowable daily intact limited only by Good Manufacturing Practices.
>
> Kirkman's Super Cranberry Extract^{TM} is naturally casein and gluten free"

Acidophilus Plus

Most autistic children have had the "earache battle" from very early on. This was more than likely due to the fact that parents were unaware their children were gluten intolerant. Gluten rich foods (wheat, oats, barley, etc.) and dairy rich foods are found in almost everything we eat and these foods contribute to heavy mucus production…mucus that laid in the sinuses. Infants and young children (to age two or so) have an immature Eustachian tube (middle ear). As they grow older, the tube takes on a marked curvature to better help with drainage. As infants and young children (again to age two or so) ingest dairy and gluten rich foods they produce more mucus. With improper drainage as a result of the immature ear and excess mucus, earaches often resulted. And, with earaches, came the next culprit….antibiotics. Antibiotics killed harmful bacteria in the system but they also killed the "friendly bacteria" our body needs. Again, the research had already been done on the effects of antibiotics and , therefore, I once again only provided the information as it appeared on Kirkman Labs information sheet.

NOTE: It was important to "rebuild" the friendly bacteria in Zachary's intestine. In order to do that, initially, Zachary was on both Acidophilus Plus and Kirkman Labs' scFOS ("food for the friendly bacteria to multiply" – as Kirkman Labs described it). Zachary still takes acidophilus plus every day, but he no longer takes the scFOS since that was only required for a month or so and his acidophilus levels should now be fine. I have, however, included information from the scFOS fact sheet as well, as provided by Kirkman Labs when I initially purchased this product.

Acidophilus needed to be refrigerated. So, again, that was a supplement we were always careful to pack on ice when we traveled. We allowed $50.00 or so for an annual supply.

KIRKMAN LAB INFORMATION SHEET ON ACIDOPHILUS STATED:

"The Friendly Bacteria Your Intestine Needs

> 'Since a high percentage of children with autism are deficient in the production of IgA, their immune system may have more difficulty in excluding overgrowth of harmful yeast and bacteria'
> Dr. William Shaw of the Great Plains Laboratory.

Why do we Need Friendly Bacteria?

Friendly bacteria insures proper intestinal health. They help digest and absorb food, promote vitamin production, suppress bad bacteria and aid in waste elimination. These friendly bacteria live throughout the large and small intestines.

What are the Benefits of Friendly Bacteria?

There are over 400 varieties of friendly bacteria. While acidophilus is probably the best known of these, other important ones include L. casei shamnosus, Bifidobacterium bifidum, B. longum B. Infantis.

The benefits of these "friendly bacteria" are numerous:

*They actively produce antibacterial substances that kill or deactivate hostile disease-causing bacteria.
*They manufacture some of the B vitamins including niacin (B3), pyridoxine (B6), folic acid, and biotin.
*They manufacture the milk-digesting enzyme lactase which helps digest dairy products.
*They improve the efficiency of the digestive tract – when they are weakened, or bowel function is poor. Chronic diarrhea or constipation can be completely eliminated with the right friendly bacteria population.
*They plan an important part of the development of a child's digestive function and immune system.

Therapeutically they have been shown to be useful in treatment of acne, psoriasis, eczema, allergies, migraine, gout (by reducing uric acid levels), cystitis, candidiasis (yeast infections), colitis, irritable bowel syndrome, and some forms of cancer.

How did Bacteria Begin in the Body?

Many autistic children are treated with too many antibiotics. Autistic children's weakened immune systems are prone to infections. One of the common side effects of treatment with antibiotics (especially the broad-spectrum type) is that levels of friendly bacteria are killed off, opening the door to yeast (candida) infestation and gastrointestinal distress, particularly diarrhea.

In addition, many autistic children have very poor eating habits including, ingesting high levels of animal fats, sugars, and can inhibit the friendly bacteria. Highly processed foods and fast foods can increase acid levels in the intestine and this highly acidic environment will damage the friendly bacteria.

Many Autistic Children's Friendly Bacteria are Very Low.

In a healthy person 85% of the bacteria is friendly and only 15% is unfriendly.

However in most of the autistic children this balance has shifted unfavorably to 80% unfriendly bacteria and 20% friendly bacteria, creating a very unhealthy condition called intestinal dysbiosis that in turn can become the seedbed for many illnesses including candida overgrowth.

Autistic children need significant supplementation of friendly bacteria every day to replenish healthy intestinal flora, rebalance the microbial populations, and enhance intestinal permeability and thereby nutrient absorption.

Kirkman's Acidophilus Plus

Kirkman's Acidophilus Plus is Dairy Free and a very potent probiotics combining the 5 most important friendly bacteria including B. infantis. B. infantis is very important for children under 8 years old.

The product is grown with a potency of 8 billion cells per gram (a gram is 1/4th of a teaspoon). It is manufactured, stored and shipped under refrigeration to insure the potency.

Kirkman Labs scFOS ("food for the friendly bacteria to multiply" – as Kirkman Labs described it)

I only used this product for two months or so but am thinking of putting Zachary on it for another "two-month annual dose" just to make sure he was still ok with his "friendly bacteria". The literature from Kirkman Labs did not state whether or not this needed to be an "ongoing" product and so, after I had raised his "friendly bacteria" count, I took him off of it. <u>If I recalled, this product was refrigerated</u>. An 8 oz powder supply was $25.00.

KIRKMAN LABS INFORMATION SHEET ON scFOS STATED:

"The Japanese have found a simple way to improve your digestive system…food for the friendly bacteria to multiply.

Antibiotics and the Harm They Do to the Friendly Bacteria

Antibiotics, when properly prescribed, are important medical tools that prevent serious bacterial infections from becoming life threatening.

Unfortunately, broad-spectrum antibiotics kill friendly intestinal bacteria as well as bad, completely upsetting the bacterial balance of power in the gastrointestinal tract. Friendly bacteria are critical to good health.

As the intestines recover from an antibiotic, good and bad bacteria fight for dominance by competing for food and attachment sites. Too often, the bad bacterium wins and then dominates.

Kirkman's scFOS is a prebiotic – a substance not digestible by the human system. It travels directly to the colon and feeds the friendly bacteria. FOS for the most part is indigestible and therefore acts as a non-digestible fiber in the diet. Feeding the beneficial bacteria Kirkman's scFOS is the best way to maintain a stable number of friendly bacteria in your system. Ailment begins in or is aggravated by a toxic or malfunctioning digestive tract.

The Discovery of scFOS

About twenty years ago in an isolated area of Japan, medical researchers discovered that the local population had remarkably good intestinal health. Eventually, it was determined that these people had an unusually high count of bifidobacteria, a friendly bacterium, in their gastrointestinal tracts because their diets were rich with foods that contained a special nutrient, selectively feeding this friendly bacterium. That nutrient was short-chain fructooligosaccharides (scFOS).

What is Kirkman's scFOS?

Kirkman's scFOS is the purest, most concentrated form of short-chain fructooligosaccharides (scFOS) available which helps one's own strain of friendly intestinal bacteria to reproduce. This naturally occurring class of carbohydrates is found in small quantities in a variety of fruits, vegetables and grains.

How Does the Body Use Kirkman's scFOS?

Upon reaching the lower intestine, Kirkman's scFOS is selectively used by the beneficial lactobacilli and bifidobacteria naturally residing there. Kirkman's scFOS provides a powerful fiber effect without the bulk or grit commonly found in other fiber products.

Kirkman's scFOS is a mildly sweet, low-calorie powder or syrup that can be sprinkled on cereal, fruit, or mixed into beverages. It contains no milk, soy, corn, wheat or chemical preservatives. It can be used in baking and makes a wonderful smooth, sweet addition to most recipes.
How Much scFOS Should You Take?

Kirkman's scFOS supplementation assures that you will be increasing the numbers of beneficial bacteria that are indigenous to the gastrointestinal system and the strains of bacteria that will most benefit the body's gastrointestinal functions….In fact, scientific studies show that just one gram

> (1/4 teaspoon) per day added to the daily diet can increase friendly intestinal bacteria over fivefold in only 4 weeks."

Other Kirkman Labs Supplements

Although I've never used these particular products, Kirkman Labs also has "yeast control" products that are used in conjunction with Nystatin. They carry other products but, again, I have never used them and so really can not comment as to what they are for or how well they work. My intent here was only to let parents know that there are many things they may want to investigate as far as Kirkman Labs' product line.

END OF KIRKMAN LABS SUPPLEMENTS/SECTION

ZACHARY's OTHER SUPPLEMENTS

In addition to all of the supplements listed above, I also gave Zachary the following:

Organic Borage Oil, Flax Seed Oil or Cod Liver Oil

As much as possible, I tried to go with organic products (no pesticides, additives, etc.) Borage Oil was high in Omega-3 something necessary for proper brain development. The brand I currently used was called Barlean's Borage Oil. It was manufactured by Barlean's Organic Oils located at 4936 Lake Terrell Road, Ferndale, WA 98248 (800-445-3529). I was able to obtain this product through a small health food store nearby.

I had originally started by giving Zachary not borage oil, but flax seed oil and cod-liver oil, also high in Omega-3. I used cod-liver oil, the least expensive option, for maybe one or two weeks. Of course, Zachary did not like it and it was difficult to get him to take it. I found <u>the use of cod-liver oil almost immediately got rid of his "sideways glances" though</u>. Later, I would use it again, only this time, I'd simply rub it on him and let it be absorbed through the skin. I also tried flax seed oil for about one year but found he started having a hard time tolerating that. It seemed whenever we gave it to him, he got diarrhea. We then went to the Organic Borage Oil we now use and he has been fine on that one. Primrose oil, although I had never used it, was also a good source of Omega-3 (although, I believe borage oil was a better source of Omega 6 and 9). The last time I purchased it, the borage oil was approximately $28.00 for a 4 oz bottle. That usually lasted me about two months.

I do not give it to Zachary every day…but almost. <u>Borage oil</u> (and flax seed oil) <u>needed to be refrigerated</u>. So, again, they were packed on ice when we traveled. Kirkman Labs also offered 300 Soft Gel Capsules of cod-liver oil with vitamins A and D for $16.00, but again, I have never tried them simply because I knew Zachary would not take them.

Moducare^{TM} Sterinol^{TM}

This was a non-prescription immune system booster. My sister-in-law had her PDD child on this one and she liked it a lot. She was the one who told me about this product. I gave this to

Zachary about two or three times a week…one capsule in his rice milk. It did not seem to dissolve very well, but, I still put it in there. The label on this product states:

> "Published research, performed by Prof. P. Bouic, Ph.D., a leading Immunologist, demonstrates that plant sterols and sterolins commonly found in all fruits and vegetables, are important in the functioning of the body's immune system. Moducare^{TM} Sterinol^{TM} is the same formulation of sterols and sterolins used in Prof. Bouic's research….."

Suggested use was for three capsules daily…I only gave Zachary about three capsules per week since he was on so many other supplements…some of them for his immune system also.

THIS PRODUCT DOES HAVE A WARNING ON IT FOR DIEBETICS.

The label on the product further states:

> "This patented formula is manufactured for Essential Phytosterolins Inc., and distributed by Purity Life, 6 Commerce Crescent, Acton, Ontario, Canada L7J 2X3 (zip code). For further information call toll free (877-297-7332)."

The capsules were kept at room temperature. A supply of 180 capsules cost me approximately $60.00 U.S.

HOW EACH SUPPLEMENT WAS GIVEN

How supplements were given depended on whether it was a rice free day or a day on which Zachary could have rice products.

RICE DAYS – days when Zachary WAS allowed to eat rice products. When Zachary's first morning drink consisted of rice milk, it included:

a) Calcium supplement with Vitamin D
b) Acidophilus supplement (would also include scFOS if he was taking it)
c) Folic Acid With B12 Supplement
d) TMG with Folic Acid and B12 Supplement
e) Moducare^{TM} Sterinol^{TM} Supplement (2 to 3 times per week)

I usually gave Zachary a non-dairy pudding cup or non-dairy ice cream at lunch. I could hide the vitamin supplements (Super Nu-Thera, Vitamin C and magnesium in that).

Cranberry extract tablets were a piece a cake…they had a fruity taste Zachary loved. He just popped one in his mouth and ate it twice a day. When I used the gluten free organic garlic pills (from health food store), I used to crush them (2) between two spoons and hide them in French fries that I would split with a knife. Zachary soon figured out what I was doing and so, I had to go with just the cranberry tablets.

Borage oil, I usually put on his meat in a small area. I made sure he ate that meat first. He did not notice the borage oil at all, probably because the dose only called for a half a teaspoon. He used to take flax seed oil for Omega-3 but since he developed an intolerance to that, I went with borage oil. He did not mind the taste of flax seed oil and he used to take that directly from a spoon.

"RICE FREE" DAYS – days when ABSOLUTELY NO RICE products were allowed (rice could not be part of the "ingredients" list at all on any foods for that day).

On "rice free" days, when his first morning drink consisted of diluted juice (diluted with water), it included:

a) Calcium supplement with Vitamin D
b) Acidophilus supplement (would also include scFOS if he was taking it)
c) Folic Acid With B12 Supplement
d) TMG with Folic Acid and B12 Supplement
e) Moducare Sterinol Supplement (2-3 times per week only)
f) Super Nu-Thera (I break the capsule and pour it into the drink)
f) Vitamin C Supplement
g) Magnesium

I often "refreshed" his cup with more liquid over the course of the day (i.e., put in more water or diluted juice) to make sure he drank all the supplements within it. That was especially important for the magnesium since I found it did not dilute properly in the drink, and tended to sit toward the bottom of the cup. Refreshing the "same cup" during the day (without rinsing it out) helped insure he got the magnesium too.

All other supplements were given the same way they were on rice days.

CHAPTER 12

Zachary's Foods/Diet

It was important to remember that as a parent, I had to adopt a new "view" when it came to food for Zachary. For him, food was no longer a way for Zachary to get nutrients, but rather a way to get calories. The "nutrients" he pretty well got from his supplements.

<u>It was critical to note that I pretty well tried to eliminate all artificial colors and flavorings from Zachary's diet. If something was not mentioned in this book, he did not eat it. That went for everything from drinks, to foods, to snacks! His foods were either included specifically in this chapter, or they were "included" within the product lines provided by Gluten Solutions, Inc., a provider of "gluten free" and "casein free" foods.</u>

Gluten Solutions, Inc. provided up to three hundred various gluten free foods....I had only found this company in the last ten months or so. I knew exactly what was in their products as well as what was not as their catalog clearly indicated the list of included ingredients as well as those "not included" and thus, I could easily tell what was gluten and casein free and low in phenols and what was not.

With Zachary, I found the best practice was to assume there was gluten in everything unless I could specifically rule it out. Based on Zachary's love for eating paper, chewing on wood, etc., I even assumed non-food items might contain gluten. In other words, I watched everything that went into his mouth.

Get ready for a shocker….

When we changed Zachary's diet…overnight he went from a "normal, gluten and casein packed diet" to a gluten and casein free diet that was also low in phenols…<u>he refused to eat for 5 days</u>!!! He was not getting that "high" I guess he was used to from the gluten and casein that acted like drugs on his brain in his "old diet". When the "high" disappeared, he would not eat. Like a drugged person, <u>it was as if he was in "withdrawal"</u>. He cried and had fits all the time. All I could do as a parent was to make sure he had plenty of fluids… I was determined to win this one! Fred and I were both in absolute tears. Each night we went to bed, I cried and cried. Each time I fed him over those first few days, he just spit out his food... whatever it was…and as I watched him spit it out, my tears flowed…day, after day, after day. On the 5th day, he finally gave in and started eating again… only now, he would be getting foods that were not harmful to him. If I had to do it again, would I do it differently? Well, I now know of more foods to "entice" him and so, it probably would not be nearly as difficult as it was the first time around. That was another reason for which I felt such an intense need to tell other parents who were dealing with autism about those things we went through. I now know about non-dairy "puddings", spaghetti substitutes, etc. that would have probably gotten him eating sooner had I known about them then.

I would never have expected Zachary's withdrawal-like behavior but it certainly was there! How else could I explain his absolute refusal to eat for five days at the onset of the new diet! But, I held firm and made the shift to foods that would no longer harm Zachary. I knew I would not knowingly give my child "LSD" or any other hallucinogen. Karyn Seroussi's book had explained how gluten and casein proteins acted like drugs on the brain of children like Zachary. So, likewise, I would no longer knowingly give Zachary foods that contained these proteins…to me, it would have been like handing him a hallucinogen or other "drug" with my own hands... and knowing what I now did, I simply could not do that...to me, casein and gluten = "drugs" ...plain and simple!

There were a few things I constantly had to keep in mind when caring for Zachary:

1) Gluten and casein = drugs … and phenols were pretty bad too…

2) Food = Caloric Intake Only. Food did not equal "nutrient" intake. Supplements = Nutrient Providers. Psychologically, this was a difficult thing to do.
3) Assume everything had gluten, unless I could specifically rule it out. I became an expert at reading food labels...and read them constantly even when repurchasing foods I had used in the past, just to make sure they were still ok. I avoided anything with casein or gluten and hidden sources under names like "malt", "whey", etc.

4) "Wheat Free" **<u>DID NOT =</u>** "Gluten Free".

5) "No Gluten **<u>Added</u>**" or "No Casein **<u>Added</u>**" **<u>DID NOT =</u>** "gluten free" or "casein free".

6) Products of companies that sold "gluten free" foods were not necessarily ALL gluten free, or all gluten free and casein free. Some of these companies also carried "other products" in their product line and so **<u>I could not assume that a company's name meant all products in their product line were "gluten free"</u>**. I found it easy to get confused over that...and it was critical to get it right! Product lines could have hidden sources of gluten under "spices" and so, I ALWAYS had to ask specifically about the contents of certain products.

It was critical to remember to ALWAYS read labels. Companies changed their products and what was once acceptable for Zachary in the past was not necessarily so in the future. Product lines changed constantly. I always read and re-read the product labels. That had saved me on numerous occasions. I had seen products in food stores that said: "No Gluten Added", yet if I read the label, there were ingredients in the product that contained gluten. The fact that "no <u>extra</u> gluten was added via some processing method" did not mean the product was "gluten free". I found I always had to check labels VERY carefully….and look specifically for the words "<u>gluten free</u>" or "<u>dairy free</u>" or "<u>lactose free</u>". I was absolutely disgusted by the fact that marketers tried to fool consumers by using "no gluten added" or "no dairy added"... I saw it as "deceptive advertising", a play on words...but this was no game...<u>my child's health was so</u>

dependent on accurate labeling. I kept asking myself, why were manufacturers not forced to tell the truth? How could they get away with these practices? Why could they not "be forced" to label their products gluten or casein free? That would have made life so much easier...saved so much valuable time for parents of autistic or special needs children such as myself. Instead, these food manufacturers were allowed to knowingly make our lives more difficult! My goal in writing this book was to help, somewhat, with that task...to make parents aware of the "marketing traps" and simply to help parents of autistic children save valuable time.

I was basically starting from scratch…only a few actual products had been mentioned in Karyn Seroussi's book and a few "I could use" in Lisa Lewis' "**Special Diets for Special Kids**". I said "I could use" here for one big reason... I absolutely hated to cook! I had always commented to my mother-in-law when we spoke of my niece who had "a ton of allergies", that "giving me a child "like that" - one with very limited food choices - would be the worse thing God could possibly do to me" - that was how much I hated cooking! But, God had something planned for me – a son whose foods would be even more limited than those of my niece! For Zachary, I was implementing something much stricter than what Lisa Lewis had in some her recipes...I was also very much limiting "phenols". Therefore, any recipes that included bananas, apples, raisins, and tomatoes in any form, were "out".

For over ten months, Zachary had absolutely none of those foods. In spite of my dislike of cooking, there were definitely a few recipes I did use though (and Zachary did love them). Lisa Lewis' book did have a lot of valuable recipes for mothers who did not mind cooking and as much as I hated cooking, the fact was that Zachary was on a very limited diet, and finding even just one or two recipes I could make that he loved was invaluable. The first half of Lisa Lewis' book provided important information on research, good web sites for parents of autistic/special needs children, available "tests" out there (urine tests, etc. – although, again, I never used any of these tests).

What can I say...I was just one of those mothers who simply preferred to go the easy route and find specialty vendors who already made the products I needed (like bread, cookies, etc.). Also, today, there were definitely more products available "ready made" and so that, too, simplified life. If I did not have to "make it myself", that was always the route I went. Even today, however, as I go through the pages of Lisa Lewis' book, I find yet more information I had missed the first time around. Now that I found life a little more "under control" as far as at least understanding Zachary's frustrations, who knows, maybe this year, I would break down and give cooking a little more of a try. A year and a half ago, though, life was still very much in a whirlwind and so I did go the easy route – buying ready made.

As far as "actual foods ready to eat (or close to it)" I was basically starting from ground zero. As stated earlier, I was never into the "re-invent the wheel thing" and so, I wanted to provide, for other parents, what I had found as far as "actual ready to use products". It was when I decided to write this book that I once again pulled Karyn Seroussi's book, "**Unraveling the Mystery of Autism and Pervasive Developmental Disorder**" and again looked at Lisa Lewis' book "**Special Diets for Special Kids"**. I had never been much for reading appendices in the past, and this time, I had deeply regretted that. Both these books had very good information in the

"Appendix" section, information on additional vendors providing gluten free foods, good web sites and contact information for parents with autistic kids. Again, for anyone with an autistic or special needs child like mine, I recommend reading these books (including the Appendices). They are both packed with valuable information. The Suggested Readings section at the back of this book provides ISBN numbers for both of these publications.

GETTING STARTED

The "Hassle" of "Separate Meals"

For Zachary, we pretty well always had to cook him "his own meal", for two reasons. The first and obvious was the fact that he simply could not eat almost everything the rest of us ate. The second was because feeding "all of us" on Zachary's foods would have proved to be too expensive. His special needs required special foods, and those usually cost more. Once we got used to the "separate meals" it was not that bad. Given how restrictive this diet was, we quickly got into the habit of doing this. It was not like I had to cook Zachary any "big meals" or anything. Cooking for him was actually quite simple. It was simply that his foods were very limited and so I had to quickly get used to the idea that variety would be basically non-existent and that, again, food was only for caloric intake and not for "nutrition" or "pleasure". Once I got passed that, I was fine. I just kept reminding myself that this was for his own good. What I found was that he really did not seem to mind the lack of variety.

Cross-Contamination

Since autistic children can be affected by gluten and casein **at molecular level**, I was always careful not to use utensils for both Zachary's food and that of other members in the family. I always used clean utensils for Zachary and made absolutely sure they did not so much as touch something that may contain gluten or casein. Zachary had his own toaster for bread in order to prevent his food from touching gluten-containing breadcrumbs in the toaster used by the rest of the family. This sounded extreme, but, that was an idea I had read about in another book (I believed it was in Karyn Seroussi's book but I did not recall for sure) and it was what I felt I had to do to ensure Zachary had a diet completely free of any gluten and casein. At first, like anything, I found it difficult, but over time, I adjusted and like everything else, it became routine.

For food items that both Zachary and the rest of the family could have, I bought duplicates of the same product, marking a big "Z" in permanent marker on Zachary's jar (this was true for things like honey, molasses, maple syrup, jam, etc. – although I used these products very sparingly/rarely since they promoted yeast growth). When the family was "out" of their supply, they could not "dip" into Zachary's. That was absolutely forbidden. I just found that keeping everything separate made life a lot easier. I had tried just telling the rest of the family members to always use clean utensils if "borrowing" from Zachary's jars, but, I found, too often, I would catch someone, including myself – as careful as I was, ready to put a knife into Zachary's jar of honey, for example, just after having put some butter on my toast. Luckily, I "caught myself" just prior to contaminating Zachary's honey with butter (a product containing casein) and my breadcrumbs (containing gluten). After "catching myself" nearly doing something like that twice, I decided it was easier for everyone if Zachary had "his jars" and the rest of the family had theirs.

The Cost

Where possible, I provided the cost of products. EVERYTHING Zachary ate was listed in this chapter or in the Gluten Solutions, Inc. catalog (it includes prices). If a product did not appear in this book, or in the Gluten Solutions, Inc. catalog (the company I found the most useful/practical for implementing a gluten free and casein free diet on my own), he did not eat it – plain and simple. So, although it seemed like a lot of money to put out, this was Zachary's ENTIRE diet. Also, it was not like he ate the entire $4.00 loaf of rice bread in a day. One loaf could last him two to three weeks, easily. Small children just did not eat that much and so the same was true for all products. Even though the initial outlay seemed like a lot, we thought of it as "Zachary's groceries" since outside of fresh meats and maybe one or two other products, **literally**, he really did not eat from a "regular" food store. I would say that 99% of what he ate came directly from the manufacturer or from a health food store. We were now in the Upper Peninsula of Michigan, and so, shipping charges did add up. Anyone in a city had a definite cost advantage there, no doubt about it, but there were ways I could minimize shipping charges, too.

Buying in Bulk

One of the best ways to save money was to buy in bulk. I always bought things by the case rather than "odd lots". Shipping charges added up fast, as we first discovered and so it was best not to be ordering every week or even every month. I "stocked up" as much as I could as early as I could. The manager of my local health food store and I became good acquaintances. I always took the time to talk to her whenever I went to her store. She was always kind enough to tell me when the products she knew I used came "on sale" and that could at times save a substantial amount.

Unfortunately, in the beginning, I had failed to make sure Zachary even liked a particular product before I sometimes bought too much of it. I had made that mistake on a few occasions. A lesson, yes, but then, with Zachary, everything was an "opportunity to learn"?

A Freezer

Since buying in bulk was best as far as costs, a freezer was a must. I froze everything (granola bars, cookies, etc) until I needed it.

Organic Products

Autistic children and indeed, many children with food intolerances, did not seem to do well with too many food additives. For Zachary, I went with organic products as much as I could and almost completely eliminated food coloring and artificial flavors from his diet.

Change in Appetite

After completely overhauling Zachary's diet, I noticed that three or four days a month, he had very little appetite. That was something I had never seen with Zachary before, he constantly ate, but then again, that was because for him, his old diet provided that "high" he longed for. . Prior to our changing his diet, he could "never get enough" because he always wanted that "pseudo-drug" high from the gluten, casein and possibly phenols.
With his new diet, the need to constantly eat went away, and I was later told by a doctor that this was actually normal, that "normal" children often had days when they simply did not feel like eating.

Time Zone Differences

I provided readers with many telephone numbers for companies whose products I used. Do not ask me why but almost all of them were on the west coast. There was a three hour difference from the east coast to the west coast, something I always had to keep in mind when calling vendors. I had enough to pay for without paying for calls to "answering machines", calls that provided no benefit whatsoever for the cost I had incurred.

DIET ROTATION – THIS WAS CRITICAL!!!

Diet rotation was critical in implementing this diet. What that meant was that since Zachary ate a lot of "the same foods", rice, for example, he had to have a day or two in the week when he ate absolutely none of that particular product...no matter how minute the amount. **This helped prevent the development of allergies to the few "allowable foods"!!!**. Rice was too important in his diet to risk an allergy to rice being developed. **Actually, Zachary's diet was so limited, that "all foods were critical in my view and thus I used a rotation of pretty well all his foods in order to prevent the development of an intolerance to the few allowable foods he could have**. An allergy to one of his staples would have made this entire project unbearable. "Good foods", for Zachary, were just too few and far between. As such, Zachary **had at least two "rice free" days a week** and **two potato free days a week**. **A rotation diet was good for all foods.** As such, meats and drinks and everything else, were rotated too! **No child should be eating the same food day after day after day. That was just asking for trouble and the development of additional problems**. The idea was to make sure Zachary had a "break" every two days or so from each food. **I can not over-emphasize how critical this was to Zachary's successful gluten and casein free diet… the only other thing as critical as this was to assume everything had gluten in it unless I could specifically rule it out!**

Gluten was hidden in/added to so many products, from salt and pepper, spices, sauces, and probably most processed foods that unless I could specifically rule it out, I assumed it was present. The difficult part in all of this was that for "trace amounts" of such things like gluten, the FDA did not require it be included in the labeling…and since autistic children could have a reaction to gluten at MOLECULAR level... I had to assume it was in EVERYTHING unless specifically ruled out!

Recognizing hidden sources of casein and gluten was paramount. For casein (the dairy protein) the obvious words for things to avoid were "dairy", "casein", "milk products", "milk solids" but there were words I was not familiar with too...the big one being "whey". Whey was the "water" part of milk just "milk without the cream" was how Fred told me to think about it...he had lived on a dairy farm and gone to agricultural college and was most familiar with that term. As for the gluten, it was pretty well everywhere...unless I specifically ruled it out as I did with the products listed in this chapter.

THE PRODUCTS...

Rice Milk

Since Zachary was on a dairy free diet, we had to find a milk substitute. His choices included soy and rice milk. He did not do well with soy milk and so we went with the rice milk. There are several brands of rice milk and soy milk out there. Not all are gluten free. **Some use barley or other "grain" proteins to process the milk and often, that was not very obvious**. If I read the labels very, very carefully, however, I saw that this was true (again, Karyn Serroussi's book had made mention of this). I found that this "information" on the use of "barley proteins", for example, was often **not under the list of ingredients**, **but rather in very small print under the "nutritional facts" section** (or somewhere else on the label and therefore, easily missed). **More "deceptive" yet potentially devastating "marketing" practices by food manufacturers**. So, that was another thing to watch for. The brand I used was called Pacific Foods Rice Milk. I used the "plain" as opposed to the non-fat. Pacific Foods of Oregon, Inc. was located in Tualatin, OR 97062 (503-692-9666, www.pacificfoods.com). Rice milk was stored at room temperature until the carton was opened. Once opened it needed to be refrigerated and lasted about ten days in the refrigerator, although I never left an open carton longer than three days. Zachary could easily drink one carton in a day. I bought it by the case full for about 6 months at a time. This rice milk was enriched with calcium, vitamins A and D and "friendly bacteria".

Water

After rice milk, this was the drink of choice. It had taken a very long time for Zachary to even like drinking water after we changed his diet. He had never drank it prior to that because he did not like it, no matter how hard and how often I had tried to make him drink it...again, I am sure that was related to the fact that cow's milk was preferred due to its "drug-like" effects.

Fruits

Fruits and vegetables were gluten and casein free but they were high in phenols and so, I limited those too…, and **I was convinced that phenols played a part in the problems autistic children experienced. I had watched the impact of phenol high foods on Zachary for over eighteen months now and if I gave him too many of these foods, the autistic behaviors showed themselves much more**! If he ate too many bananas or apples for example, the "hand flapping" started up again as did the "pushing my forehead along the floor" behavior. I had seen it over and over again. More than two fruits high in phenols a week was just too much for him even now.

Prior to the implementation of his new diet, the only fruits Zachary really ate were bananas, apples and raisins. He never seemed to like anything else. Zachary absolutely loved apple sauce! Bananas, apples and raisins were fruits that were very high in phenols. I once read that children will crave the foods they should not have and Karyn Seroussi's book, "**Unraveling the Mysteries of Autism and Pervasive Developmental Disorder**" had made a brief mention near the end of the book that phenols may also be a problem for autistic kids.

Well, I tested her theory out on Zachary. At least for him, I found it to be very true. Whenever Zachary ate bananas he was either very irritable or had a hard time sleeping. Apples were the really odd one. I cannot explain this in any way, but, when Zachary ate apples, it seemed to trigger in him a need to "gnaw" on things. So intense was this need that he would chew on things you would never expect. The drywall around the windowsills in his bedroom in Illinois were gnawed or "chewed away" right down to the metal strip contractors put around the window frame before applying the drywall. He would also chew on toys, wood, etc. I did not know if he was getting gluten from some of these products but I did know that apples were really bad for the "need to chew"/"need to bite" (even himself). I took apples completely away from his diet for over ten months, and with that, the need to gnaw/bite disappeared. After ten months, I tried again and gave him an apple. I gave him three apples in one week. Well, sure enough, the "need to gnaw on something" or "bite" came back. Zachary tried to chew the plastic blinds for our French doors. When I cut him back to one apple per week, he seemed able to tolerate that without having to "gnaw" or "bite".

I also did the "banana" test. If I gave him more than one banana a week, he got very irritable and had trouble sleeping at night and there was more hand flapping and "pushing of his forehead along the floor". Raisins had a more immediate impact. Within two hours of eating a box of raisins, Zachary went into "fits" and became uncontrollable. Whenever I "added" one of these "new foods" to his diet, I added them back one at a time to see the "impact" and thus, the "one food" for that week was the only thing which was different in his diet in over ten months (bananas were first). After two weeks on the "banana trial", I "tested" the apples. A couple of months later, I added the raisins. I added these foods back over a period of time to get a very good feel for how he was reacting to them. <u>To this day, more than two bananas a week is too much and it is the same for apples</u>. So, at the age of four years and three months, he gets one banana a week and one apple a week and that is it. I gave him those two fruits, the only two for the week, three days apart, usually on "rice free" days (see DIET ROTATION section). Raisins, to this day, are still completely out. I tried giving him white raisins. He would not even touch those. Yet, he practically devoured the regular raisins I gave him.

The day I decided to do the "raisin test", we were actually in the grocery store when I gave him a box of raisins. I knew he loved them and it helped to keep him content. That "test" to reintroduce raisins was on October 22nd, 2001. As we went through the store, Zachary was sitting in the cart, eating the raisins. As we went down the aisles, he would say: "Um, delicious raisins". People passing by smiled as they heard him. I was sure they all thought it was "so cute". If they only knew!!! Anyway, that was around 2:00 p.m. By 6:00 p.m, Zachary was impossible to control. Again, this had been the only change to his diet. In addition, he kept saying: "clothes off"… something he had not said in quite some time. When he used to get very stressed out, he wanted his clothes, socks, shoes/boots, hat…everything… removed. He just could not tolerate them. Usually, he now tolerates all his clothes, but once in a while still wants his boots/shoes off when he should have them on (probably the impact of bananas and apples still in his diet to a limited extent). Anyway, to this day, raisins are still "OUT"! Knowing now that some foods can have an almost immediate impact on children like Zachary, I probably will not be doing too many more "tests" in public places. Had his reaction to raisins been "more immediate", that would have been horrible to go through in a public place...to say the least!

That pretty well concludes what fruits Zachary ate. Zachary has never taken to actually eating an orange or any other fruit. Due to the texture of pears, oranges, all other fruits basically, he still refused to eat them. He did not like the "fibrous" part of fruits. I thought that pears would be ok (being so similar to apples), but he found them too "slimmy" compared to apples and refused to eat them. I tried blueberries, strawberries, kiwi, white grapes (not red – too high in phenols – recall raisin incident), etc…. so far, nothing...he would not even touch them, yet alone put them in his mouth! I am hoping this year, he takes to more fruits...or that I can at least introduce more of them in the form of juices. I am hoping that now, since he at least takes juices from other fruits, that familiarity with the taste will help him eat more actual fruits this year...we will have to see!

Juices

The only juice I could ever get Zachary to drink prior to changing his diet was apple juice. Zachary never liked orange juice or any other juice I tried to give him. I tried several times to get him to take new juices since the inception of his new diet, back in March of 2000. I even tried them very watered down. Still he did not like them. The one juice he did take was an organic white grape juice made by Cascadian Farms out of Rockport, WA 98283. (Web: cfarm.com, Tel: not available – see store locator on web). I was always able to obtain this product through a health food store. I would put just two teaspoons or so of the frozen concentrate in an eight oz sipping cup of water. That was the only juice he drank for the first eighteen months of this diet.

As he got more used to this juice, I increased its concentration slightly over time to make it "taste better", always being careful to see if he had an adverse reaction to it (usually manifested as diarrhea). Only recently (since October of 2001) has he started drinking a product that contained orange juice. This juice was called "Five Alive" and many regular grocery stores carried it. In Canada (where Zachary started drinking it) I bought it in concentrate form. In the U.S., I had only found it in 64 fluid ounce cartons. "Five Alive" was made by Minute Maid Company (a division of Coca-Cola) out of Houston, TX 77252. The consumer information hotline number on the carton is (800-888-6488). "Five Alive" contained the following (per the carton label): water, orange juice (<u>from concentrate</u>, sweeteners (high fructose corn syrup, sugar), lemon, grapefruit and tangerine juices from concentrate, natural flavors, lime juice <u>from</u>

concentrate. It contains 41% juice, is pasteurized and contains no artificial flavors or preservatives (again, per the label). This was a juice that Zachary liked. It was not as strong as orange juice and I could easily "mask" his vitamins in it.

I often diluted the juice... ½ juice ½ water, but, right now, I am not that concerned about it and often give it to him straight from the carton. He really never gets more than two eight ounce cups in one day…and usually, those are on "rice-free" days. So, in total, he gets about four eight ounce cups a week. He has been drinking it for about two months now and so far, he has done fine with it. In recent readings (since I introduced this juice to him), I noticed that some experts say yeast can be found in juices made from "concentrates". I have not taken Zachary off of it but I will keep an eye on him to see if any "complications" show up. I think I will probably keep it diluted and see how he does. This was "too recent" a finding (the fact that juice concentrates could have yeast) for me to "test" anything prior to the writing of this book but I did want to make parents aware of that and so, I included it. I actually saw this issue with juice "concentrates" when I pulled out a book I had read over a year ago... I had missed it then! I have also been slowly introducing pineapple juice as well. With that one, I can get the "not from concentrate" at a regular food store. It comes in a can. I use the Dole brand name for this one. I also started to give Zachary plain orange juice. Again, I was careful to purchase the "not from concentrate" at the local food store. I use the Tropicana (pasteurized) brand.

Zachary also did quite well with organic pear juice…again, something I was able to get through a health food store. I tried carrot juice as well but that did not work. I am still hopeful on that one though since it is a "light" juice that goes down pretty well and it is a great juice from a nutritional perspective – packed with beta-carotene and that helps boost the immune system. Since Zachary has just now taken to the "Five Alive" juice combination, I am hopeful I can soon introduce carrot juice slowly too...starting with a "diluted juice" first and then working up to a pure carrot juice. For the most part, I have rarely seen carrot juice in a store. I did find it once, in a can. I do not feel that this would be the way to go though. My experience with carrot juice (having made it fresh at home with a juicer in the past) was that it did not keep long even in the refrigerator. I found it always best to just make it fresh for myself. That will be the way I go for Zachary when I attempt to introduce carrot juice this year...I will make it fresh. If I can get him to take carrot juice, than I can slowly mix in other vegetables as well.

That about covers Zachary's intake as far as "juices".

Vegetables

Zachary used to love eating spaghetti/tomato sauce. However, when we changed his diet to gluten and casein free and low in phenols, we got rid of tomatoes too since they were high in phenols. For about eighteen months, he had none…nothing at all made with tomatoes. I then tried to "re-introduce" tomatoes on a very limited basis. This was after I had reintroduced bananas and apples on a very limited basis. I gave Zachary about one to two teaspoons with a big bowl of rice noodles. He had that maybe three times a week. Unfortunately, I found even that was too much for him to tolerate (see chapter entitled "A Small Setback"). I found the sauce, even just that small amount brought back some of his spinning behavior and his need to "push his forehead along the floor". He is now "off" tomatoes again.

Zachary used to love to eat mashed potatoes…before we changed his diet. Unfortunately, we did not know that it was because of the gravy that he loved them so…gravy that I am sure contained gluten. Almost as soon as his diet changed, Zachary refused to eat plain mashed potatoes (only had a little 100% canola oil spread, sea salt and organic pepper on them). He could not tolerate the texture in his mouth and would spit them out… no matter how "smooth" or how "lumpy" they were. He still does not like them. So, then came the French fries. That was pretty well the only way Zachary would eat potatoes…then, and now.

Cascadian Farms (listed above under "Juices") also made organic French fries. Store bought French fries will not do…many, if not all, appear to contain gluten, sprayed on them to keep them from sticking or found in other ingredients used to make them. I still buy some Cascadian Farms Organic French Fries for convenience sake...although I now made my own fries as well. It only took about ten minutes to peel three or four potatoes anyway…I bought a French fry slicer (available at any household goods store) so making my own fries was not that big a deal. My sister-in-law advised me that she had read that "red" potatoes were best for children with autism. Do not ask me why…I do not know…just something she read somewhere…so, that was usually what we used.. but on occasion, we used white potatoes too when we were out of the red ones. At first, since Zachary refused to eat most foods, we had to come up with creative ways of making him eat. We would all go on walks, Anika holding the bowl of French fries, Fred holding Zachary on his shoulders, and me, feeding them to him as we walked along. We found if we kept him distracted, it was always easier to feed him. We only had to do that once...the first week of his diet...just to get him eating. It was an enjoyable walk for all of us and we all cheered each time Zachary ate a fry.

While on the subject of French fries…what to cook them in. We found Zachary tended to react negatively to corn oils. The best oil for him was 100% safflower oil…again, available in most food stores. <u>I found a lot of labels said "pure safflower oil" but if I read the label, there was often other stuff in there also</u>. I purchased only 100% safflower oil. He was also fine with 100% extra virgin olive oil, but that tended to be more expensive. When making any "fat rich foods" such as French fries, I always removed excess fat with paper towels in order to help limit Zachary's fat intake...another must!

A Story On French Fries…

On a trip to visit family in Canada in June of 2000, Zachary started getting a lot of diarrhea. Nothing seemed to be different in his diet…but then, I was still fairly new at it. He had only been on it for three months or so. Anyway, I had read in Karyn Seroussi's book (p. 212) that MacDonald's French fries were ok. In Illinois, we had often given Zachary McDonald's French fries and he seemed ok with them. I just "naturally" assumed they would be fine in Canada as well. …stupid me, I assumed that manufacturing practices did not vary from state to state or country to country for one company...not to mention the fact that I also assumed they did not cook anything with gluten in their oil…in addition to French fries…things like breaded chicken, breaded onion rings, and so on...boy what a bad assumption...and did I learn that the hard way!

In Canada, I gave Zachary McDonald's French fries...out of nowhere, he just got sicker and sicker… each time I thought he was "pulling out of it" , I wanted to build up his strength again and thought the fries would be ok. I knew, they have a lot of grease, but I still thought he should be able to tolerate them a little. Zachary did not want to eat anything else, no rice cakes, no rice bread, nothing! Anyway, each time I gave him some fries, about the only food he would eat, he seemed to get worse and worse…to the point that he had diarrhea on and off for about ten days.

Well, again, stupid me, I finally figured it out…it was the French fries that were making him sick. I had not made the connection because in the Illinois, he had been perfectly fine on them...they were a staple in his diet. They must have been cooking onion rings or breaded chicken in the same oil as the fries, or the fries themselves were manufactured differently in Canada because Zachary's reaction could not be explained any other way…that was the only food that was "different" in his diet since I now packed everything I needed for him, except for fresh meats. I thought the fries were safe, but obviously, based on his reaction, they were not. Karyn Seroussi's book stated that many autistic children were impacted by casein and gluten at molecular level…boy, did I learn that the hard way! Zachary was barely eating.

I forced a few tablespoons of fluid down his throat every few hours to keep his kidneys running. After ten days of what seemed to me to be constant diarrhea, I was ready to admit Zachary to the hospital and have him fed by intravenous. Luckily, it was right at that time that the little voice in my head said: "think, what is REALLY different in his diet?"… and that was when I figured it out. I had been so concerned about the "immediate situation", the "diarrhea" that I did not see there **had** been a change to his diet – the fries were different. So, bottom line here, eating out was now completely out for Zachary...and I had learned a valuable lesson. I could no longer assume manufacturing practices were the same everywhere for the same company and I could no longer assume only "safe foods" were cooked in the oil used in restaurants...no more restaurant fries for Zachary!

The only other vegetable Zachary liked was corn. Unfortunately, he really could not eat that…at least not in its "on the cob" or "kernel" state…not then, not now. I had long suspected that corn did not agree with Zachary. He never seemed to digest it properly (as very evident from his stools) and it threw him into "tantrums" more than once. Again, it was one of those foods he loved. After over a year without corn on the cob, I thought I would try giving him ½ a cob to see how he would do. Well, needless to say, he loved to eat it…so much so, that within a couple of minutes he had eaten all the kernels on the cob. I had been busy putting the dishes in the dishwasher and by the time I had turned to check on him again, he was actually eating the cob itself. It was another of those "I cannot believe what I am seeing moments".

From then on, every time I saw Zachary "enjoying his food just a little too much", I suspect something was wrong. Sure enough, that evening, he was restless and irritable and had a very difficult time sleeping. He has not had corn on the cob since. Popcorn was also out for the same reason. Interestingly though, he was better able to tolerate processed corn… especially white corn and so, every once in a while, I would give him white corn chips from a health food store. He could also tolerate some "corn-containing" cereal as well (see section on grains/cereals).

Again, Zachary never took to other vegetables. I continued to try giving him carrots, squash and other vegetables, but so far, no luck. I am hoping this year will be the year he starts eating both fruits and vegetables a little more because I have noticed some changes in his like or dislike for certain food textures lately (see Grains/Cereals below).

Grains/Cereals...and yet, another important lesson!

Karyn Seroussi's book had mentioned a cereal I tried to find in a local health food store. They did not have it on the shelf. That was when I learned another valuable lesson. If I knew the manufacturer, **most times, the health food store could get a product for me even if it was not on the shelf**. They had these books that listed tons of distributors they represented but since they could not carry "all foods from all distributors", the particular products I wanted were not always on the shelf...but that did not mean they could not get them for me. **So when I did not see something I wanted, I always asked**. So far, I have been able to get pretty well everything I need…and I have now lived in a small town in the Upper Peninsula in Michigan (not exactly a populated area) for well over a year!

This was where things got a little better. I found a company on the Internet by the name of "Gluten Solution, Inc.". They were located at 3810 Riviera Drive, Suite 1, San Diego, CA 92109. (Their phone number was 888-845-8836 or 810-454-8277 at web site Glutensolutions.com). Anyway, this company, one of my absolute favorites, provided **over three hundred gluten free foods** from various manufacturers. Again, **the name of the company, "Gluten Solutions, Inc." could easily make one think that all their products were gluten free...that was not the case...the company carried other "special diet" products as well, and some of those could contain gluten. I always had to remember to check each product**. There was also another company...that one was listed in Karyn Seroussi's Appendix B...an Appendix I only discovered while writing this book. That company was called **The Gluten Free Panty** (P.O. Box 840, Glastonbury, CT 06033). They could be reached at 800-291-8386 (for orders), 860-633-3826 (for inquiries) or via the web at **glutenfree.com.** This looked like another great company! Until now, however, as Kirkman Labs had been my "one stop shop" for supplements, **Gluten Solutions, Inc. became my "one stop shop" for a whole slew of gluten and dairy free foods**. It had taken me a long time to find this company on my own...but, now, I had found it...another valuable source I just had to share with other parents of children on special diets or with special needs. So, there was hope at the end of the tunnel. Any parent can call this company to get a copy of their catalog. They will gladly send it to you and what was really neat about Gluten Solutions, Inc.'s **catalog** was that i**t listed what the products contained as well as what they did not contain**! So, I was told whether or not the foods were dairy free, gluten free, corn free, soy free, egg free, etc., etc., etc. This in itself was FANTASTIC! **Talk about a time saver**! All their stuff shipped via UPS.

Their catalog included bagels, muffins, breakfast foods, breads and buns, mixes, brownies, cakes, dessert mixes, cookies and cookie mixes, crackers and snacks, flavorings and cooking aids, flours and grains, pasta and pizza crust, soups, sauces, cookbooks, instant meals, dairy, egg and cheese substitutes and gluten free sampler kits and a ton of other stuff.

As with all foods since Zachary had been on this diet, I still read and re-read labels in spite of what appeared in the catalogs. I was always extremely good about that...there was just too much at stake. I had worked too hard to totally trust anyone else with Zachary's diet. Most the foods in this catalog, I knew were gluten free, but many still had dairy…and for Zachary, that was not good. But, at least the company's catalog told me if a food contained dairy in its catalog...before I bought it...and many of the products, I found, were without dairy too. Life had finally began to get a little easier. It was in Gluten Solutions' "catalog" that I got the list of grains that did or did not contain gluten. Again, I was not out to reinvent the wheel here…I figured, they specialized in this, they had to at least know which grains did or did not contain gluten….I did not need to "re-research that basic point myself". My goal was to give parents of autistic children time saving tips/resources...not to reinvent the wheel and waste my time proving the already proven.

I knew what it was like to have the devastating news that your child was autistic and I knew how much additional time just "dealing with that" was involved...dealing with the tantrums, the frustrations, the overwhelming behavioral problems and the overall helplessness. I had learned the hard way that there was not that much out there as far as truly time saving tips on "where to go" and "what to do when you first get the diagnosis". I, myself, had found bits and pieces of the puzzle a little here, a little there...and again, that was why I just had to write this book. If it helped just one family, just one child to overcome autism, to me, that was worth it. Back to the work at hand...

To recap… **<u>grains that DID contain gluten</u>** included: wheat, barley, oats, bulgar, triticale, wheat berries, kamut, spelt.

<u>Grains that DID NOT contain gluten</u> included: amaranth, buckwheat, quinoa, rice (brown, white, and wild), millet, corn grits.

Below, I provided a list of Zachary's Cereals – these were all casein and gluten free and I could get all of these through a health food store.

Note: Since Zachary did not take cow's milk he ate these with rice milk. If it was a rice free day, I gave him the cereal with a little juice on it instead of the milk and he took it just fine….I have even used water instead of rice milk or juice and had him take his cereal on rice free days that way. I often had to get very creative when it came to Zachary's food intake.

An important observation... in the beginning, Zachary did not like his cereal very “mushy” and so I only sprinkled his cereal with juice, water or rice milk in order to keep it pretty crunchy. He did much better with the texture issue as time went by. He now started to tolerate it a lot “mushier” than he used to... and herein lies my hope for the introduction of yet more foods this year!

Cereal Name	Company That Makes It	Comments
Mesa Sunrise	Nature's Path 2220 Nature's Path Way Blaine, WA 98230 Web: Naturespath.com Tel: 604-940-0505	this one was excellent – contained most nutritious grains of all (quinoa, buckwheat, amaranth, etc.)!!! Good for "rice free" days.
Corn Flakes (regular or honey'd)	Nature's Path 2220 Nature's Path Way Blaine, WA 98230 Web: Naturespath.com Tel: 604-940-0505	I only gave this one to Zachary once a week or so (no more) because of his corn sensitivity…also good for "rice free" days.
Perky's™ 100% Natural Nutty Rice	Pacific Grain Products, Inc. Box. 2060 Woodland, CA 95776 Web: pacgrain.com Tel: 530-662-5056	Good but not one of Zachary's favorites although I knew Karyn Seroussi said her child loved it!
Toasted Granola & Trail Mix	Ener-G Foods, Inc. Box 84487 Seattle, WA 98124 Web: See Glutensolutions.com or Tel: 800-331-5222	Got this one through health food store, but think also available via Gluten Solutions, Inc… again, good one for "rice free" days.
Nu-World Amaranth Cereal Flakes	Nu-World Amaranth, Inc. 18 Manchester Ave Earlville, IA 52041 and Box 2202 Naperville, IL 60567 Web: Nuworldamaranth.com Tel: Not available.	Again, got this one through Gluten Solutions, Inc…good for "rice free" days. Also "amaranth puffs"…Zachary likes flakes better, "puffs" were "too light" and got way too mushy too fast.
Maple Buckwheat Flakes	Arrowhead Mills Box 2059 Hereford, TX 79045 Web: Not available. Tel: 800-749-0730	Another one that Zachary really liked a lot.

There were more available through Gluten Solutions, Inc… although I have not used them yet.

Pasta

When cooking pasta for Zachary, I first gave him no spaghetti sauce...just noodles with 100% safflower oil spread, sea salt and organic black pepper. In September of 2001 or so, I added one, sometimes two teaspoons of a store bought spaghetti sauce, thinking by now, his gut might have healed enough to allow this food to be added. I knew tomatoes were high in phenols and that was something he had not tolerated well in the past. I hoped that although this was a store bought brand and therefore, surely it contained traces of gluten under "spices", that maybe after a year and a half, he would be ok with it. Again, I was wrong and I learned that the hard way! I found that even one or two teaspoons (two or three times a week), was still too much. Autistic behaviors returned. See more on this in "A Small Setback" chapter. Zachary would have to go back to "plain" rice spaghetti...just seasoned with sea salt, organic black pepper and maybe a little safflower oil spread.

Again, I obtained various pastas through Gluten Solutions, Inc. (they had several to choose from) and most health food stores carry some too. It was just critical to stick to "gluten free" grains like rice, amaranth, quinoa, etc., when buying pasta.

Every once in a while, Zachary also had a spaghetti-type food made of corn and quinoa flours. It was made by Quinoa Corporation, Box 1039, Torrance, CA 90505 (Web: Not available, Tel: 310-530-8666).

Note to the wise...when I cooked pasta from these special grains, they got quite "guey"… the trick I was told (by my sister in law whose child had numerous allergies) was NOT to stir the pasta too much when cooking. Breaking the pasta into very small pieces, about one inch in length also helped a lot. What I did for Zachary was I made sure the water was really boiling well, put in a few teaspoons of 100% olive oil, broke the pasta in very small pieces and let it cook (brown rice took a while but it was very nutritious). At first, it was difficult for me not to go over to the stove and "stir" the pasta as I used to do for regular spaghetti…with this stuff, I could not do that. I just took a fork, put it straight down to the bottom of the pot and turned a couple of times to separate, gently. Doing that in a couple of spots in the pot helped prevent ending up with one big "gooey" mess. It seemed the less I agitated the pasta, the better.

Flours

Buckwheat Flour, White Rice Flour, Brown Rice Flour, Tapioca Flour and Potato Flour were pretty well available through health food stores. A good company for these products was Arrowhead Mills, Inc., Box 2059, Hereford, Texas 79045 (Web: Not available, Tel: Not available. Tapioca Flour could be obtained through Country Life Natural Foods, Box 489, Pullman, MI 49450 (Web: clnf.org, Tel: 800-456-7694 or 616-236-5011).
I was not "a cook", and these flours tended to be hard to work with and so I went with "mixes" as much as I could. Gluten Solutions, Inc. had several of those. But again, I think **almost every food store I have been in carried these flours**.

Other Grain Products

I guess I would call these "cous-cous type" looking products….only "stickier". They were excellent from a nutritional perspective, but so far, Zachary did not want to eat them because of their texture. I had forced him to eat some once...that had been enough of a challenge that I thought I would wait longer. I was hopeful perhaps this year he would because of the recent change I noticed whereby "mushier" cereal was ok.

Quinoa – whole grain - available from Quinoa Corporation (as listed above under Pasta) and roasted buckwheat groats made by Birkett Mills, Penn Yan, NY 14527 (brand name was Pocono, Heart of Buckwheat…product also seemed to possibly be called "Kasha", Web: thebirkettmills.com, Tel: 315-536-3311).

Breads

I chose to use rice breads. Again, this was something I could get through the health food store. I keep the slices/loaves frozen until I used them. I only took one or two slices out of the freezer at a time. Since Zachary was still quite young, he did not go through that much of it anyway. The company/brand I used was Food For Life Baking Company, Inc. , Box 1434, Corona, CA 91718 (Web: Food-for-life.com, Tel: 800-797-5090). Each loaf was about $4.00 but it lasted a while simply because Zachary was young and at that age he did not eat "that much". There were other companies that made similar products. This one was just the one Zachary preferred. I used the white rice and brown rice breads (without raisins, of course!). I found these breads moister than others I had tried. There are also bread mixes that are gluten free (i.e., through Gluten Solutions, Inc., but I have never tried those). For me, it was easier to pick up Zachary's breads at my local health food store. My view was that when it came to life with an autistic child, anything that simplified matters was great!

Eggs

I used to give Zachary a two egg omelet, on rice free days only. I found, however, that if he got too many eggs, he would not sleep well at night. So, I went to omelet every three days. In addition, I used only one yolk with three egg whites. When I cooked his omelet I used a little safflower oil spread, sea salt and organic pepper. I always gave him his eggs and bacon mixed together (I broke the bacon up and mixed it in after I had cooked it and drained the excess fat separately).

Meats

Again, as much as possible, I only gave Zachary fresh meats. If meats were not fresh (like ham, sausage, etc.) , I went with uncured meats since they had no added preservatives (nitrates, nitrites, MSG, colorings, no antibiotics or growth hormones given to animals, etc.). **I had heard that some studies suggest high protein diets or too much meat was not good for the kidneys and so I was very careful to make sure Zachary did not eat "too much" in one day.** A meat free day a week was probably a good idea also (although I just very recently thought about doing that).

Note: Many health food stores did not have actual uncured meats in their freezers but if I asked, they could usually get some from one or more of their distributors. Another good place to get them was through local food coops. Food stores or other parents with children on special diets were usually aware of local food coops when I inquired about them.

Chicken: Zachary usually ate chicken about two or three times a week. I bought either the boned breast or boneless breast and cooked it in the oven in a casserole dish. All I did was clean it and add about 1/8 of an inch of water to the casserole dish. I put the lid on and let it cook for about fifty minutes. Usually, when it was boneless chicken, the water was pretty well all gone when it was cooked. For chicken breast with bones, I put a little more water because I wanted a "broth" to pour on top of the chicken to make it less dry...that also provided the "cold fighting" properties found in chicken broth. At times, I actually gave Zachary a "cup of chicken juice" as I called it. That was basically just a cup filled with chicken broth. He did not drink it on many occasions, but, every once in a while, I could get him to do so.

The only thing I added to his chicken other than the water was sea salt and organic pepper. After a few trials, I easily figured out just how he liked it and chicken was always a favorite for him. Zachary would also drink the bouillon from the cooked chicken. I called it "chicken juice" and he always came running for it. The breaded chicken fingers as prepared in Lisa Lewis' book was one that Zachary really enjoyed also. I found I could modify the recipe and use Potato Flyers (see snacks section) or his special potato chips (see snacks section) and he liked that even more. I bought Zachary's chicken at any regular food store.

Steak: I only gave Zachary the boneless, "minute steak". It was the one that was "pre-tenderized" or "pre-beaten" by the butcher as I called it. I just put it in a frying pan with a bit of safflower spread, cooked it thoroughly, added a bit of sea salt and pepper and gave it to Zachary. **I found I had to remove any "tough" parts and cut the meat in dime size pieces for him to take it. He would not eat big chunks of any type of meat. Any variation from the size he liked tended to make him "gag" and when that happened, it was usually the end of the meal!** I bought Zachary's steaks at any regular food store.

Ham: I bought ham from the health food store. It was all natural, boneless, uncured ham. Since it had no preservatives or other additives, it was quite expensive, so usually, only Zachary ate it. A one and a half pound ham could cost about $10.00. It was best to cut it up after purchasing it and put it in the freezer in small portions that only Zachary could eat. I found twenty or so of these hams to be more than enough for the year. The brand I bought was Pure Farms Boneless Honey Baked Uncured Ham. Health foods stores varied greatly as to what brand of meat they carried simply due to logistics. All health food stores carry some brands. I just had to ask when I went there. Because I had to buy this through a health food store, I bought it in bulk and kept it frozen. I purchased this product through Whole Foods, Inc.

Bacon: Like the ham above, I bought uncured bacon. Thus, it had no preservatives or other additives. A pound was about $5.00. Again, I bought the Pure Farms brand and bought this through a health food store. Another good brand was Yorkshire Farms. They were located at 9 Styvesant Drive, Swedesboro, NJ 08085 (Web: yorkshirefarms.com, Tel: 888-786-2331). I bought bacon in bulk and kept it frozen. Since bacon was so fat, while cooking it, I removed the liquid fat from the frying pan. The best thing to do was to use an old canned vegetable tin can that had been emptied, sit that on the stove (away from the element, of course) while I cooked the bacon. Slowly, I remove the liquid fat in the frying pan with a spoon and dumped it into the tin can. I then placed that can in the freezer. When it was completely full, I discarded the can in the trash and got a new one. When the slices of bacon were nice and crispy, I laid it on a paper towel and removed any additional fat that I could.

Note: Autistic kids such as Zachary were often on very high fat diets because of their limited selections. Therefore, it was important to remove as much fat as possible.

Uncured Beef Wieners: Again, I went with an uncured product from Pure Farms but there are many meat vendors out there that provide uncured products. It was simply a matter of asking what vendor the food store carried. Zachary has done well with this one although I found the wieners contained "gristle" that needed to be removed. I usually cut the wiener in two to remove the "gristle" and then further cut the product into dime size pieces before giving it to Zachary. I purchased this particular brand through Whole Foods, Inc. and Zachary liked this product a lot.

Breakfast Sausage: Again, I went with an organic product. I used Valley's Family of Farms Uncured Pork Breakfast Sausage Links. Valley's Family of Farms was located at 507 West Main St., La Farge, WI 54639 (Web: organicvalley.com, Tel: 888-444-6455) these were about $4.00 for an eight ounce pack (eight sausages). Zachary loved these. I usually gave him three at a time. They needed to be cooked for twelve minutes (in boiling water), then browned in a frying pan (since they were already high in fat, I did not add anything to the pan prior to browning them) and served.

I know there was also a company called Shelton's that made organic meats but I have never used their products. I am sure there are several others.

Salt and Pepper

Yes, I learned even salt and pepper were often hidden sources of gluten...as were pretty well all "spices" (as labeled in the "lump all" category for so many store bought products). Therefore, Zachary only ate **sea salt** (I could pick that up at any food store in the salt aisle or any health food store) and **whole organic black peppercorns** (I just put those in a grinder and they tasted great). The organic black peppercorns I got at a health food store. Again, I always went organic stuff for Zachary. His pepper was made by a company called Frontier out of Norway, Iowa 52318 (Web: frontierherb.com, Tel: 800-669-3275). One bag was about $14.00 and that lasted the entire family about one year. Note that in our family, all we used was sea salt and this special black pepper. It needlessly complicated matters to constantly worry about accidentally giving Zachary the "wrong kind"…putting salt and pepper on food, especially at first, was often so automatic that I found I had to pay extra special attention and, honestly, there were many times when I was reaching for the "wrong salt and pepper... so, I decided to completely do away with the old stuff.

Cooking Oil/What To Use Instead of Butter

The only oils I used for Zachary were 100% extra virgin olive oil or 100% safflower oil. Again, "pure safflower oil" on a label did not mean 100% safflower oil and that was critical. Oil products often had "other stuff" in them that Zachary could not have. . There were products that appeared to be "safflower oil" in regular food stores, but when I read their labels, they had WHEY (the liquid or "watery" part of milk but without the cream) or other things autistic children should not be eating. So, again, as always, I was careful to constantly read the labels.

Since he could not have butter due to the dairy restriction, when Zachary had toast or eggs, I used Soft Safflower Oil Spread made by Hain Food Groups, Inc., Uniondale, NY 11553 Their consumer affairs was at 734 Franklin Ave, Suite 444, Garden City, NY 11530 (Web: Not available, Tel: 800-434-HAIN). I have always been able to get this through a health food store. Spectrum Organic Products, Inc made another product that I just recently started using. They are located at 1304 South Point, Blvd, Suite 280, Petaluma, CA 94954 (Web: spectrumnaturals.com or Tel: 707-778-8900). The product is non-hydrogenated Spectrum Naturals Spread made with canola oil. It tastes very much like butter (although a non-dairy product) but it is not recommended for frying.

Sugars

I always tried to **minimize sugars** for Zachary since sugar promoted yeast growth. I usually used honey, molasses or pure maple syrup for sweeteners, and then, only rarely and sparingly). Some experts suggested removing all sugars, including natural sugars (found in fruits, honey, etc.), from autistic children, however, I could not see doing that. Not only was it very difficult to do, practically, but I felt Zachary needed some sugar and I believed the many supplements he was taking would help with the yeast control issue. I bought these at regular grocery stores but, again, read labels carefully to ensure the product was 100% pure.

Jam/Preserves

I used preserves made by Smucker's (the red raspberry or strawberry preserves – not the jam). I purchased these through any regular food store. Again, as with all sugars, I limit how much he got. I only very lightly spread some on Zachary's rice toast. You could barely tell it was on there. Again, Zachary had "his own jars" (I bought the smallest ones I could find only because I did not use that much of the product in the first place). "His jars" were not to be used by anyone else in the family – that was strictly forbidden in order to prevent cross-contamination. His jars were marked with a big "Z" in black permanent marker and placed in the door of the refrigerator – in "his section".

Peanut Butter/Almond Butter

I bought organic peanut butter and almond butter (tasted very good) from Whole Foods out of Austin, TX 78746 (Web: Wholefoodsmarket.com, Tel: Not available. Use the store locator on web). I believe Whole Foods was now under a company called Gaiam (gaiam.com at 800-869-3603). These products are available online through that company. I used to be able to get this at the health food store, but since moving, now I get it via Internet/UPS. I could probably get it through my local health food store though if I asked. I did not use regular peanut butter because most of the brands out there had salt and that was a hidden source of gluten. Also, I stuck with organic foods as much as possible for Zachary to minimize exposure to pesticides. This product was $5.00 for a sixteen ounce jar. He had a weaker system than a normal child to start with and I did not want to stress it needlessly.

Cooking Aids/Baking Powder/Xanthan Gum/Egg Substitutes

Yes, you guessed it…baking powder too!!! It was like I said… you had to assume EVERYTHING had gluten unless you specifically can rule it out. For those of you who love to cook, a company called the Hain Food Group, Inc. out of Uniondale, NY 11553 made a gluten-free baking powder. An eight-ounce jar cost me $3.19 at a health food store.

Xanthan Gum was a natural thickener. Again, Gluten Solutions, Inc. provided that. A four-ounce jar cost me $4.50. Dairy substitutes (Soy, Potato drinks), Egg substitutes ($4.95 for sixteen ounces) and Cheese substitutes (I did not use these) were also available through this company. For parents with children on gluten and casein free diets, I strongly recommend calling Gluten Solutions, Inc. to at least get their catalog…it has over 300 products in it! It was also a great way to find "other sources" of such foods.

Sauces

I did not use any of these when I cooked but again, store bought sauces of any kind were a hidden source of gluten. Gluten Solutions, Inc. had gluten free sauces for cooking. The new company I had recently found, The Gluten Free Panty, also provided things like gluten free **mustard, mayonnaise, catchup**. Again, I had never used any of these simply because I literally just found out about this company as I completed the writing of this book...but, I am very excited about trying some of their products.

Cookies/Crackers/Snacks

We quickly learned to take snacks almost everywhere! For most of this stuff, I went through Gluten Solutions, Inc. They had a good selection. Again, it was important to continuously read labels because ingredients did change. For example, I used to buy a particular brand of cookies for Zachary, Pamela's Walnut Chocolate Chip Cookies, and he loved them. I bought these at the health food store when I lived in Illinois. I was always careful to read the labels of everything I bought. When these cookies first came out, they indicated, "wheat free, gluten free and dairy free" on the package. Within a couple of months, I noticed the label had changed. One of the "frees" was missing. The "dairy free", I believed. Anyway, I made mention of it to one of the store clerks at the customer service counter. He told me he thought that I was wrong, that they only had the two "free" statements on them. I had been so fanatic about sticking to this diet and reading labels, I was SURE that they had had all three.

At my request, he finally called the company and asked if they had changed their labeling and sure enough, they had. I had several cases on order and so I had to know for sure. At that time, these particular cookies were not processed on "dairy free" machines and so, due to the possibility that a child who was sensitive to dairy may have an adverse reaction, they chose to remove that part of the label. Zachary's favorite cookies were now out. I had to assume they contained dairy. I was not sure if the company later went to "dairy free" equipment. I did not buy this particular cookie again only because by now, I had found a replacement. I may look into it again because I know Zachary did love those! My point here, again, was that as a parent I always had to be careful, constantly reviewing labels. If something seemed different but I was not sure, I called the manufacturer before giving the product to Zachary.

Carrot Muffins – I got delicious gluten free muffins and dairy free muffins from the health food store. They were made by Natural Food Mills, Box 1434, Corona, CA 91718 (Distributor: North Farm Coop, Tel: 800-236-5880). Again, I bought in bulk and kept these frozen. I took them out on "rice days", one at a time, as needed. I simply popped one in the microwave for about fifteen seconds to thaw, cut it up and put a little 100% safflower oil spread on it and served it to Zachary as a snack. He loved them.

Granola bars – I got these through Gluten Solutions, Inc. but they were so good that they deserved special mention. They were made by Ener-g (Web: Go to Glutensolutions.com, Tel: 800-845-8836) and were one of Zachary's all time favorites…and mine, actually (I sneak one every once in a while…but I knew Fred did too!). These were much bigger than granola bars you bought in the store and each one had 290 calories (not good for me)... and that was great for Zachary since for him, food was for caloric intake! A pack of eight was $6.00. I kept these frozen until I need them.

Crackers – again, these are available through Gluten Solutions, Inc. but worth mention. The brand I use is Bi-Aglut. Zachary loves them and they are rice free so they are a good snack for rice free days. Another brand I use is called Hol-Grain Crackers, made by Conrad Rice Mills, Inc., 307 Ann Street, New Iberia, LA 70560 (Web: Holgrain.com, Tel: 800-551-3245). Zachary really likes these, but there are many different rice crackers out there that are available at health food stores.

Pretzels – Zachary was corn sensitive and since these were made with corn, I did not give him more than a little handful at once. They were made by Ener-g, and again (Web: Go to Glutensolutions.com, Tel: 800-845-8836).

Potato Chips - Since regular potato chips were packed with salt and that salt can have gluten on it, not to mention that the chips may have been cooked in oil used for other products, I went with a product called Olive Oil Potato Chips made by Good Health Natural Foods, Inc, Northport, N.Y., 11768 (Web: Not Available, Tel: Not Available) I think they run about $4.00 per bag.

They were available in lemon, cracked pepper, rosemary or plain. Lemon was Zachary's favorite and they had a nice "tangy" taste but all were delicious. Again, I had **always been able to get these through a health food store.** I used these as a snack on "rice free" days.

Potato Flyers – another snack everyone liked. These cost about $4.00 per bag. If I would let him, Zachary would eat an entire bag of these in one sitting. This snack was made and distributed by Robert's American Gourmet, Box 326, Sea Cliff, N.Y. 11579 (Web: robgourmet.com , Tel: 800-626-7557). This was another product I had been able to get at any health food store. The company made several varieties…the **ONLY** one Zachary can have was the "ORIGINAL Potato Flyers"…the other varieties had cheese, or some other product Zachary cannot eat.

Chocolate bars - These are non-dairy. The brand name I used was Tropical Source and they were distributed by Cloud Nine, Inc., 300 Observer Hwy, Hoboken, NJ 07030 (Web: cloudninecandy.com, Tel: Not Available). Note of caution…since Zachary had very few sweets, he would really come running when I said "chocolate" to him. Although there was a great desire to give him more than I felt he should have, I always remained "strong" and did not give in to his "begging glances"... at times, that was very hard to do, but again, it was in his best interest not to give him too much "chocolate" since sugar promoted yeast growth. The bar could be separated into "triangles", "squares" or "rectangles". Anyway, I always asked Zachary if he wanted a triangle, a square or a rectangle. It did not take him to long to figure out that a rectangle was best because he got more…but I very rarely gave him that (not even once a month). A "triangle" was usually all he got…and being young, he was still fine with that. Although I did give Zachary treats like this now and then, I always found Zachary did better without them. So, they are part of his diet, but not a significant part of it. He was lucky to get two or three triangles a week. These are large bars and they cost about $4.00 each. **I picked them up at any health food store**.

Rice cakes – I used only the "plain" and pick those up at any food store.

Ice Cream – I used a brand called Rice Dream. The only one Zachary can have was the Neapolitan. It was rice based and he loved it…non-dairy of course! It was made by a company called Imagine Foods, Inc., 350 Cambridge Ave, Suite 350, Palo Alto, CA 94306 (Web: imaginefoods.com, Tel: Not Available). It cost about $6.00 per quart and was another product I could get through most health food stores…again, if I did not see it, I would ask and I was usually able to get it.

Ice Cream Cones – Again, I just recently found a gluten free ice cream cone available via the Gluten Free Pantry (800-291-8386). They run about $7.00 for 8 waffle cones. I have not tried these yet, but am anxious to. Zachary will be thrilled!

Dairy Free Pudding – Imagine Natural Foods, 1245 San Carlos Ave, San Carlos, CA 94070 (Web: imaginefoods.com, Tel: Not Available) made non-dairy pudding in lemon, butterscotch or chocolate flavor. These were among Zachary's favorites as well as mine as they were great for hiding his vitamin capsules (I opened the capsule and mix the vitamin powder into the pudding and Zachary could not tell it was there). These puddings keep for over nine months (non-refrigerated) so I bought them in bulk and I **could get them from any health food store.**

Pop – the **<u>ONLY</u>** pop Zachary ever had was 7-Up. I found it to contain the least amount of artificial stuff, less coloring, etc. If I gave Zachary pop, it was on "rice free" days but I usually diluted it quite a bit with water (two thirds water, one third 7-Up). **Pop had a lot of sugar in it and that promoted yeast growth**. I only <u>very rarely</u> give Zachary pop. Water alone was best for rice free days!

These were the main products/companies I used. I provided them only because I had none of this information when I started Zachary's diet and it had literally taken me months to find these. My intent here was again, to save parents time if they wanted to consider a gluten and casein free diet and one that was low in phenols too! The above was certainly enough to get anyone started on a casein and gluten free diet.

<u>Going through this made me realize one thing. There was a HUGE unmet need in regular food stores. With all of the people I have come across who have special dietary needs that require casein, gluten, yeast free foods, etc., you would think some food chain would have figured it out by now. Each year, more and more children were diagnosed with autism, "ADD", "PDD", and a whole slew of other "learning difficulties/labels". I certainly hoped that food stores would wake up to this fact soon and start to better meet the needs of the public in general...because persons with special dietary needs were EVERYWHERE and there were A LOT OF THEM</u>. For me, time saved away from these tasks meant I could spend more time focusing on Zachary and his special, non-dietary needs.

CHAPTER 13

Zachary's Progress – In Illinois (April 2000 to Mid –August 2000)

In addition to changing Zachary's diet, we now realized that he needed a lot more one on one time. It became the family's project to "save Zachary". We were determined to do it and that was that. Failure was not an option. Sure, there were and still are difficult times, but we just resolved to take things one day at a time. In the beginning, just ten minutes at a time was hard. We now saw Zachary's behaviors for what they were and understood how ill he really was. We had to show Zachary that our world, the real world, was more interesting and fun than whatever he was seeing in his own mind as a result of this "drug-induced type" state he was in due to his inability to properly process gluten, casein and phenols.

The one great blessing we received almost immediately after changing Zachary's diet (two to three weeks into the diet) was the fact that for the first time in longer than I could remember, Zachary now slept through the entire night. Like most infants, when he was first born, he had been up a lot for feedings. Then, for a few months, he actually slept pretty well all night. That only lasted for a few months though. After that, Zachary would wake up each and every night, two to three times a night. Almost always, he woke up crying or screaming. Usually, he ended up in our bed and after about ½ hour or so, he would fall asleep.

Often, however, no matter what we did to comfort him, he pulled away from us and just cried and cried for hours…and he stared at one spot, constantly…like he was seeing something there which totally captivated his attention, through all his tears and screams. Those were exhausting times. We were so much into the "routine" of bringing him to bed with us that we simply saw it as "normal" for him. Finally, after 2 ½ years, all of us slept through the night and it has been that way ever since. Sure, like all other children, once in a while he woke up during the night, and we took him in with us, but those days were rare, and when they happened, he certainly was not waking up crying and screaming like he used to. The extra hours and better overall sleep were great blessings given what lay ahead for us as a family.

The first, easiest thing to do was to focus on more physical outpourings of affection. We hugged and kissed him now more than ever and made it a point to do so much, much more. Even though he now slept through the night, it was not unusual for me to take both my kids to bed with me just to give them more hugging and that security that mom was there during the night. Unfortunately for Fred, he slept in a spare room more often than either he or I probably would like to admit. The reason I took both my children to bed when I took Zachary was twofold. I wanted to make sure Anika did not feel left out and I felt that her hugging Zachary would also help the children bond to each other, and that was important to me. Anika, after all, was also part of this huge project and as it would turn out, she would be an immense help.

Although he was two and a half by the time we figured out what was wrong with him, Zachary had always been in the same bedroom as Anika. We had an extra bedroom for Zachary, but ever since Zachary had been born, she had wanted his bed in her room. When he outgrew his crib, she insisted he sleep with her. So as Zachary outgrew his bed, her single bed went into the spare room and the double bed from the spare room went into the kid's room so that they could sleep together at Anika's insistence. I was fine with that. I also knew how many other families slept with their kids. When I still worked at Ameritech I had once made a comment to co-workers that I was tired because the kids had slept with me the night before. My co-workers knew how old my children were. Almost immediately, three of them chimed in saying they had thought they were the only ones who slept with their kids…and some of their children were eight to ten years old. We all laughed and agreed that with all the hours we put in at work, that was some of the best "hugging time" we had with our children.

It was unfortunate that society had become so obsessed with "proper parent-child relations" that parents were afraid to admit such things in public for fear of being thrown in jail for child abuse because society automatically assumed child abuse. That was a sign of a sick society, not necessarily of a sick family. I had to develop patience to allow the children to sleep with me so often. No matter how big the bed, they had a tendency to sleep in "star formation", arms and legs spread out, or the ever-popular "perpendicular alignment" so that I ended up with about six inches of a bed that was six feet across.

Anyway, if Zachary was with me, "<u>being there</u>" when he woke up was easier than having to run to his room early each morning, something I did most mornings. The reason that was so important was because <u>right from the time he opened his eyes, I would start "working" with him</u>. I would touch his hair and say, "hair", then his eyes and say, "eyes", then his eyebrows, eyelashes, nose, cheeks, lips, mouth, teeth, tongue, chin, neck, shoulders, arms, hands, fingers, fingernails, tummy, bellybutton, back, legs, knees, feet, toes, and toenails. Each day, I would do this, starting from the hair and going as far down on his body as possible before he was even out of bed. If he continued to stay in bed, I would initiate play with my "<u>bellybutton bug</u>". That was always a favorite and it could always make him laugh. I would take two fingers and pretend I was a bug going along his body until I got to his bellybutton and then I would tickle him a little. There were days when I could be there with him playing in bed for up to an hour before he decided he wanted to get up. I would <u>count his fingers and toes</u>. He always loved it when I got to the end of the five fingers and said, "five fingers" in an upbeat voice. Soon, he would put up each of my fingers, wanting me to count them out loud as he lifted each one.

Since autistic kids were usually very much behind in social skills, early in the "save Zachary" project, I told Anika, now seven, she had to do everything she could to get Zachary's attention to get him out of "his world". It was not long before she figured out how to do it. She used "<u>flowing fingers</u>" as I called it. We were all in the basement of our house (in our family/rec room) and I saw her march right up to Zachary, take both her hands and "flow" her fingers down Zachary's face. Then, she ran off saying, "<u>you can't catch me…you can't catch me…</u>". She did this for probably a week. It was not long before Zachary was in fact running after her. Anika also vividly participated in playing "My Boy"…another one of Zachary's favorites.

In "<u>My Boy</u>", Fred, Anika and I would each take a hold of Zachary, usually one of us held his shoulder, and the other two had one of his legs so that Zachary was completely off the ground. Then, we all "fought" for ownership of Zachary, each of us gently pulling Zachary toward him/her. We made it so that one person looked like s/he was "winning" but then, someone else would "win" and we would go back and forth with him like that a few times. He absolutely loved it.

One thing Zachary did not love was "horseback rides". Regardless, we tried over and over again. Often, Anika "rode" with him, making sure he did not fall. I think that was when Fred and I most felt the effects of "age" on our backs and knees. The room was forty feet long and that was a lot of "riding" back and forth. Eventually, Zachary got used to it, and the more he got used to it, the "wilder" the horse got/had to be, not to mention the fact that the poor "horse" got more tired and sore, so much so, that the only way to end a ride was to "fake death". At times, even that was not enough for the kids to stop riding! It got to the point that Zachary was now asking for the horseback ride by motioning he wanted "on". He pushed Fred on the back, pushing him toward the floor and that was the sign to assume that dreaded position that was so hard on the knees... when Fred was too tired to play, I would be the horse. To Anika, it did not matter who played the horse, she loved it more than Zachary did…then and now!

Another favorite was "zoom rides". Zachary and Anika had always loved the sensation of vertigo. Fred and I debated back and forth as to whether or not to encourage certain behaviors in Zachary and this was one of them. Zoom rides were so much fun for the kids that we decided to allow them. A zoom ride was no more than Fred picking up Zachary (or Anika) in his arms and turning while he held him (or her). Zachary's back (or Anika's) rested on his forearms so that the child getting the "zoom ride" was in a horizontal position looking up at the ceiling. Of course, you had to exercise judgment when doing this so as not to get too dizzy yourself and fall or lose control and Fred was always good about that, making sure the kids were always safe. But they absolutely loved "zoom rides".

Verbal reinforcers were and still are very important to Zachary. For example, it did not matter what we were doing with Zachary, we would always say, "Good job" or "yooo-hooo". After a "zoom ride", I would say, "good job doing a zoom ride" or in the morning, "good job counting fingers with mom", "good job letting mom count your teeth", when we would go for a walk, it was "good job walking with mom" so that he always knew or was told "what we were doing" and he was always praised for cooperation/participation.

We would take Zachary on countless walks and trips to the park. Luckily for us, there was a beautiful little park we could go to about a block and a half away and another, larger park about three blocks away. Both were close enough to walk to and that proved to be a good training ground. We lived in a huge duplex and I recalled when we first started the daily walks how I had not even made it ten feet pass my property when Zachary would throw himself down on the pavement, right in front of the neighbor's house. The neighbor happened to be outside at the time. Julie had been our neighbor for about five years now and she knew Fred and I were good parents. I think that was why she was absolutely stunned when she saw me simply walk right over Zachary and come over to talk to her. She had this "What are you doing?" look on her face, totally puzzled as to why I ignored Zachary like that. I explained to her that Fred and I had just found out Zachary had autism and that I could not reinforce these behaviors in any way. I had to simply ignore them. So, as Zachary had his little fit on the sidewalk, I talked with Julie. It did not take too long to get rid of that behavior once Zachary realized he was not getting anything out of it. I was always so ambitious and excited when I decided to go for a walk and get outside, but it was never long before reality set in.

I could go forty feet, then down the block, then all the way to the park without a scene. If I had the misfortune of walking past a new lawn ornament on the block, that was always difficult, especially if it was "twirly" in nature, like a wind catcher of some kind. Zachary always wanted to "spin" things and anything like that would attract him and ruin the walk. You had to fight to get him away from it. Eventually, he got better with dealing with them and a firm "no" sufficed to go on. Once I was at the park, I was "home free" since Zachary loved it there. Of course, that was only if no child at the park had brought a bicycle or any type of toy with wheels. If that was the case, then Zachary would just run over to the bike, tip it over and start spinning the wheels…and then I had another fight on my hands. I always thought to myself, I should be enjoying these walks, but often, they were absolutely draining. If I had to pull Zachary away from some wheeled apparatus at the park, be it a bike or something else, then I would often have to carry him home on my shoulders or in my arms as he kicked and screamed since he would not leave on his own. As we walked each day, the neighbors got used to seeing us always out together, Zachary holding my hand with his little fingers… or Zachary crying on my shoulders… or Zachary kicking and fighting in my arms.

Slowly, but surely, the walks got better. Our neighborhood in Illinois was a great one. We lived on a cul-de-sac and although there were about twenty five families living in duplexes on that street, we pretty well all knew each other. Each year, during the summer, we had a block party, including games for kids and adults, the fire truck "hose down" (for adults and children alike) and truck inspection for the kids. In our suburb, the fire department came out and hosed people down in the street at block parties in the summer if they were not too busy with their normal duties and were asked to come a couple of weeks before the party. If you were lucky enough to be the last block party for the fire department that day, the firemen stayed a little while and ate with you. It was great for kids and adults alike. We always used to give a good donation to the fire department for taking the time to do it. I guess for them, it was better than sitting in some firehouse all day when there were no emergencies. It was also great for community awareness as they spoke to the kids about what to do in case of a fire. Needless to say, our block was a great one. People knew and cared for each other. The block party was always a terrific way to welcome those who were new to the "street" each year. On Saturdays, if two neighbors were out talking on the sidewalk, it often was not long before there would be five families out there talking. We really enjoyed each other's company. Given how closely knit our neighborhood was, it had not taken much time after finding out that Zachary was autistic before the entire street knew it. And I did not say that in a negative, "gossipy" way, what I am saying is that our neighbors who cared very much for us were all very saddened by the news we had been given about Zachary and you could see it hurt them too.

As the days and weeks went by though, we continued to walk and the walks got easier. Now, when neighbors saw me walking by with Zachary, they would come up to me and comment that he seemed to be doing much better on walks, but I had not "seen" Zachary's real problem until much later, July of that summer. We were now in very early May of 2000.

On May 7th, Zachary had slept with both Anika and me. Fred had slept in the kid's room. On the morning of May 8th, around 6:00 a.m. I awoke to a funny sensation. I had been sleeping on my stomach, without blankets, something I rarely did. Zachary was already up and standing by the bed next to me. As I laid there sleeping, he kissed me from the back of the leg up to the cheek...about eight kisses in all....bang, bang, bang....one after the other in rapid fire sequence. I was stunned. He had NEVER kissed me before that. I cried and cried. For the first time in a long time, my tears were tears of joy, not sorrow. I had cried each and every night for more than a month and would continue to do so for close to two more months...autism had so devastated my family... but this time, the crying was good. I never forgot that date... May 8th, 2000… my first kisses! From then on, the kisses flowed freely.

That same week of May, I had a dream that must have come from God himself. I dreamed I was in a special room with Zachary, in my house. My dream was in color and I could see all the colors in this room perfectly. When I awoke that morning, I felt so strongly about this dream that I told Fred, "you have to watch Zachary today, I need to paint". Fred looked at me, puzzled. That was the very first thing I told him that morning. I explained my dream to him and so he understood my need for the "room of colors".

I had grown up in a family of ten children. My mother, needless to say, was a stay home mom and her children were her life. She had always said that children needed to be "stimulated", that they needed to always be made "part of the happenings in life". Every book on behavior therapy that I had read since learning of Zachary's autism emphasized the need for a simple room, basically white walls, a table with two chairs for one on one interaction and no distractions. My dream was so vivid and so specific and so against all that, as were my mother's words, that I now recalled, that surely this dream had been sent to me from heaven. I went to the store and got the paints I needed for my "room of colors". Then, I went back home, emptied the room and started painting. All of these paints were very glossy/shinny.

Per my dream, the ceiling I painted a royal blue. The wall on the left when you entered the room I painted a vivid royal purple. The wall next to that one, I painted a vibrant green. The wall next to that one, I painted a brilliant red. The last wall, I painted a bright yellow. The closet doors and the door to the room, all of which were along the purple wall, I painted a shinny, pumpkin orange. As I took a break once the walls had been painted, I rested on my back in the center of the room. It was like being in a Rubik's cube. Each corner of the room had a different color combination. Any child would have loved a room like this one. My break was over, but the masterpiece recreation of my dream had yet to be completed. On the green wall, I painted huge shapes, each over a foot high and up to two feet in length. There was a red circle, an orange triangle, a blue square and a purple rectangle. All were at Zachary's level on the wall. On the red wall next to it, I painted big black numbers, one through ten. Each number was about one foot in height. Under each number, I painted the appropriate number of "x"s, one "x" under the number one, two "x"s under the number two and so on, all the way to ten. Again, everything was at Zachary's eye level. On the yellow wall next to the red one, I painted all the letters of the alphabet in various colors. There were red letters, blue letters, brown letters, purple letters, orange letters, green letters. I visually split the wall in half and started painting. In the far left corner was the letter "A". I went across and painted a "B". I painted as many letters as I could up to the middle of the wall. The letters were anywhere from eight inches to over a foot in height. There had to be variety. They were not one right next to the other but rather went a little up, then down, then up, then down. For that same half of the wall, I continued painting all the way down toward the carpet, ending in the middle of the wall, at the bottom, with a "Z". I then did the same thing, only backwards to the other half of the wall. So, the far, top right corner of the wall had a "Z" on it. I worked my way toward the center of the wall, "Y", then "X", and so on… again, all the way down, this time ending with an "A".

What that gave me was a wall that provided challenge for Zachary because the letters were not in perfect order as you read them across the wall and it also gave me one other thing. The design of my wall made it such that with his hand, Zachary could literally touch each letter. The masterpiece in my dream had now been perfectly reproduced and it was beautiful. My mother would have been proud. It certainly "stimulated" the eye and the imagination. It had taken me three very long days to complete. I painted all day and went to bed around three a.m. each night. I was exhausted, not to mention the fact that I had multiple colors of paint all over my hair. I must have looked like quite the work of art myself. I cleaned up and put fans in the room to help it dry and get the smell out and went to bed. Again, it was approximately 3:00 a.m. Zachary had been kept away from my project, for good reason.

After a little rest, I got up and returned to the "room of colors" to check things out. The paint was now dry. I was so excited. I did not realize Zachary was also up. Before I knew it, he was in the room with me. I kissed him good morning. His eyes were alive with fascination. He looked all around the room. Then, he walked up to the "<u>alphabet wall</u>", put his hand on the capital letter "H" and said "AAACCCHHH", then he went over to the capital letter "A" and blurted out "AAAAAAAA". You could have knocked me over with a feather! Zachary had never uttered a single letter before that. His entire vocabulary consisted of about 5 words - if even that. He had lost so many words he had once used in the past. How was it, I wondered, that he knew these letters?

I quickly figured it out. Having worked in telecommunications, Fred and I were big on computers. Zachary used to love them, too. We had one program in particular that was his favorite, <u>Dr. Seuss' ABCs, by Living Books</u>. (A Broderbund Company). We had paid about $14.00 for this software. Zachary could sit there and either listen to a narration that went through each letter of the alphabet, big and small (the "READ TO ME" option) or he could click on the interactive part of the program that also went through all of the alphabet, big and small (the "LET ME PLAY" option). Each letter had a little "script" that went along with it. For example, on letter "A", it said: "Big A, little a…what begins with A? … and then it gave a lot of words that began with "a"…all of these words appeared on the screen, along with a picture of each item/word and so that Zachary could read along as well as see "what" that was. The "Let Me Play" option allowed Zachary to discover all kinds of fun hidden things that related to the specific letter on the screen. This was <u>a FANTASTIC program</u> for any child. It took about twenty minutes to get through the "Read to Me" and Zachary used to love sitting there and listening to it. He could listen to it three times in a row in one sitting. He also enjoyed the "Let Me Play" option tremendously as he was quite good with the mouse for a two and a half year old.

I knew that this had to be where he had learned the letters. I just did not realize he actually "knew them" until he blurted them out in our "room of colors". Within a couple of days, he was saying and touching each letter with the palm of his hand as he said the letter. His pronunciation of the letter "Y" was particularly appropriate. Zachary would go through the entire alphabet, pretty well saying each letter almost perfectly, but, when he got to "Y", he would have this drawn out "WWWHHHHYYYYYYYY". It was particularly funny when he learned to sing the "ABC song" because he would still have that drawn out "WWWHHHHYYYYYYYY". Fred and I kind of found it funny in a way and at times, when Zachary said that letter "WWWHHHHYYYYYYYY", we told him we had asked ourselves that very same question many a time.

In addition to the alphabet, we worked on numbers, counting each "x" under each number and on shapes. In no time (a matter of days), he knew all those too. He was repeating everything I was showing him and taking it all in. In the morning, he now often ran into the room and went to his favorite shape, touching it with the palm of his hand and saying "cirrrrrrcle". That room became our primary study room for the month of May and most of June. I purchased a little table and two chairs for the room. Looking back, that was a waste of money. Zachary preferred to simply sit on the floor. <u>I touched everything in the room. I would touch the carpet and say, "carpet"</u>, and he would repeat it, I would touch the wall and say, "wall", and he would repeat it, I would say "ceiling" as I pointed up, and he would repeat it. <u>Everything I said, he repeated. I worked with him on all the body parts, and those he repeated too</u>. After a while I wondered if that was all it was, just repetition, or if he actually understood. I had read a lot about autism and the "echolia" that was exhibited by most autistic children. <u>Echolia</u> was just that, the repetition of words. Everything I had read on it though seemed to indicate that this was all it was, <u>simple repetition</u>. Zachary had only been on his diet/supplements for about three months. Still, I knew that <u>for Zachary, it was not</u> <u>simple repetition</u>. Sure, he was only repeating the words physically, not conversing, but he was taking it all in and learning. He had a fantastic memory. Now, he became a sponge for new words. I could see him absorbing everything. I just knew he understood.

The first situation whereby I KNEW for sure that he understood was a rather funny one. Zachary was having one of his more stressful days. Yes, there were still many in spite of our progress. Fred once made a comment that, "**<u>if we were so stressed out, imagine how difficult it must be for Zachary himself"</u>**. That was so true. I rarely spanked Zachary, but he had received a small slap on the butt in the past on probably one or two occasions. Anyway, I do not even remember what it was he had done to make me lose my temper. He was still always breaking things, making an absolute mess of the house whenever the opportunity presented itself (almost every hour) and he still had a lot of very difficult days. On one of those days, I turned to him and said, "You better listen to mommy because I am going to slap your butt". Since it was summer and we were in the house, all he had on was a t-shirt and a diaper. He started running away from me, hiding his little behind with his hand as he exited the room as quickly as his little feet would allow, kind of looking back to see if I was following behind. It was so cute I just cracked up right there and started laughing... but he had given himself away… I now knew for a fact that he understood what I had said. That little brain of his was working much more than he had let on in the past.

To further stimulate his brain, I sang songs to him and played classical music when he went to sleep. He loved to be sung to. During the day, I would act out the songs. "The Itsy Bitsy Spider", "Hickory Dickory Dock", "Old MacDonald Had a Farm", "I'm A Little Teapot". Every child's song I knew, I acted out and I involved him by touching him as I did it and he loved it.

The month of May went by quickly. Although we were making great progress with Zachary, he still had "his days", those extremely long and difficult days that just never seemed to end. Every once in a while, he still would hit his head in frustration, throwing himself down on his back and inevitably hitting his head on the floor as he went down. We actually considered putting a bicycle helmet on him in the house. I found something simple to help a lot with this situation. Whenever I saw Zachary getting frustrated, and I knew it would just be a matter of time before he "went down", I started saying "gentle, gentle" as I held him best I could as he "went down in frustration". Frustration episodes at bedtime were also difficult, as he would often throw himself back from a seated position down onto the pillow, often hitting the wall as he did it. Again, the use of "gentle, gentle" and my holding of his head as "he went down" decreased the intensity of the motion. I found that I could not stop "the motion" itself, but I could decrease its intensity significantly by the use of those two words and my hand around his head. Eventually, the intensity with which he "went down" decreased significantly. I found myself using the words "gentle, gentle" for several motor problems including any "going down episodes", leg and arm banging, hitting, etc. Those two simple words eventually helped him learn how to control his motor movements and frustrations. When everything got to be too much for the rest of us, we took trips. We were without family in Illinois and that made it very difficult. We could not go out to eat as a family and it seemed our entire life focused on Zachary. The last week of May, exhausted from the month's happenings, we found ourselves visiting family, again, in Canada.

Most of the month of June was spent in Illinois, however, and again, during that month, I spent a lot of time at the park with Zachary. I drew letters in the sand and he called them out. Then, I mixed letters and numbers. Then, I drew "happy faces", stickmen, dogs, cats, chickens, rabbits, elephants, giraffes, anything I could think of to keep his interest. Each animal drawing was accompanied by a sound provided I knew it (I still did not know what sound a giraffe made). I drew shapes, and slowly added to each shape to show Zachary how they were part of the world. For example, a square plus a triangle made a house, a circle with numbers on it made a clock and each time, as I drew the "combined shapes", I told him the name of the new object. Zachary was absolutely fascinated with shapes and numbers.

Teaching him colors was more frustrating. Over and over I showed him objects, told him the color and then tried to see if he knew it. What was unusual with colors was that he did not seem to be able to learn them, or at least that was what I thought at first. I worked with him on colors over and over and over. When I asked him a color, he would often give me the wrong answer. Finally, one day, even though I still thought Zachary did not know his colors, he started taking objects and one at a time, he called out each color for that particular object…he seemed to know them all…and remember, I thought he did not know any of his colors because that was what he had "indicated" when I worked with him on this particular subject. Now, I knew he knew them, and knew them perfectly...at least the basic colors (red, green, blue, purple, pink, black, brown, orange, yellow, white, gray). It was almost as if he wanted to wait to "know them all" before he showed me that he knew even one of them. Things were still difficult with variations within a color (i.e., navy blue vs light blue).

As I worked more and more with Zachary, I came to see how he would "play with me" by often giving me the wrong answer on purpose. I noticed this one day, as we worked on the computer. I knew Zachary knew all his letters and numbers and yet, when asked to "click on a letter or number", he would purposely select the wrong one. In fact, he would pick every other choice before selecting the correct one…that I knew he knew…just because that was a fun thing to do. I cannot explain his reason for doing this, but that was the way it was with him. Some days, he would pick the right thing first off. Other days, he would prefer to pick all the wrong answers first or pick the right answer "in the middle". It varied depending on what he felt like doing.

The important point here was that given what I experienced with Zachary, in spite of the fact that he knew all his letters and numbers, you would not necessarily know that if you "tested him". He made a game out of picking the wrong answers, or he simply found it "interesting" to do so. I could now see why so many of these children could be labeled as "mentally handicapped". Therefore, as far as I was concerned, intelligence testing for Zachary or any such children needed to involve parents who knew what their child did or did not know and the "games" they played to help ensure testing revealed accurate I.Q. levels or knowledge bases. I could see how a child such as Zachary could need to be tested several times by someone to properly evaluate his knowledge, to get a **true** picture of what he actually knew. Any one time test would really be a "luck of the draw" based on how Zachary felt like behaving on that particular day.

I decided to give Zachary another test of my own. Continuing with my mother's theory that children needed stimulation, I suggested the entire family take Zachary to the zoo. Fred just about cringed at the suggestion. A year earlier we had been to Brookfield Zoo near Chicago. It had been a complete disaster. Zachary was very cranky and in spite of our efforts to show him the animals, he was not interested. I recalled how on that trip to the zoo Zachary could not see the elephant, so plainly there - in front of him – because of the fact that a little squirrel was about three feet in front of us and twirling a nut in his hands as he ate it. The "twirling" of the nut captivated Zachary's attention, not the elephant. We had tried to raise his head and have him "see the elephant", but that only made things worse. He started screaming from the top of his lungs. Things went downhill from there! Every parent around looked at us, wondering what was wrong. Here this quiet child had just exploded into loud screams out of nowhere. Any parent of an autistic child knows all about "those stares".

Anyway, that had been about a year ago. In spite of his reluctance, Fred agreed to try "the several hours outing thing". We packed up snacks for Zachary and our precious Red Flyer Wagon that we had used to take Zachary on so many "wagon rides" and headed out. Zachary enjoyed car rides and so getting there was uneventful, despite the longer than usual ride as a result of that never-ending summer construction on Chicago highways. Soon we were at the zoo and off for the adventure. Amazingly, this time, Zachary enjoyed it... he noticed the elephants, the giraffes, the lions, the bears, the dolphins, the monkeys, the birds, the water fountains... and yes, the squirrels too. The outing had been a great success. Fred, Anika and I were thrilled. Zachary slept all the way home. He was totally exhausted.

Having done so well at the zoo, we thought we would try the Field Museum in that same month. The Sue dinosaur exhibit was on display and that was something we wanted Anika to see. So, once again, we headed out for a family outing. This time, we took a stroller instead of the red wagon. Since Wednesday was "free admission" day, we went on that day. That in itself was a mistake. Every school in the area must have had a trip to the Sue exhibit on "free Wednesday". There must have been thousands of people there...the place was jam packed. We found a place to park near the planetarium and walked over to the museum. It was a beautiful day and we rather enjoyed the walk. We made it to the museum and went over to the Sue exhibit in the large exhibit area where you first come in. After that, we started touring the rest of the museum. We started on the upper floor and then came back down. On the main floor was an animal exhibit. There were bears, monkeys, turtles, snakes...just about everything you could want to see... Fred and I had been commenting on how we needed a couple of days to see everything - it was too much to see well in one day. Everything was going well...both kids were enjoying it and so were we. As we walked around the animal exhibits, I would tell Zachary the names of all the animals. For the most part, he just looked and remained quiet, probably because he knew all these.... bear, monkey, tiger, and so on. Then, when rounded a corner and I went over to the orangutan display. I told Zachary, "orangutan". To my surprise, Zachary said, "orang...tan". I turned over to Fred and said, "Did you hear that, he said orang...tan"? We were both thrilled, as was Anika. I was so thrilled in fact that I tarried in front of that display a little longer. Fred and Anika had moved on. I had mentioned to them that there were lions "over there". That was where Fred and Anika went. I did not know how it happened, but that was the last I saw of them in the museum. We got separated and with all the people in there, I could not see them any more. Anika had been tired of walking and so Fred had been pushing her in the stroller and I had Zachary on my shoulders (a good forty pounds or so). I looked and looked for them, but to no avail.

I went to a security guard and asked if I could have them overhead paged. I explained how Zachary was autistic and that he was getting a little tired (we had been looking for Fred and Anika for over half an hour). To my utter surprise, the guard informed me that the Field Museum, this huge place where tens of thousands come each year, had no public announcement or P.A. system. "So, what do you do if a child gets lost?", I inquired. "We take them over to the information booth and wait for the parent to show up", he responded, as he pointed to the booth. "What?", I said. I could not believe my ears. "This is how you handle lost kids...in Chicago!". I walked away. I knew Fred had surely noticed we were missing within a couple of minutes. He was also "a very protective parent", so I knew Anika would be ok with him and that he would not let **her** out of his sight.

Knowing I would be unable to hold Zachary on my shoulders for very much longer, I started the walk back to our car that had been parked at the planetarium. I knew Fred and Anika would eventually have to go there to get back home. Zachary was fine throughout the entire ordeal "we" were going through, enjoying the ride "with a view" from mom's shoulders. The perfect Chicago tourist taking in all the sites. We finally made it back to the car. I put on the air conditioning, gave Zachary a snack as he sat in his car seat and we listened to music as planes went overhead and either landed at or took off from Meigg's Field by the lake.

After about an hour, Fred and Anika showed up. Fred had his "panicked, stressed out look" on his face. I could see him coming but he had not seen us sitting in the car yet. I got out of the car and placed myself in his line of sight. Anika saw me first and she told her dad. I could see the relief on his face. We were all happy to be back together, everyone fine. We headed back home. That was enough of the "big city" for us.

With each passing day, weather permitting our outings now consisted mainly of walks to the park. On one of our many trips there (we often went two or three times a day), I put Zachary in the "baby swings" and slowly pushed him back and forth. It had taken him quite a while to get used to them, but he was finally at the point where he enjoyed it. Anyway, on this particular trip, a woman was pushing her child in the little baby swing next to mine. Her child must have been about a year old. As she pushed her baby, she called out, "wwwwooooonnnnnee… tttttttwwoooooooooo…thththththththrrrrrrreeeeeee".

Upon hearing that, Zachary just looked over in amazement. He looked at the woman and her child and then at me. He had this look of, "mom, she knows that too" on his face…a look of both puzzle as to where she had learned "that" and a look of fascination all rolled into one. It was the first time I recalled Zachary ever actually "noticing" anyone. He had never shown interest in anyone outside the immediate family before. But, now, he was realizing that "other people" knew some of the few things he knew. It was as if he finally understood there could be some form of "communication" with "other people" walking around. And, that made "this world" a little more interesting now. I went out of my way to continue to show him how things I was teaching him fit into the world around him. I was absolutely determined to show him "real life" was more fun than anything in his "autistic world".

Unfortunately, that month, Zachary had to take another trip to the doctor's office. I suspected he had another earache. He had that same crankiness he always had with earaches. As I started to speak to this doctor, in the immediate care facility (after hours, evening clinic), I explained Zachary had autism. I also told him that we had no insurance, but that we were fine with paying cash. I could hardly believe what happened next. Even though there were other patients waiting to be seen in the facility (nothing urgent it seemed), the doctor actually took the time to read Zachary's records quite carefully. Zachary's pediatrician worked in the basement of that building and so his file had been sent upstairs since I once again had been "put off" long enough that I was forced to take him to the evening facility.

The doctor read the records for close to a half hour... and he asked me questions that had to do with Zachary's progress...not just questions one would ask about earaches. Other than the physician who confirmed our fears about Zachary's autism, he was the first to treat Zachary the way he needed to be treated, as a very sick child. I realized then and there that because we were paying $80.00 for the visit instead of the usual $10.00 co-payment, this man could actually take the time to be a doctor and treat his patient the way a doctor should treat a patient. When we did have insurance, Zachary never spent more than 10 minutes in the presence of a doctor...it was always the HMO/PPO "in and out" visit. Not having insurance was actually a blessing because, for the first time, I realized Zachary's care was much better without it... even though it was more expensive.

Like the month of May, June went by quickly and had brought many little joys, the kind of little joys parents of autistic children cling to in the hope that their child was indeed making progress. I came to notice ALL the "little things" I probably would never have noticed had Zachary not been ill. Every step forward became a treasured memory. Although many of these steps were "baby steps", every once in a while I got one that I just knew was a breakthrough, as had been this episode with the "123 lady in the park".

It was also around this time that I noticed the extent to which Zachary used family members as tools, ways to get something, rather than people with whom he could communicate and have fun. More and more, he would take my hand and use my hand to show me "what he wanted". If he wanted a snack, he would take my hand and put it on the pantry door. If a toy needed to be fixed or pulled apart, or a puzzle made, he would take my hand and push it toward the object to indicate he wanted me to "do something" with that particular thing.

To him, people were primarily "tools" to get things done. Social interaction was basically non-existent. Zachary never initiated play with other children and on most walks to the park he did not notice them at all. There was no desire there to play with other children. Things that "spun", like the wheels on their bikes, were more interesting to him than the children and that was what usually captivated his attention. In addition to "spinning wheels", he would find object to spin on the wheels. Zachary would put rocks, little pieces of paper, anything he could on the spinning object. As the wheel spun, he would focus on the rock or piece of paper, or whatever he had placed there. I did all I could to minimize these autistic behaviors. I always explained to other children at the park why Zachary tipped their bikes over to spin the wheels and amazingly, most of them were very understanding and said it was ok with them. Yet, I felt this need to constantly force him to interact with me by drawing in the sand, showing him new things as I touched them with his hand, like tree bark, tree needles, tree leaves, grass, gravel, sand… everything became an opportunity to teach him something. I did everything I could to get his attention away from bicycle wheels and other "autistic behavior stimulants" at the park.

Getting his attention away from these often proved challenging. Creativity was a must. I would sweep him up in my arms, giving him a "zoom ride" as I took him away from the undesirable object and moved him closer to something I wanted to teach him about. Picking him up "upside down" in my arms was another favorite. He loved to be carried upside down (and still does). I would put the lower part of his legs on my shoulders (by bending his legs at the knee), and with my arms tightly around his stomach and holding on to his clothes tightly with my hands ("just in case" he tried to get away from me), I would walk a little ways with him upside down.

A ride on my shoulders was another way to distract him and always a favorite. Often, when things got to be too much, that was usually how I ended up taking him home. I taught him how to "give me five" that month. In spite of how tired I was, I always felt I had to be interacting with him, constantly stimulating him to discover "our world". I came to feel guilty if I took a few hours for myself, almost to the point of driving myself crazy, I think. Finally, I came to the realization that I had to make more time for myself - and Anika, especially, and that it was ok for Zachary to play on the computer by himself, or watch a video or two while the rest of us "took a break". We had purchased a lot of educational videos for him and that was "learning" too. Life went on in ten-minute intervals, in 30-minute intervals, in one-hour intervals. We lived one minute at a time, one hour at a time, one day at a time. My sister-in-law had given me a gift I cherished deeply. It was a small plaque that stated, "Mothers of boys are busy from son-up to son-down", words that rang so true.

Our life was a constant whirlwind. Plans were no longer for "next week" or "next month". When we took trips, they were usually "on the spur of the moment". I say "on the spur of the moment" because they usually happened after several weeks of intense and exhausting focus on Zachary, to the point that we could not take it any longer and had to "get away". So, when either Fred or I suggested a trip to Canada, it often was not very difficult to convince the other spouse to go. We had made a list of "things to pack" for both kids and kept it in a file in our home office. It was always right there, ready to be pulled out at a moment's notice. It included everything we needed for Zachary, clothes, shoes, boots, specific foods and snacks, sea salt and pepper, list of his supplements, diapers/wipes, sippy cups, toys/videos/educational cds…everything. I also included all of Anika's things on the list too. It just made packing a lot easier. I found that without such a list, packing either took much too long or we forgot something we needed. I had made many copies of the list and would bring one with me for "re-packing" at the other end when it was time to come back home. To this day I still use that list.

It seemed each time we went to Canada we realized how we longed to be closer to family. Twelve-hour trips were too long for Zachary and when he got stressed out, the entire family was stressed out.

Whenever we got back from a long trip, Zachary was absolutely thrilled to be back home. He loved to play with his own toys and sleep in his own bed. Fred and I had gone back and forth as far as what toys we should or should not allow him to have. His urge to "spin" things was still quite strong. For a while we put away everything that Zachary could 'spin' and there was a lot of it. Any little thing that even moved on any toy, he attempted to spin. I would estimate that close to 85% of his toys had been put away at one time or another. Then, we decided that the only way to really know if he was getting better was actually to let him have access to those things that were once so obsessive to him when it came to spinning. So, within a few weeks of putting them away, out came the toys again. The stress on the family seemed insurmountable. All aspects of our life had been so violently uprooted, tossed around and we were still trying to figure it all out…to pick up the many shattered pieces. The reality of autism had set in now.

The old family we once had was gone, killed by this adversary and, understandably, we were having a very difficult time adjusting to the new family dynamics.

Fred and I, like all couples, had had our share of fights, but we were still very close and loved each other very much. Having an autistic child tested that love. It seemed in those first few months after finding out Zachary was autistic we argued more than ever. We had never argued so much as we did during this time. Anika's world was falling apart, too. All this fighting, all this stress made her think we were surely going to get a divorce, in spite of our attempts to reassure her that such a thing would never happen, that we were just really, really stressed out over Zachary. She would say that she was trying her best to help, and we knew that. Still, I saw Anika - a couple of times - walk away with clenched fists. We told her over and over again that the fighting was not her fault at all and that things would get better soon. But, I could certainly see the impact on Anika. Most times, when she ate, it almost had to be "<u>in secret</u>". She loved so many things Zachary used to love but could no longer have...things like cheese, macaroni and cheese, common cereals, regular toast, ice cream, cookies, etc. We never ate as a family any more. We either ate first or Zachary did. We could never be all together at the table because Zachary would want our food. That was very difficult.

<u>I constantly had to remind Anika never to leave so much as a morsel of food of anything anywhere</u>. The <u>counters were always wiped clean right away and all leftovers put away immediately</u>. <u>Regular cereal was placed high</u>, on top of the kitchen cabinets away from Zachary's reach. It was difficult explaining to her that what was good for one child was seriously detrimental to the other. I, myself, found it difficult to tell one child one thing and the other the exact opposite when it came to food. I would tell her, "eat this, it is good for you" and turn right around to Zachary and try to make him understand that for him, cheese was dangerous. That was the case for so many foods. Anika felt very "guilty" that she could eat certain foods... and that her brother could not. I kept reminding her that it was for his own good, but that did not seem to help too much. Watching her diet became important too. She had always been a slim girl and I certainly did not want her developing an eating disorder. When family came over to visit, I was always making sure no child or adult gave Zachary something he should not have. I fed everyone and had everything put away, leftovers and dirty dishes, before I myself would sit down to eat. This autism thing had totally changed our lives. All our hopes and dreams for Zachary had been shattered only in March, and although just three months later he was doing great strides, he still had a long way to go.

Our hopes for Anika's future were also at risk. We did not want her having the burden of a sick brother later in life. Already, I could see what Zachary's illness was doing to her. She felt all our time went to Zachary but we made it a point to be more sensitive to her needs in spite of all the time necessary for "saving Zachary". We found the best thing was to make her understand why we had to do this - that it was not just for Zachary, it was for her also. I let her sleep with me often during this time and hugged her a lot at night while Fred slept with Zachary or in the spare bedroom.

The stress, on all of us, was immense. Our focus as a family on "saving Zachary" was exhausting all of us. Like every human, I asked myself, "why me?" I had read so much on autism that I was sure it was a matter of a genetic predisposition manifesting itself through food intolerances. One time, during a particularly bad argument with Fred, when I was "feeling sorry for myself", I blamed my husband and blurted out that all this was his fault...that the "genetic sewage", as I called it, came from his side. After all, he had one sister with a PDD child and another sister whose child had all kinds of allergies. There was none of that on my side. It had to have come from "his" 50% of the genetics. At the time I said it, I was angry, still mad at having to deal with this situation. Of course, I regretted those words later, but, too late, they had already been spoken. Fred had always been such a wonderfully supportive husband…how could I have said that to him. I knew he cried over all this just as much as I did. I was fortunate in that my husband was a very forgiving man. He knew I was angry and hurt.

We both knew the whole situation was totally stressing us out as a family and we wanted to be closer to our relatives. So, in mid-June, we decided to move closer to Canada. If we did not have enough stress in our lives already, we had just added more. And we had decided not to go through a realtor but sell the house on our own. Our duplex was in a nice neighborhood, but ours really had not received many updates since it had been built. We spent about $12,000.00 updating our home prior to putting it on the market. Homes in our area had just skyrocketed in price in recent years and I knew we could sell it fast and at a good price if it "looked good". So, we had painters come in and repaint the whole place…it just about broke my heart to see the paint go over my "room of colors"…I could not look. There had been so many memories there. I think it equally broke the painter's heart…the paint I used was so bright that he literally had to sand it down before he could paint the wall, and it still took three heavy coats of fresh paint to hide the paint I had used. He was not expecting that and it slowed down the project a little. I had spent three days in there…and so did he! The rest of the contracted painting team laughed as they checked in on his progress... the last guy to the job was assigned "that room" and all the other painters were thankful they had arrived early enough not to get that particular room. The team of painters included four men and it took them just over two weeks to finish the entire house. Everything was repainted.

The man who had lived the house before us had painted the railing to the upstairs gray, along with the kitchen cabinets, bathroom cabinets, the wood trim and doors throughout the house. All of that had to be repainted. I did not know what it was about people and their need to paint over wood. I liked wood and would never paint over it myself. In addition, the kitchen floor and the upstairs loft had really bad squeaks in the floor at about the most walked on area. If there was one thing I hated, it was a squeaky floor. There was nothing like trying to be quiet at night not to wake the kids and then hitting "the squeak". I insisted those be fixed. The longer I lived in that house, the more I came to hate that gray paint and those squeaks. I told Fred that as a woman, I would never again buy a house that had squeaky floors like this one did right in front on the stove and at the top of the stairs just off the loft area. I did not want to lose a perspective buyer because of that. Although the house was only ten years old, the floor in the kitchen was a ten-year old linoleum and it was yellowed. We decided to completely redo the kitchen floor and fix the squeaky loft as well. If we were going to sell this house, I wanted it to move quickly in order to minimize the stress on Zachary and the rest of us. It took two men an entire day to re-do the sub-flooring for the kitchen floor and lay down the new floor covering. Finally, we put new carpet throughout the house except for the basement. That carpet was only two years old and it still looked great. We also had a huge two level deck in the back and had that re-stained.

The couple attached to our duplex was an older couple. Bob was around fifty years old. That man absolutely loved to landscape. His side always looked fantastic. I had done a lot with the flower beds on my side since we had moved in but they never looked as great as his did…not even close. Anyway, Bob offered to do the yard work for us. He mowed our lawn (something he used to do whenever we went on vacation, without us ever asking), put all the new wood chips in the flower beds and made them look quite nice. I always used to tell him he should go into landscaping. He did a lot of work and it looked great! I would really miss Bob…what a guy… and I would miss his wife, Julie, and the others on the block too, but for us, it was time to leave the city. I think Bob and Julie were glad we had decided to "upgrade" before leaving because if we had sold our side "as is" prior to the upgrades, we would have significantly dropped their property values since we were the "attached" duplex to theirs.

I attended a "For Sale By Owner Seminar" and got all that rolling. We received a lot of calls and showed our home to several families. Some families came back four or five times. We were constantly showing our home to interested buyers. We had twenty six hundred feet of living space, a home large enough for any family. Real estate prices around Chicago were outrageous as far as I was concerned and our home was reasonably priced for this fast growing area. Anyway, within five days, we got a buyer that seemed to fit the bill. He was very interested. Our place looked like a "showcase". We had completely emptied the house and put everything in the garage before the painting had begun and never moved it back in. We literally lived in the basement, sleeping only on mattresses. We lived like that for a total of about three weeks. I had several very interested buyers, but the one in particular had come back five times and really wanted to buy it. He simply had to arrange for financing.

Again, the stress of the whole situation soon became too much for all of us. I told Fred to take the sign off the front lawn. We had had enough people interested that we should be able to sell it without further showings. The last week of July, we gave Bob and Julie the keys and a telephone number where we could be reached and we headed up to Canada, again. I told Fred, "either one of these families we have shown it to buys it, or we did not sell this year!" Well, we did sell and for a better price than I had hoped for. Of course, our neighbors were thrilled! We had received the best price of anyone selling in this area in the past year and a half or so.

We stayed in Canada that last week of July and returned to the US in mid-August, about ten days prior to our closing on the house. It would be while we were in Canada that I would come to understand more about Zachary's particular situation.

Zachary always just loved water a little too much for my comfort. My babysitter who was one of my neighbors had an above ground pool that was about six feet deep in the middle. The pool bumped up and rested against a small hill, so that if you were on the hill, you could easily fall into the pool. Jennifer was a great babysitter, but you never knew what a child could do and so, I had always given her strict orders with both Anika and Zachary, that if they were outside, they had to have a life jacket on, every minute. I did not care if they were playing in the front or the back (we lived on a quiet cul-de-sac); I wanted both my children to wear life jackets when they played outside at her house. My neighbors, although I loved them dearly, must have all thought I was a fanatic I am sure. Well, my fears were not unwarranted.

While in Canada during the month of July 2000, on Anika's eighth birthday, Zachary's lack of flexibility as far as "direction changes" almost cost him his life. My in-laws owned a cabin by a lake and kept telling Fred and I to go there to "relax". On my daughter Anika's eighth birthday, there would be a small family get together with a few of her aunts, uncles and cousins up at the lake. All day, Zachary had worn a lifejacket if he was outside; even if there were many adults around, I had always had a fear of him drowning. Before we knew it, it was close to 10:00 p.m. and we still had not done the birthday cake thing.

We finally got around to the birthday cake for my daughter who had turned eight years old that day. Zachary was almost three years old. Since Anika was born in July, I thought I would put sparklers on the cake instead of candles. I had just made myself a cup of decaffeinated coffee and seen Zachary next to me while I was making it. Less than two minutes later, the sparklers were lit on the cake and we were all singing "Happy Birthday". While we were still singing, my sister-in-law, Christine, said, "where's Zachary?", thinking he would like to see the sparklers. As soon as Fred heard, "where's Zachary?", and knowing how much Zachary loved the water, Fred instinctively ran outside in a heightened state of alert.

It was now getting to be quite dark. I started to calmly search for him in the bedrooms, thinking for sure that he would be playing under a bed or something. As we searched every room and the attached garage/storage area, it soon became evident that Zachary was nowhere to be found. Almost everyone went outside to search for him. I was a total ball of nerves and stayed inside, thinking we must have just missed a spot in the three-bedroom camp. I began to search closets, look under every bed, etc. Where could he have gone? I had **<u>just</u>** seen him about two minutes earlier. That was right about the time Lucky, my sister-in-law's Australian Shepherd barked outside. Australian Shepherds were farm dogs, and if they did not have a herd to protect, the family became the "pack", and especially the smallest member of the family became the one they naturally wanted to protect most. Although Lucky had barked, no one had paid attention to it…we were all inside... so we thought!

In spite of the fact that Fred had been sitting by the door in a rocking chair, Zachary had indeed managed to somehow sneak past him and everyone else and go outside. On one side of the camp, there was a creek, flanked by a road that curved near the property we were on. A fifty-five mile per hour limit would not allow a car enough time to see Zachary and stop had he made it to the road. I knew that if Zachary spotted a road, he would follow it. If he got to the road and decided to walk "the line", he would follow it...that could be the sideline indicating the shoulder or the centerline...whichever one he happened to "get to". Then, he never went "off course" unless forced to by someone else.

On the other side of the camp he could get lost in the bushes. From the front of the camp, it was probably about eighty feet to the lake. Once outside, Zachary could be at the lake within thirty seconds. There was a small dock going into the lake. Fred went up and down the property shoreline, a span of probably seventy feet. As he went by the dock, at 10:00 p.m. or so that night, he thought he saw something moving at the end of it. There was Zachary, at the very end of the dock, facing away from shore, chest high in water, with a watered down diaper, holding on to the very end of the dock with his little left hand. Had he taken one more step forward or lost his footing, he surely would have drowned. Looking back on that night, I knew that because of his lack of flexibility in changing direction, Zachary would not have "come back" toward shore.

This had been too close for me! As Fred and I went to bed that night, I said to him, "Come to camp, relax…. we're leaving in the morning!". The experience had only further stressed Fred, too, and he totally agreed that being close to water like this was just too dangerous for Zachary. The funny thing was, I had never realized just "how much" Zachary lacked flexibility in changing direction until that experience in the summer of 2000. Before that, I had attributed his screams in stores when I changed direction to his having wanted to see something more closely in an aisle or to his not having been able to touch something he wanted to touch, to those terrible twos that never seemed to go away. His throwing himself on the ground early on when we went on walks, I just saw as "autistic behavior", not recognizing at the time that this was more than that, that the problem was the whole "change in direction" thing. As I thought about it some more, I now "saw" the problem…it was the "change in direction". It all made sense now.

I recalled that on early walks, if the parent taking him for the walk, or the family, together, decided to go the way opposite to that Zachary wanted to go, he would throw himself or "collapse" down on the pavement, on his back, screaming and refusing to get back up. He would pull the "jelly legs" routing if you tried to make him stand. Looking back, I could now see why that was, but back then, I did not make the connection, that this particular problem with changing direction was part of his condition. I used to just see everything as part of the catch all of "autism" but I did not see "the particular problem" until the near drowning episode. I now "saw" the real issue and how this immense lack of flexibility had nearly cost him his life. I resolved to work on making him more flexible when it came to changes in direction. It would still take a lot of work to get Zachary to overcome this particular problem.

When there were no "distractions" at the park, I would <u>practice making Zachary "change directions" without his realizing it</u>. He would get so into playing that he would not notice what I was doing. I would show him, "<u>walking backwards", then "walking forward", "walking sideways", "going up the stairs", "going down the stairs", as again, I made a game of direction changes and explained to him what I was doing as I did it</u>. I would make him chase me in the park, again, switching quickly from one direction to the other...over and over. Eventually, walks to the park did become fun again and I really enjoyed them. As often as we could, we would go as a family and all get involved in Zachary's play time. If kids Anika's age were there, I would just let her do her own thing because I knew how hard all this was on her too.

Although we spent most of our time with Zachary, we were seeing we needed our time too. Anika was in swimming lessons three times a week and on a soccer team. That helped her tremendously. Fred and I took turns taking her out to restaurants. We found it very difficult never being able to go as a family any more. We used to love doing that. For Fred and I, quiet time usually came while Zachary was on the computer or while he watched a video. We kept these to educational videos and software. No junk!

We spent a lot of money on educational videos and software for both Zachary and Anika. For Zachary, some of the best ones we had were called "Baby's First Impressions TM" by Small Fry Productions out of Atlanta, Georgia 30360 (800, 521-5311, www.small-fry.com). There were several videos, each covering a specific subject such as shapes, numbers, animals, foods, seasons, body parts, opposites, sounds, etc.. These were excellent. Another good series was by Babyscapes TM. These included videos on colors, letters, numbers, and shapes in motion. BabyscapesTM was at Box 37038, Las Vegas, NV 89137 (888-441-KIDS, www.babyscapes.com). Another good series was the Richard Scarry's Best ABC, 123s and Learning Songs Video Ever. These were available at most major retail stores. The best series for Zachary, however, were the Dr. Seuss Beginner Book Video Series by Random House (Randomhouse.com). These were available through Amazon.com under the "videos" section. At first, Zachary did not like these much, but later these videos became absolute favorites and their "silly" themes were enjoyable for the entire family. These were all excellent videos and well worth the cost.

For Zachary, the best educational cds we had found for computer use were the following:

Living Books (a Random House/Broderbund Company). This company provided the following software: a) Dr. Seuss' ABCs (Zachary's all time favorite for a very long time – the one that had taught him the alphabet without my even knowing it – also available as a video through Random House!), b) Dr. Seuss' Green Eggs and Ham, c) Dr. Seuss' Cat in the Hat, d) The New Kid on the Block, Poems by Jack Prelutsky and many more. These were excellent programs as they all had a "Read To Me" feature whereby Zachary could just listen as the pages "were turned" or a "Let Me Play" feature whereby he could interact with the "book". This company could be reached at 800-776-4724. Broderbund also made a program called "Kid Pix" that allowed children to use clip art, "paint" and develop creativity. Another excellent software program.

Knowledge Adventure made several programs under the Jump Start brand name. Again, these were excellent. These included: Toddler, Preschool, Pre-K, Kindergarten Reading, 1st Grade, Reading for 1st Grade (one of their best for Zachary right now), and several others. This company could be reached at jumpstart.com or 800-542-4240.
Knowledge Adventure also has the "Reading Blaster" and "Math Blaster" line of products and again, these were excellent. For these products, we contacted blasternaut.com or 800-542-4240 (same number as the "Jump Start" series).

The Learning Company made several programs under the "Reader Rabbit" brand name. Again, these were excellent. These included: Playtime for Baby, Toddler, Preschool, Kindergarten, Math (Ages 4-5), Reading (Ages 4-6), 1st Grade and several others. This company could be reached at learningco.com or at 617-761-3000 (customer service).

Scholastic made a product called "I Spy Junior". I found I could really use these programs to help develop Zachary's vocabulary. I would point to things on the screen and tell him what they were. I also used the "I Spy" books by Jean Marzollo to teach him the names of dozens of everyday objects/things. The books could be picked up at pretty well any bookstore. The Scholastic software could be obtained through Scholastic.com.

As far as music, we played a lot of classical music for Zachary. That, we often did just by finding a good classical music radio station, although we had our own CDs as well. He also loved to listen to soft harp music when he went to bed. For travel, we found that a series available through TIME LIFE Music kept Zachary the most entertained/happy/ quiet. This was the "100 Kids Songs" from "Mommy and Me"™ and "100 Sing-A-Longs for Kids". We had purchased both of these via Time Life Music as a packaged deal. Time Life Music could be reached at Timelife.com.

We found another tool, a "healing" CD put out by John Hagee Ministries. It cost approximately $20.00 and consisted of verse after verse on healing as contained in the Bible, set to a soft, musical background. We played that CD for Zachary quite often. For those who are interested in obtaining this CD, it can be purchased through John Hagee Ministries at web site jhm.org or 800-854-9899 (product #O3C).

A word of caution on CDs. Zachary's love for spinning was not limited to inexpensive things. He used to constantly put a finger through a CD hole and then spin the CD on his finger as fast as he could. Unfortunately, we lost many a good program that way. It got very expensive very fast to have to replace CDs. I do not even want to think of how many we had either totally lost or had to replace because of this. So, I started to work more and more with Zachary as he worked on the computer (although he was quite capable of working on his own). The computer was a powerful tool for Zachary and we encouraged his use of it, in spite of his young age. There was software out there for one year olds and we believed autistic children such as Zachary needed all the advantages they could have, and the computer was something he absolutely loved.

Although the cost of some of these resources did get to be pretty substantial, there were ways to limit expenses. A list of "recommended gifts" to family members to have some of these items purchased for birthdays, Christmas or other special occasions was always an option.

The entire subject of computers/CDs brought me to another discussion that needed to be addressed. One of the many books I had read on autism went through "good jobs" for these children. As I read that book, I got very discouraged. I think it was surely written by someone who did not fully understand how brilliant many of these children often are. The jobs were primarily janitorial, some assembly line type work, etc. I must say that I really disagreed with that author...so much so, that I ended up tossing the book in the trash because that WAS where it belonged.

In working with Zachary over the last eighteen months or so, I found that his love for learning was great. He loved to solve puzzles, work on the computer (I say work because almost everything he did was educational), count, and now, read also. I think any position that involved the use of these skills would be a valid career choice for such children. That would include things like computer programming, private investigator, chemist, medical examiner, FBI agent, mechanical engineer, etc.

If there was a puzzle of any kind to be solved, or things that needed to be "in order" or "where they belonged", these I saw as ideal career choices for autistic children. My point here was simply to tell parents not to underestimate their children or to drastically lower their expectations for their child. Zachary needed a chance before he needed a label. I was not willing to label him as quickly as everyone else wanted to. Older books on autism indicated that up to 75% of these children were mentally handicapped with Intelligence Quotients of 60 or lower. Not being able to communicate properly because his brain was not functioning properly as far as "normal communication" did not make Zachary "mentally handicapped". And, knowing what I now knew of Zachary and how he made a game of "giving wrong answers", I saw this all the more. I truly believed many of these children were in fact quite brilliant. <u>Everyone was good at something</u> my mother always said. I was determined to <u>find that</u> "<u>something</u>" for Zachary and <u>encourage it</u>.

Having worked with programmers in the past, I knew that even a self-taught programmer was often better than one who went to school to learn computer programming because a self-taught programmer had a "talent" and "love" for the discipline. I promised myself that as Zachary grew, I would focus on his talents rather than focusing on his weaknesses. We lived in a world that always wanted to emphasize social skills, and I have to say, that in today's society, not having the "block's biggest partier" was not necessarily a bad thing. Social skills would come as Zachary continued to develop. In the "grand scheme" of things, did it really matter to me down the road whether or not Zachary learned to say hello to another child at age two or at age four...probably not. I knew that Zachary could and would be a value to society. The inability to physically verbalize something or difficulty in communicating did not mean that he was mentally handicapped and I never forgot that. I would not allow one or two tests to label a child as "in the 1st percentile or 50th percentile. For too many children, I now felt, testing was not really "intelligence testing" but rather a way for schools to make their case for more funding! It is also easier to blame failing schools on "brain damaged children" than on incompetence and lack of accountability within the school system itself.

Again, this brings me to another unpleasant discussion...the fact that autism, like so many other learning difficulties/health issues was **<u>too often a matter of BIG BUCKS</u>**!

The more "special needs" kids schools have the more money they get and make no mistake about it. In Canada, for example, it used to be that money for a "special needs" child was actually "Velcroed" to THAT child. My sister-in-law in Canada saw first hand how laws changed and now, funds for "special needs" children, such as her PDD child went to "special programs" not to the individual child and so, in most cases, the school used this money "at their discretion" for "what they needed" to "build up" their programs. My sister-in-law, in Canada, for example, fought and fought for her PDD child (now 11).

About $17,000 had been allocated to the school for Andrew specifically, and when "Velcroed" to the child, Andrew had his own "aide" at school for most of the day. As the laws changed and the funding for special children "went to the program in general", Andrew lost **his** special aide. The school did not care if he learned. His mother went to school to help with her son almost everyday. She was less than pleased with what she saw as "special education". With no aide "**for him**" specifically, Andrew was being left behind at an increasing pace. With too many "special needs" children (up to six or seven) for one aide, children were falling behind - more than ever. Lessons, my sister-in-law had seen, were almost non-existent or unplanned. "Something" was simply "pulled out of a bin" and that was the lesson or homework given. When my sister-in-law suggested role-playing exercises in communication, the school "could not allow it" because that could not "be added" to the computer's software for the board of education...the "administrative software" did not allow for that. As a result, my sister-in-law pulled her son out of school and decided to home school.

Andrew was doing much better now. But, the school insisted on coming to the house to "check up" on him. After all, they had lost funding...$17,000 for one child alone. My own sister was also a schoolteacher at elementary level (many teachers in my family) and each time I went to Canada, she saw Zachary's progress. She also told me one time that there was no way Zachary would get the time he needed in a school setting. Surely, I felt, the same situation existed in the US.

"Special needs" children, I believed, were quickly becoming the "money generators" for the school system...the "reasons" for "more funding from the government". How else could you explain the fact that so many children were now on medication in schools? Did not the fact that a child was on "medication" in and of itself "prove" to the government that these were "special needs" children? Parent after parent told me how "the school" had suggested medication for their child – even when the parents and other adults saw absolutely no need for it. Only the "school administration" saw the "need". Why was that?

I am not saying that medication was not necessary for some children, but rather that I believed it was being used more and more as a "reason for additional funding". Unfortunately, as my sister-in-law saw first hand, for too many of these children, school had simply become a "glorified babysitting service"…and an expensive one. The genetics of the last generation had not deteriorated such that so many children could now be so "learning disabled"...I just did not believe that! Also, why was it that we now had all these "hyperactive" children in our schools, children that now "needed" medication? First, I would certainly question one's definition of "hyperactive" in our school system. Could the fact that we had so many "hyperactive children" possibly have anything to do with the fact that children often now received only ten minutes to eat lunch and had perhaps fifteen minutes of outside play time. The fact was that today, kids had less time outside to play and burn energy. Recess was shorter or non-existent as children were sent to "detention" instead of going outside to burn off some of their energy.

I was a very active child when I was young, but being energetic should not make you an "automatic" candidate for drugs. There are always alternatives - that was how I looked at things. I did not have to put Zachary on prescription medication for hyperactivity... magnesium supplements could help him with that and $15.00 provided a one-year supply of magnesium supplements. Prescription drugs "proved" that a child was "special needs" and, for schools, that was more profitable! **<u>Too often, when you want the real answer to something, unfortunately, today, look no further than the all mighty buck!</u>** <u>My advice to any parent would be to find out how much your child was "worth" to the school system if labeled as a "special needs" child...and then, to get a second opinion from an independent source, someone who had absolutely nothing to gain financially from evaluating a child as a "special needs" candidate</u>. Only then would I, as a parent, even consider labeling my child as such.

I firmly believed that **<u>for those children in today's schools who were indeed "special needs", those funds should absolutely be "Velcroed" to that specific child ... not to "the system"</u>** as that was simply asking for abuse and misappropriation of funds...with the child being the ultimate loser in the end! I was sure not all schools looked at children as "budget dollars", but I feared too many did. John F. Kennedy once said: "*Children are the world's most valuable resource....and its best hope for the future*". Too many schools - and parents - had forgotten that!

CHAPTER 14

Zachary's Progress – In Michigan (August 2000 – Present)

Almost every book I had read indicated that autistic children needed a "routine" and that taking them out of the "routine" was too stressful for them. That may be true to some extent but with everything going on in our family the summer of 2000, it was no understatement to say that Zachary had no routine at all. If anything, he strived on change and that was a good thing because life was full of change. We made several trips to Canada. There were three weeks of constant contractors with changing work crews showing up at various times (up to five vehicles at a time) at our house as we prepared it for sale…the painters, the window washers, the window "fixers" (a couple were not opening properly and so we had those repaired), the deck cleaners/ stainers, the squeaky floor fixers, the linoleum layers, the carpet layers…and then all the potential buyers who came to see our house, many on several occasions...it seemed never ending. There was the "living in the basement" for three weeks, the packing up of everything we owned, the constant showing of the house to potential buyers, the moving of all our possessions into a truck, and the moving away from a familiar house and neighborhood to a new one...with a few trips to Canada mixed in there. If that was not "changing routines", I do not know what was!

In spite of it all though, overall, Zachary did very well during this time and continued to strive. He liked to see "what those people were doing in our house" and at times, it was difficult to keep him out of their way (as it would have been with any three-year-old). He did not care about the "routine". He was fascinated by all the "goings on", curious, as any "normal" child would be.

We decided to move to the Upper Peninsula of Michigan, closer to our family in Canada. When deciding on a home, the realtors in the towns we considered all asked if we were interested in "lakefront" property. Given our near drowning episode with Zachary that summer, the answer to that was always a quick, "absolutely not". We had looked at homes quite close to the border but did not find anything that would really work for us and so we settled for something three hours from the border. On August 24th, we drove north to the Upper Peninsula, ready to close on our new home the following day. No one had informed us that the county fair was going on and that there was not a hotel room to be had for at least an hour outside of the area. So we drove an extra hour (eight hours in all that day).

That night, we slept in a hotel (another break in routine) and Zachary was fine. The next morning we got up, fed the children and by noon, headed out, driving the one hour back to our new town. On the way there, I saw something on the road. Then - again, I saw it...wild turkeys...and they were huge. I was driving and told Fred, "did you see that...the turkeys on the side of the road"? Fred had this look on his face that I perceived as disbelief, so I said, "What, you don't believe me"? He replied, "No, I've never seen one and I am just thinking I probably won't get to see one again". He thought he had missed his only chance to ever see a wild turkey. It turned out that we saw over a hundred during that one hour drive. How funny!

Our "closing" in Illinois was handled by our attorney. Procedures began at 3:00 p.m. They were not complete until around 6:00 p.m. as a result of complication on the side of the buyers of our house in Illinois. We had informed the realtors for our new home that we would not close on this one until after the first closing had completed earlier that day. We were all exhausted to say the least… throughout all of this, we had both Anika and Zachary with us in the car, driving around, waiting on the call from our attorney in Chicago informing us that the first closing was complete and that we were now able to finalize the second. We were in "closing procedures" until about 7:30 p.m. By 8:00 p.m., we were in our new house. This was a newly built home. Oddly, the house was very hot - and try as we may, we were unable to get the thermostat/furnace to shut off...in August! It was extremely hot and muggy in there. The only way to get the heat to turn off was to throw the breaker for the furnace. We spent approximately the next hour or so feeding the kids and unloading a few critical items from the moving truck - the king size mattress we would all be sleeping on and a few blankets for the night.

Then, around 9:00 p.m. all the fire alarms started sounding...and it was loud. Our fire alarms in Illinois were both carbon monoxide detectors and fire alarms in one. We did not know what was going on and right away, since we could neither see nor smell any fire, my thoughts went to carbon monoxide. Was the fact that we had turned off the furnace turned off some ventilation of some kind so that carbon monoxide had accumulated in the house? We knew nothing about that stuff...all we knew was that all the alarms were blasting. Within a matter of thirty seconds or so, we were all in the car.

I called the realtor from my cellular and explained the situation to him. I told him he had to get someone out to the house to figure out what was wrong as soon as possible and that we would be sleeping in a hotel that night since we could not take any chances. The realtor felt so bad about the entire situation, knowing what a long day we had had, and with an autistic child, that he called the contractor out that very evening. At 12:30 a.m., that same night, the realtor came to our hotel room. Since we had been in our car for most of the day during the Illinois closing procedures and chose that as the place to stay to wait for word that everything was clear with the closing of our old house, the realtor knew our car from having spoken to us next to it on so many "updates" during the day. My attorney from Chicago would call the Michigan realtor's office to let us know how things were going in Chicago and the realtor would inform us of any incoming calls via cellular. We drove around town and went to a local park to keep Zachary quiet and came to the real estate office on an "as needed basis" until we were finally ready to close on the new house.

That night, the realtor tracked down our car by going to various area hotels to see if it was there. He finally found the right hotel and called us from the hotel lobby. I met him there and he explained how two wires were just barely touching in the thermostat and that was what had prevented it from shutting off, and that it was now fixed. He also explained how in Michigan, the law required that all new homes have fire alarms "wired" to the fuse box. When Fred threw the breaker for the furnace, it activated a timer of some kind and one hour later the alarms sounded. I was informed that this was how the alarms were set up. OK, fine, I was too tired to discuss anything else. I was more upset for Zachary than the fact that we had to sleep in a hotel when we should have been in our house. Zachary's hearing had always been very sensitive to sound and those blasting alarms did not help his situation.

We slept at the hotel that night and returned to the house in the morning. Within a week, everything was pretty well unpacked and put away. That summer, Zachary's "routine" had been non-existent, and in spite of it all, he did exceedingly well and adjusted to the new house almost overnight without a problem.

The first weeks in our new house went by quickly. Not long after we moved there, I had a horrible nightmare. I dreamed Zachary got up during the night and went outside. In my dream, it was winter and very cold and Zachary had almost nothing on, a diaper and t-shirt only. When I awoke, I told Fred about the dream. Given Zachary's near drowning as a result of his sneaking out of camp at 10:00 p.m. in Canada, we both agreed to get additional locks. I called a locksmith and had him install <u>deadbolts</u> on my doors. They were low enough for Anika to reach, but well out of Zachary's reach for a couple of years at least. The locksmith informed me that it was against fire code to have the locks so high because my children needed to be able to get out by themselves in case of a fire, should both parents be overtaken by smoke inhalation. Our new house was a ranch and Anika knew how to open the windows and get out should a fire occur. We had the "blasting fire alarms" too...and Fred, being from a farm background, still got up around 4:00 a.m. to get work done because those were the best hours of the day for his "quiet time". Because of Zachary's constant "waking" in the first two years of his life and also now due to the fact that he was autistic, Fred and I were both light sleepers.

Although Zachary usually slept through the night now, I explained to the locksmith that the odds of my child sneaking out in the middle of the winter and shutting the door behind him, automatically locking it, were much greater and a greater possibility than a fire. Zachary had already snuck out once at night and almost died, I was not about to risk it again. The locksmith understood. He had me sign a waiver stating his company would not be liable in the event of a fire and installed the deadbolts. He put one on the front door as well as one on the door leading to the garage. Before we knew it, September was over and October had rolled in with all of its color.

Prior to moving, Anika had asked whether or not we could have a dog "at the new house" and in October, I finally broke down and decided to get one for her. We lived on 1.3 acres and that was plenty of room for a dog. Our yard was at least six times the size of the yard we had had in Illinois. Unknown to Anika, I got up one morning and started looking on the Internet. Soon, I found exactly what I was looking for, an Australian Shepherd pup, male, three months old - about six hours from where we lived.

I showed Fred the printed article, with picture of the pup. Of course, Anika wanted to know what I was looking at and as soon as she realized what it was, she was overcome with excitement to say the least. I phoned the lady who had advertised the pup on the Internet. It was still available. Anika and I got in the car and headed out. Most people would never drive six hours one way to buy a dog, but this dog was a special type of dog. Australian Shepherds were farm dogs that herd cattle. If they did not have a herd to protect and gather, the family became their "herd"...and they protected it! Anika insisted it be "her dog", but my intent in buying this particular dog was just as much for Zachary as it was for Anika. Lucky, the dog that had barked to warn us when Zachary snuck out of the camp was an <u>Australian Shepherd</u>. These dogs were among the most intelligent of all dog breeds. As herding dogs, they had this <u>instinct whereby they immediately went into action when a member of the pack went astray</u>. Well, it would not be long before that dog proved to be the perfect dog for the kids.

Within a week of buying Patches, we started taking him to the park next to Lake Michigan in the area where we lived. This was a beautiful park and we spent a great deal of time there with Zachary. During that first week we had Patches, on one of our park outings, Zachary broke away from me and started running off. The dog was still just a pup at three months old and all the kids at the park loved to play with him. We had moved to an area of the park where there were fewer children and Zachary had broken away from me and was running toward the lake – of course! The pup immediately went after him, grabbed Zachary by the arm of the jacket, pulled him down to the ground gently to stop his escape and laid on top of him. This was the dog for me! I was thrilled. Later, as Zachary tried to break away again, the dog would position himself perpendicularly in Zachary's "run path", blocking him from going any further.

My sister-in-law had told me how her dog acted as a school crossing guard whenever her daughter came home. My sister-in-law lived just outside of town, and there was a big curve in the road close to her house. Due to lack of funding, the school bus crossing guard program had been eliminated. Each day, when Lucky heard the bus coming, she would run out in the middle of the road, in front of the bus, wait for Jamie to get off, make sure she heard no cars coming and, then "escorted" Jamie across the street when it was safe to do so. Another time, at my in-laws camp, my sister-in-law had a woman come up to her saying "what a great dog she had". She had been watching Lucky for close to a half hour.

There was a main road not too far from camp, and a smaller side road led to the camp itself. The side road had a little dam below it, but you could not see it from the road. My niece and nephew often played by the dam. On that particular day, this woman observed Lucky and could not believe her eyes. This particular side road was only wide enough for one car to fit comfortably on it. When Lucky heard a car coming down the side road, she ran up and literally parked her butt in the middle of the road, forcing the vehicle to come to a stop prior to arriving at the area in the road where the children were playing below near the dam. Lucky then walked across the area of the dam, the car following behind, and then, as soon as the car had passed the area where the children were playing, she would get out of the road and let the car go. Australian Shepherds were great dogs for anyone who had children... but since they were herding dogs you had to have a yard that was large enough for them to run at pretty good speeds since they needed to burn up that energy. This was not a dog you could keep tied up all day...they tended to get cross if you did that. These dogs needed at least ¾ of an acre to run. Less than that did not seem to be enough.

On a trip to Canada once, Zachary was falling asleep in the car and his head was really slouched over. Patches was laying on the seat beside Zachary. When he noticed Zachary's head going further and further down in front of him, Patches placed his neck area underneath Zachary's head in order to provide support or a "pillow" for Zachary. Another time, he saw Zachary was losing his balance while playing outside and he rushed in front of him to break his fall. Like I said, these were great dogs for kids and this breed, in particular, was fantastic for children with special needs. Although Patches always wanted to play with Zachary, it would take Zachary a long time before he would actually initiate anything when it came to the dog, but, sure enough, while on that same trip to Canada when Zachary's neck was strained as he slept and Patches provided a "pillow", Zachary would later reach over and actually "pet" him for the first time. We were all thrilled. Patches quickly became a "star" addition to the family.

My determination to bring Zachary into "this world" continued in the beauty of the Michigan fall. Zachary was now identifying a lot of shapes, including stars. I had put stars on Zachary and Anika's bedroom ceiling, the kind that glowed in the dark. I literally put about one thousand of those stars on their bedroom ceiling. Of the one thousand stars or so on his bedroom ceiling, I had put some in specific patterns. If you looked closely, you could see a big balloon, a happy face, a cross, a huge rainbow, a heart, a circle (Zachary's favorite shape), and the big dipper.

One night, as I was getting ready to put the children to bed, I made a point to show Zachary the stars in his bedroom and then took him outside, to show him the stars in the sky. You could tell he understood… stars were these shinning things in the sky. In Illinois, due to all the lights of the city, he had never seen them. In Michigan, he had never noticed them simply because he was always inside, in bed, by the time they came out. With the fall, however, as the days got shorter and the nights longer, the stars came out earlier and so now, he actually saw them. His little eyes just glowed as he looked up at all those twinkling lights. After that, when I would put him to bed, I would say, "Look at your stars" and he would look up at the ceiling, and that was often enough to calm him down for the night... not always, but often.

It was also around October of 2000 that <u>Zachary started to put more words together</u>. He used to talk with only one word, unless it was a short phrase or "idea/concept" that naturally went together...like "See you later". But now, for the first time, he was starting to put words together that did not necessarily belong together. He was starting to say things like "yellow circle". His pronunciation of words continued to be fantastic, even for "big" words like "caterpillar", "alligator", "elephant", "rhinoceros", etc. He was singing more now. We would hear him singing "Twinkle, Twinkle Little Star", "I'm a Little Tea Pot", "Baa, Baa, Black Sheep" and a bunch of other songs he now knew. Although he did not always know all the words, he would sing them the best he could and then kind of hum the rest under his breath. When Anika noticed him singing, she would sing too, as we did, always encouraging any new, positive behavior. Before we knew it, it was November.

It was <u>during the month of November</u> that I took Zachary to the park and for the first time, he <u>actually showed interest in another child</u>. There was a little girl there, about three years old. She was hidden behind her mother so that we could not see her, but we could hear her crying. Zachary actually extended his neck to see her, wondering what was wrong. That was another one of those "golden moments"... a small sign of social interaction, of "noticing" other children...another glimmer of hope. Whereas I had missed so much in his behavior when he was younger, and missed so many of the signs of autism, now, I noticed everything about his behavior, down to the most minute detail. Each day, I had more and more to be thankful for. By the end of November, Zachary could count all the way up to 57...in perfect order.

Zachary was making great progress and with the holidays approaching time went very fast. Anika was now on a swim team. She went to practice twice a week and had swim meets almost every weekend. It was our time together. We camped out in school gymnasiums throughout the Upper Peninsula, as did the other parents during swim meets...only I made it a point to really take time to hug Anika while we rested on her sleeping bag between events. She loved the extra attention...without Zachary... and I loved that time to be "just with her" too! I was so thankful to have her for a daughter.

Anika was a blessing in and of herself, but she was also a fantastic sister for her brother, and just as determined as I was to "save Zachary". Often, she would ask me if I thought we were doing a good job of "saving Zachary" and I told her yes. She would ask if she was helping a lot in "saving him" and I always made sure she knew her help was invaluable. There were many times she would help us to just keep an eye on Zachary and keep him entertained. With Zachary, an extra pair of eyes in the room was always handy. He always got into everything. More than anyone, Anika could get him to play and run after her. She was a constant ball of energy and could easily keep up to her brother whereas Fred and I were more prone to getting discouraged and tired at times...and yes, we "felt" our age a little more (Fred and I were both in our late 30s).

Although the winter months were the most difficult since it was harder to go outside and play for any length of time, it would be during the month of December 2000 that I noticed a lot of change in Zachary.

Like most families in America, we celebrated Christmas. That year, I had only put the tree up in December. Zachary had one particular video that had a Christmas tree in it. One day, as we were sitting there watching this video, he walked right up to the Christmas tree and <u>pointed for the first time ever and said, "Christmas tree"</u> clear as a bell. Anika and I were sitting nearby and had once again been lucky enough to witness another leap forward. Fred, unfortunately, was in the office, but he was thrilled when we told him about it. That was on December 23rd, 2000. On the 26th of that same month, he pointed his finger to six or seven things and called them out as he touched the computer screen for each object. I had previously purchased "<u>I Spy" books,</u> by Jean Marzollo, and now, he pointed to everything I asked him to point to. "Show me the star"...he pointed to it, "show me the pig"....he pointed to it..."show me the turtle"..... he pointed to it....everything he knew, he pointed to. These books became a great opportunity/tool for teaching him about new things and for increasing his vocabulary. Of course, he still had "his days", but <u>more and more, it was toward the end of the day that things got bad</u>. Mid afternoon naps were now out and Zachary often grew quite tired by night. Fred and I were always relieved when it was finally time for bed.

By now, Zachary loved to brush his teeth. At first, he did not like it but <u>I found the trick to brushing his teeth was counting them as I brushed them</u>. He loved anything that had to do with counting. As time went on and the months past, you simply had to say "brush teeth" and he would run to the bathroom and open his mouth. That came in very handy for dental visits. I often wondered if the toothpaste had gluten but I did not think so since he did not seem to react to it in any negative way. I used Crest toothpaste. Regardless, I never put very much toothpaste on his brush…barely smearing the middle section was enough. I recently started to brush his teeth without counting them out loud. Although he found it a little stressful, he was ok with that.

Zachary also loved to take a bath at bedtime... actually, at any time. He simply loved water. Often, I would put <u>Epsom salt in his bath</u> since many books I had read said it helped calm autistic children. As he took his bath, I often <u>made bubbles</u> for him. Again, that was something he loved to do at any time. Big bubbles, little bubbles, any bubble was fun to him. Of course, the bath often "woke him up" and he thought he should be allowed to resume his "activities" rather than get to bed.

Zachary has always been a softhearted child. You need only speak firmly to him and he started the old "quiver lip" and broke out crying. Once, when my brother came to visit, Zachary got a hold of a pencil and was running away with it. My brother was afraid he would hurt himself and in a louder than usual tone, said "no", but it was not a shout or anything... simply a man Zachary hardly knew giving him <u>a stern "no"</u>. He stopped dead in his tracts and started the lower lip "quiver lip" thing as I called it…then he broke out in tears. My brother had only been worried for his safety. He did not mean to scold Zachary in any way. Regardless, often now that was all it took, a firm, "get to bed" and Zachary ran for the covers. There was plenty of time the next day to resume fun activities.

Christmas time was always a special time for Zachary. I had purchased <u>a carousel that played Christmas songs</u> when Zachary was still a baby. Each year, around Christmas, I would take it out for the kids and put it in their room. Now, Zachary loved that carousel more than ever. He liked the mirrors, the lights, the turning motion, the music. I still use it to "de-stress" him. When he is having a bad day, I take it out and let him play with it.

At Christmas in 2000, Zachary also received a little wind up train. It had a key in the side and you just had to wind it up and let it go on the floor. It would go all the way across the floor. Zachary loved it. As the days went on, <u>more and more Zachary's play with toys was appropriate</u>. He actually pushed cars along the floor instead of just tipping them over to spin the wheels. <u>The need to spin had decreased significantly</u>. Sure, it was still there, but much less so. Whereas before Zachary could spend hours spinning if you let him, now, he spun a few minutes, often a few seconds (ten or so) and moved on. On December 31st, 2000, another leap forward. Fred was always the one who made pancakes for Zachary from a gluten-free mix. On that day, he asked Zachary, "Do you want pancakes?" and Zachary replied, "No". It was <u>the very first sign of actual "conversation" taking place</u>.

Although I had read that winters were supposed to be worse for autistic children, here we were in December, and Zachary was making great leaps forward. <u>He was very discriminating</u>. While playing a game once, I had stated something was a circle. He corrected me and said "oval" and he was right, it was an oval. That month, I also spent a lot of time teaching Zachary the <u>phonics</u> for each letter. By the end of the month, I would say a letter and he said the sound for each letter I called out. Soon December of 2000 came to an end, and with the start of the new year came so much more hope for Zachary. Fred and I were slowly getting our son back, and Anika, the brother she so dearly loved. Zachary was still a long way away from being free of autistic behaviors, but the grip autism had once had on him was slowly being released.

January of 2001 brought still more good news. While watching a video on January 1st, 2001, one that had the word "apple" in it, Zachary looked as though he was starting to sound out phonics, like he was attempting to read the word. When he went to bed at night, I often laid next to him until he fell asleep. Many times, he said things like "green circle" while he laid in bed, something totally unrelated to anything I was saying to him...it was simply "something to say" for no reason at all. He said it over and over and over...almost as though that was what he was "seeing" in his head at that moment. On one night in particular, I was absolutely amazed. He started with the letter "A" and said, "A is for apple, B is for bed, C is for cat" and so on. He did the entire alphabet that way, giving an accurate word for each letter of the alphabet, ending with "Z" is for zebra". He had videos that took him through the alphabet like that but the amazing thing was that then, he started over, using different words for each letter, most words different than what he had used the first time through, and again, the word was accurate for each letter. At times, he said all his shapes before going to bed, "circle, square, triangle, rectangle, star, heart, hexagon, octagon, pentagon, trapezoid"...**it was as if he was in "neural overdrive", "ordering" his world while he was still awake, putting things "in order" before he went to sleep. It was the wierdest thing I had ever seen.**

Although Zachary made great progress in certain areas, he was still well behind in others. He still was not potty trained and social skills were still very, very limited. At almost three and a half there was no desire to use the bathroom. I had bought a potty training video and although he liked it a lot, still nothing. I used to sit him on the potty, sometimes for quite a while, hoping that if he "saw the stuff" in the potty, he would make the connection. I took a game of chess and put all the pieces on the board, on his lap as he sat there. Within fifteen minutes, he could identify and say the name of each piece... a pawn, a queen, a king, a bishop, a rook, a knight and upon request give me the proper white or black piece. I played games with the pieces, blowing a particular one off the board completely. Zachary thought that was absolutely hilarious. I even found games to do with the plunger to keep him entertained.

I actually moved a television set and VCR into the bathroom to help pass the time. Sometimes, I think he got a little too comfortable in there, or had a little too much fun. We also blew bubbles and that was a favorite too. In spite of the games and the long hours of "training", still nothing. I could not believe it. How could he be so intelligent in so many areas and yet be so behind in others. The whole potty thing was most discouraging. I was so tired of changing diapers. I tried, and tried and tried to potty train Zachary...for over six months. Still, no desire whatsoever to use the bathroom on his own. I finally gave up, figuring he would learn how to go on his own. I had put so much work into this and it was a total failure. My sister-in-law confided in me how her son, now eleven, still needed a diaper at night. I was so discouraged! Depression was actually starting to "set in". I actually started including "God, help Zachary be potty trained this year" in my prayers. During that time, Anika received a chess computer game and now Zachary came to really enjoy watching her play chess on the computer...that was about the only positive thing that had come out of all this.

February was a typical February. We had lots of snow and shoveling helped distract us during the difficult winter months. All I pretty well did that month was try to potty train Zachary and work on phonics. Soon, he started to actually be able to read a few words. I was absolutely amazed. Again, how could a child be so intelligent and yet have such difficulty with a simple thing like potty training?

March was soon upon us. I spent March break in Canada helping my sister with her nine children. She had gone through a serious depression and I wanted to give her a little bit of time to herself. So, while Fred visited with his family, I babysat ten children. Zachary always did better with me and I felt he was too difficult to leave full time with my in-laws. My in-laws had a long hallway in their house and Zachary would spend quite some time just running up the hallway, then running down the hallway, running up the hallway, then down again…over and over and over. This was my son, and it was hard on me. I could just imagine how difficult it must have been for his grandparents, in spite of how much they loved him. Anika loved to play with her cousins and so she too was with me although I took her back to the farm to visit too.

Fred took Zachary a couple days that week, but it was difficult to work on a farm with a special needs three year old to watch and so, primarily, Zachary stayed with me. I was thrilled to get back home after that babysitting job! I loved my nieces and nephews dearly, but that had been exhausting on me. The youngest of my sister's children was fifteen months old and she had a very serious diaper rash. The best thing for that was to keep her bottom dry and "aired out". Zachary had himself had some bad diaper rashes in the past, but nothing this bad. I slept my niece bare butt in a crib all week and I slept next to her, on the floor with Zachary. Being a light sleeper, I would hear her whenever she wet. So, two or three times a night, I got up and changed her bedding... and got at least one load of laundry going during the night. When my father-in-law saw me come into the house the night before we returned home, he said, "You look like you haven't slept in a week". He was right.

We finally did make it back home that last week of March... and I think I had never been happier in my life to see my own bed. I slept from about 4:00 p.m. until the next day. The next morning, I got up and started working with Zachary again. Needless to say, he had not received as much attention as he was used to in the last ten days or so. On March 23rd, I gave Zachary a full banana...a rather large one. Prior to that, I had limited him to half a banana. The hand flapping reappeared! The more Zachary learned phonics, the more he could make out words and sound them out. Here he was just a little over three and a half and already, by March 28th2001, he could read the following words: zero, zebra, bat cat, mat, hat, sat, sun, fun, dog, frog, hug, kiss, mom, dad, banana, tomato, log, bus, jam, ham, can, van, man, ten, men, bug, tree, pot, hot, star, moon, leg, egg, pop, mop, run, food, rat, cup, up, top, cap, cot, got, get, pig, wig, big, bib, bed, gum, bag, tap, fox, box. He was now counting to 100 perfectly. It was exciting to say the least. Luckily for me, Zachary had always been a "hugger". As I tried to make up for the attention he missed earlier in the month, it seemed I hugged him more and more each day.

With April and May came the sun and still more progress. The month of April got off to a bad start. On April 1st, 2001, I awoke at about 6:00 a.m. to Zachary who had come into my room, thrown himself onto his knees on the floor, and with his butt between his legs as he sat and rocked himself back and forth, his eyes closed and his arms holding his head, he blurted out, over and over again, "It's ok...it's ok... it's ok". I was in absolute shock. What was wrong? I did not know but I rushed over to him, put my arm around him and repeated gently, "It's ok, it's ok" as I picked him up and brought him to bed with me. "It's ok" were words I had always used to calm Zachary down whenever he was having a difficult time and now, he was using them to calm himself down. That was the only time something like this had happened since we had changed his diet. I wondered if he had somehow gotten a hold of something he was not supposed to eat, but I really did not think so. We were always overly cautious and cleaned everything constantly, counters, floors, etc. Anyway, he calmed down fairly quickly and went back to sleep as I hugged and "sniffed" him. "Sniffing" him on the neck always calmed him down, and it still does to this day...do not ask me why, I simply know it does!

During April, I used Zachary's need to order things to teach him basic living skills. As I peeled potatoes to make him French fries, I called him over to help. I pretended to drop some of the peels on the floor. He picked them up without any prompting from me and put them back in the little pile of peels on the kitchen counter. Each time he picked some up, I reinforced his behavior with a "good job helping mom peel potatoes" or "thank you". "Good Job" and "Thank You" were big reinforcers for him and I had used them for the past year. Slowly, I asked him to do a little more. I would say, "put the potatoes in the bowl", or "put the peels in the garbage". At first, I noticed a need to put the peels in the trash one at a time. After a while though (maybe a couple of weeks later), he figured out that that was not too efficient and started to put the peels in the trash by the handful. If he dropped some, he was always careful to pick them up and dispose of them properly. Then I had him help me with rinsing the potatoes. Zachary never missed an opportunity to play with water. He now responded to multiple simple commands: "Let's go walking", "let's put your hat and coat on", "let's put your shoes on", "let's go to the park", "let's go to the store", "put that in the trash", "give me a hug", "give me a kiss", "show me your bobo" (a French slang for the area that hurts).

April went by fast. Since we had failed to rake the mountain of leaves in our yard in the fall, I undertook that project in April. Fred helped me best he could. We had 1.3 acres and most of it was "cleared" but we had literally, over a hundred trees on the property...mostly oak. It took me about eight days of raking, almost non-stop to pick up those leaves. Never again would I do that. It was during one of these raking days that Zachary was almost hurt very badly. He had "no fear" or concept of danger. He did not perceive danger the way a normal child would. We now live on a very small side street...there are only four houses on our street and traffic was light to say the least. We were all in the front yard, raking one day. The very front of our property had a small hill. We had been in front, raking for close to an hour. Out of nowhere, Zachary decided it would be fun to run down that little embankment. From the corner of my eye, I saw a car was coming, and although we lived on a very quiet street, this car was driving a little fast. I yelled, "Zachary, NO!" He stopped. The car was about fifteen feet from him by the time it stopped also. That was all I needed - we were getting a fence!

That project would be the next one we tackled. We looked on the Internet, comparing the available options and tried to figure out what it would take to do the job ourselves. We had decided to go with a six foot, chain link fence. We finally decided to go with a local company and have it done. They could not put the fence in until the first of June -that was the best they could do. It turned out that given other developments in April, we would pretty well be home bound indoors anyway. In late April, we noticed charges against our bank account that could not be explained. Fred and I both held a Masters of Arts in Finance and were very much on top of finances in general. So, when these particular charges came through, they jumped out at us right away. Our bank could not explain it. We knew right away the withdrawals were fraudulent and it did not take long for us and also the bank to figure out we had been victims of identity theft. Having caught it right away, we suffered no financial damage whatsoever, just a great shaking of our confidence in the financial systems of this country. I documented everything. My file was close to an inch thick and unfortunately, that was all it became for our institutions... another file with no resolution whatsoever as to how it happened or how to prevent it from happening again! We spent the better part of May protecting ourselves from any further financial violations by calling major credit reporting agencies and having a fraud alert placed on our records, etc.

Before we knew it, spring was almost gone and summer would quickly be upon us.
On June 3rd 2001, Anika did her first communion. June of 2001 would be a month to remember. June 7th through 10th, our new <u>fence</u> went in. What a relief. I could finally be outside with Zachary and not have to chase him as he tried to run off into the neighbors' yards. I had latches installed, high up, where he could not get to them. They were the kind that automatically locked the gate when you went out and swung the door shut. So, for Fred, Anika and I, they were very convenient. We could all go in and out easily but Zachary could not. He needed the help of someone to get out. He was never outside alone but now, he was restricted to our back yard and that allowed the rest of us to enjoy the outdoors a lot more. We made a lot of campfires in our back yard. Luckily, we lived in a town that allowed them since many residents had over an acre of property. Last fall, whenever we made a campfire and tried to get a little quality family time, we found it would not be long before Zachary would get up from his camping chair and start running around our "fire pit".

Needless to say, when that happened, as it often did last fall, the quality family time was over and either Fred or I would take Zachary into the house for a bath. There were times when he could start the "fire dance" after just five minutes of lighting the fire, and at other times, he would go up to a half hour or so...it varied. Thankfully, this year, the "fire dances" were pretty well all gone. Zachary now sat in his chair and enjoyed watching the flames or he would go and play in his sand box located further away in the yard. In 2001, we found his love of water to be more of a problem than fire. June was a trying month, but there were definitely some joys.

It was during the month of June, that we got another great breakthrough. <u>Zachary started to "pretend"</u>. He had not done that before. I had a turquoise plastic cup and turquoise plastic ball that happened to fit perfectly on top of the plastic cup. One morning, while I was still in bed, Zachary took the cup and put the ball on top of it. Then, he went up to Fred who was working in the office and he said: "IIIIIIIICCCCCCCCCCE CCCRRREEMMMM CCCCOOOONN". Fred had no idea as to what Zachary was saying. Zachary tried again. "IIIIIIIICCCCCCCCCCE CCCRRREEMMMM CCCCOOOONN". Again, Fred looked at him with a puzzled look. Not able to figure out what Zachary was saying, Fred came into the bedroom with Zachary and asked if I could make it out. "Zachary, show mom", I said. There came those words again, "IIIIIIIICCCCCCCCCCE CCCRRREEMMMM CCCCOOOONN"....only this time, mom knew exactly what he was saying. I repeated, "Ice Cream Cone... very good Zachary". I took the cup and ball from him and pretended to lick the ice cream cone. Zachary thought that was absolutely hilarious. He spent much of his day trying to make us all take some of his cone.

Fred told me later that when he failed to understand what Zachary was saying, Zachary looked at him and said it slower. Fred told me how Zachary must have thought "he was stupid" because the more he tried to communicate it, and the more Fred failed to understand, the slower Zachary pronounced it for Fred. Not only had Zachary pretended he had an ice cream cone, but he had initiated the play with Fred. Zachary did more pretend play as time went on. He pretended to be a frog, to bark like a dog, meow like a cat and so on. Soon, he could do just about any animal sound you asked: a cow, a rooster, a pig, a duck, a donkey, a sheep, and so on. Zachary also loved the movie "Toy Story", both the original movie and "Toy Story 2". Both of these movies had been made by Walt Disney Productions and Pixar. He started saying, "To infinity and beyond"... just as Buzz Lightyear did in those movies. It was funny. Yet, he was still very far behind in social skills and I knew that. There were other areas to work on too.

Many times, our "work" was outside. We took walks all over the place. Zachary had always loved the outdoors and weather permitting we spent a few hours outside each day. The fenced in yard was wonderful. June 11th, however, we found two deer ticks in our yard. The area where we now lived was polluted with deer. We were only two miles or so from a national forest and the deer, at night especially, walked through many of the city streets freely on the edge of town. Some of my neighbors had commented that they had seen up to ten deer in their back yards. They were nice to watch. Prior to having our fence, we would occasionally see a deer come within ten feet of our house. Now that we had the fence, they were prevented from coming in. Although the deer were now "out", the deer ticks were still very much "in".

Not wanting anyone in the family to get Lyme disease from the deer ticks, Fred and I resolved to clear out the rest of the bush we had in our yard. Zachary's lack of pain sensation as we had seen in the past made us fear that even if a tick bit him Zachary would either show no discomfort or be unable to tell us about it. That was all we needed! We cut every shrub inside the fence – a section of property 161 x 200 feet. Only trees remained. Anything less than six feet high was gone. Our muscles were in serious pain throughout that project. It took us close to ten days to complete that project. We brought in about ten truckloads of topsoil in order to seed a new lawn where there had once been bush. Talk about a project.

Fred spent days moving the dirt from where the trucks had dumped it in the front of the house, to the back yard, a distance of approximately two hundred feet – one way. We ordered two truckloads at a time, and Fred would take one wheel-barrel load at a time to the back yard. Each truck had eighteen cubic yards of topsoil. Fred literally created little "paths" on the lawn he went back and forth so much. I think the topsoil company wondered how we moved it all so fast. I told Fred he should write: "Fred's Excavating" on the side of his wheel-barrel and show it to the truckers. Fred moved dirt for hours – each day! Through it all though, he kept his sense of humor and "sang the cheer" he came up with to encourage himself. "One wheel-barrel, two wheel-barrel, three wheel-barrel, four... you can do it... more, more, more... talk and load, just give me a hand...you can do it, we know you can". The first time he sang it, sweating as he loaded more dirt, I found it so funny that I just about wet in my pants.

The entire project would take close to a month. With the brush clearing project out of the way came another trip to Canada. Fred spent the rest of the month and half of July there, helping his parents with haying on the farm. I would come back and get Anika the last week of June. She spent about two weeks there and would come back when her cousins (my sister and her children) came to visit. I kept Zachary with me in Michigan to continue working with him. I took him to special events at the park and went for walks with him along the beach on several occasions. With the return of summer, I was looking forward to finally teaching him how to swim at a local beach. We had just returned from one of these special summer events at the park. It was Sunday, June 24th, 2001. Zachary was exhausted and so I let him play on the computer in the living room, one of his favorite activities.

I thought I would write a quick email to Fred and Anika. I was not out of the living room more than two minutes when I heard a thump in the living room. Zachary had decided that instead of playing at the computer, he wanted to mark up the computer table with a lead pencil. He had climbed onto the table to do that and as he marked up the table, he failed to realize how close he was to its edge. He fell onto the television stand next to the computer table and then onto the floor. I rushed to the living room when I heard the thump. Zachary was standing there, in front of the table, crying. In retrospect, I was surprised I did not faint from what I saw.

I knew right away he had broken his left arm...it looked awful. Between the wrist and the elbow, right in the center of those two joints, his arm had a very odd, almost forty-five degree angle. His arm looked much longer than normal – kind of like the length of an extra hand had been added to it. The bone had not gone through the skin, but I knew right away his arm was broken. I quickly grabbed the phone and requested an ambulance. Then, as I was speaking to the dispatcher, I realized it would be faster for me to take him in myself. The hospital was about ten miles away. I told the dispatcher to forget the ambulance but to call the hospital to tell them I was on my way in with Zachary. I gave the dispatcher Zachary's birthday and headed out the door with him as quickly as I could. I was a total wreck; tears were now flowing on both our faces. I felt so bad. I only figured out what had actually happened after I came back home from the hospital and saw the markings on the table. I had not noticed them when it first happened... all I could see was Zachary's broken arm.

It was approximately 4:15 p.m. At the hospital, the nurses were nice as were the doctors. They kept telling me not to blame myself, that this happened all the time with kids, that you could not watch them 100% of the time. That did not help...I still felt so horrible. I explained to the hospital staff that Zachary was mildly autistic and that he had no insurance. On two or three occasions I asked for an estimate of the costs. I had been informed that Zachary required general anesthesia. Even though the bones had not come through the skin, with little ones like him, the doctors stated they preferred to put them under completely. I felt so guilty over the whole incident - I wanted Zachary to experience the least pain possible. He had broken both bones in his left arm and the breaks were about an inch apart. He was asleep for about fifteen or twenty minutes while his bones were reset and cast in surgery.

Even though the procedure was a non-invasive procedure, with the skin not needing to be cut at all, the hospital still categorized this as “surgery” since a bone surgeon/specialist had to reset them properly. I called Fred in Canada to let him know what had happened. As I sat there in the waiting room, I thought back over the past year and how we had been through so much... the autism and all that it had involved, the near drowning, the near hit by a car, the identity theft, and now this. When was life going to get easy again? I picked up the Bible on the table next to me and started reading the section on Psalms. My eyes first fell upon Psalm 102...”Prayer for an Overwhelmed Saint”. I laughed and cried at the same time.

I began to read, “Here my prayer, O Lord, And let my cry come to You. Do not hide Your face from me in the day of my trouble; Incline Your ear to me; In the day that I call, answer me speedily...” As I read, a horrible thought came over me. I knew that thousands died each year from general anesthesia...would Zachary be one of them? I looked down at the Bible again, and once again looked for comfort in its words. I scanned the pages...Psalm 55, “Cast Your Burden On The Lord”... “Give ear to my prayer, O God, And do not hide Yourself from my supplication. Attend to me and hear me; My heart is severely pained within me, And the terrors of death have fallen upon me, And horror has overwhelmed me. Cast your burden on the Lord, And He shall sustain you;”. I glanced over to Psalm 57...”Prayer in the Midst of Perils”...”Be merciful to me, O God, be merciful to me! For my soul trusts in You; And in the shadow of Your wings I will make my refuge, Until these calamities have passed by. I will cry out to God Most High, To God who performs all things for me.” The more I read, the more I believed. Zachary was in God’s hands I told myself, not man’s. He would protect my son - I trusted Him to do so. Zachary would be ok. About ten minutes later the doctor came in and told me Zachary was in recovery and that I could go see him. From the bottom of my heart, I said, “Thank You God!” to the Lord who had protected my son. I got up, and then thanked the doctor also. I went to the recovery room. Zachary was awake but tired. We were taken to another room upstairs where we would stay for a couple of hours just to make sure he was fine. The doctor saw no need to keep him overnight. Finally, after another exhausting day, we were able to go home.

Within a week or so, I received the first bill. It was close to $4,000.00. The bills for Zachary’s broken arm would total about $5,500.00. Fred and I could not believe it. Most of the charges were for the hospital, not the two doctors (surgeon and anesthesiologist). I asked the hospital how they could justify such charges. I had close to $600.00 in charges just for nursing care. The nurses had not been in Zachary’s actual presence more than an hour or two. I did not know any nurse who made $600.00 or even $300.00 an hour. Then there were charges for surgery. Zachary had been put in a completely sterile environment for this procedure. I told the business office that this was a non-invasive procedure... that the skin had not even been cut... that this procedure could have been done on a sheet on top of a manure pile and Zachary would have been fine. Putting him in a completely sterile environment for this procedure was not necessary. The business office person then stated, “Well, if it was my child, I would want the best.” I told her again, “IT WAS NOT NECESSARY!” ... and this time I added...”HOW CAN YOU SLEEP AT NIGHT CHARGING PEOPLE SO MUCH FOR SIMPLE PROCEDURES LIKE THIS?” There was no response. She then offered to put me on the “payment plan”. I stated that I did not need “her payment plan”, that I could afford to pay for my son’s procedure...and again, I stated, “How can you sleep at night”? I hung up.

Zachary went to bed around midnight. I spent the better part of the night watching over him, making sure his arm stayed elevated to reduce any swelling. He instinctively knew to do that though....both during his sleep and his waking hours. Zachary had to have a fiberglass cast on for approximately six weeks. Summer had just started, and now he could not even go in the water. If he did, it would ruin his cast and he would have to get another one. Life had just gotten a lot tougher. I had to keep this child away from all water for six weeks...a child who loved to play in water...outside, at the kitchen sink, in the bath, at the park.... everywhere! How was I possibly going to do it? I just had to - there was no other option. I was not about to pay a fortune for another cast. In the morning, I pulled out the bag the hospital had given me. It had Zachary’s clothes in it from the night before. There had been another casualty, a special t-shirt I had bought for Zachary while we still lived in Illinois. I had purchased it at a truck stop about a month after finding out that Zachary had autism. I had done a quick weekend trip in April of 2000. It was upon my return home that I had found this t-shirt in a truck stop where I had stopped to get a bite to eat. On it were the words: “Be patient with me... God isn’t finished with me yet!”

My son’s special t-shirt had been cut from each sleeve to the neck and down each side to remove it from Zachary the night before. I looked at it and cried. Why was life so difficult now? Oh well, there was a sweatshirt he did still have though, and that one was just as “fitting” for Zachary. It was his “Bugs Bunny Tasmanian Devil Sweatshirt”. Given all the things he destroyed over the last year, that one also was a “sweet memory” shirt. Although I missed seeing the “Be Patient...God Isn’t Finished With Me Yet” shirt, like with so many other things, I found it useless to attach myself very much to anything because the odds of it being damaged or destroyed by our little “Tasmanian devil” were pretty high. As I cried a little over the ruined t-shirt, I thought again how difficult the last year had been. Even a simple thing like a haircut was a major undertaking. Although I had usually cut Zachary’s hair with a pair of scissors in the past since he did not have that much of it, when it started to thicken and grow quickly last year I decided to have a barber do the job. I was terrible at cutting hair, as Fred could then attest to (he used to ask me to do it once in a while), and so, I figured I had to go with a barber and get Zachary’s haircut very, very short. It had been April of 2000.

I had taken him to a barber with thirty years of experience. Zachary hated any type of “motor” back then and so I knew even hair clippers would scare him... although I did not realize to what extent. I explained to the barber that Zachary had autism. I told the barber, “You have two minutes...”. Then I held Zachary while the barber hurried to cut his hair with the clippers. That thirty years of experience paid off, in two minutes, the barber was done. Even though it did not take long, Zachary was still in tears. That was his first and only trip to a barber. I decided once again cut his hair myself. Most times, now, I cut Zachary’s hair while he slept...and, over time, I actually did a pretty good job. As I had looked at Zachary resting in the hospital the night before, playing with his hair, I realized he was due for another haircut.

The following week, my sister was supposed to come visit me...and she was an expert at cutting hair. She had nine children, seven of whom were supposed to come visit. Due to Zachary's broken arm, I thought about calling her to cancel, but, she had gone through a depression that year and she had so anticipated this trip as had her children. I decided not to cancel. On June 29th, I headed up to Canada with Zachary, one more time. I stayed a day or so at my in-laws before returning back home with Zachary, Anika, Patches (our dog that had been in Canada with Anika), my sister and her seven children. The two vehicles followed each other. I think my in-laws must have thought I was completely nuts for undertaking this project. While we were there, Zachary was Zachary. The broken arm did not slow him down too much. Feeding him still consisted of basically chasing him around the room and putting food in his mouth. My father-in-law always commented that Zachary should eat at the table. I simply replied that this was far down on my list of priorities - that I was just happy to see him eat... then the discussion was usually over. But, he was right. Zachary eventually needed to learn to eat by himself. So I started working on that too.

In June, at least, I had learned something that did come in handy. My sister showed me how to cut Zachary's hair and how to do it in a way that kept him entertained. It was so simple. All I had to do was give Zachary a bowl to hold and <u>I counted the "clumps" of hair as I cut them and put them in the bowl</u>. Zachary loved counting and so that was the trick to keeping him quiet and still while I cut. This brought a sense of "order" to the process of cutting hair.

I found that <u>with Zachary's "need for order", it was always best to let him finish what he was working on, no matter how insignificant it seemed to me, prior to taking him on to the next thing</u>. I found that to be true in almost everything. <u>If things were not exactly in order, he got very stressed out. Everything had to be in its place.</u> At times, that made even the simplest tasks quite difficult. For example, I remembered that back in January of 2001 while taking Zachary for walks we barely got twenty feet away from our property before he noticed something was "out of place". A snowplow had gone by to clear the roads after a snow storm, and Zachary noticed that there were little chunks of snow on the street. Of course, to him, they belonged on the snow bank with the rest of the snow. He proceeded to try and put every single "stray" chunk of snow back on the snow bank. There were literally dozens of snow chunks along the road. After about half an hour of that, needless to say, I could no longer take it any more. We had only walked about thirty feet from our property...so much for the enjoyable walk. We then headed back to the house. Zachary was in tears because I had pulled him away from his "unfinished work" with the snow chunks.

From the start of our battle with autism though, as much as I could I allowed him to finish his tasks before making him "go on" to something else. I usually took the extra time needed. If he had to throw all the shoes in the closet before going for a walk, I would let him do that. If he felt the need to put all the sticks in our yard in one pile, I would let him do that. If he felt he had to pick all the dandelions he saw while on a walk, I would let him do that. Eventually, he came to realize himself how time consuming that was and on his own, he stopped doing many of these "<u>complete the task" behaviors</u>. He no longer had to put all the chunks of snow back on the snow bank - he did not have to pick up all the rocks or sticks, or dandelions, or flowers. <u>He, himself, came to the conclusion that it was futile to try to do these things because there was just "too many</u>

of them" to "completely finish the task". I think he first gave up on doing these "complete tasks" because he simply tired out. Perhaps then, he noticed "nothing bad had happened" from not "completing the task" ... he just came to see that some things, you simply cannot do...and that it was ok.

It was also in June that Zachary started to play with the telephone. He picked it up, said, "hello... goodbye" and then hang up. Of course, it was no time before he figured out the buttons were fun too!

July had finally arrived. On the third of the month, Zachary had a follow up visit for his broken arm. It went well. His bones were healing nicely. On the fourth of July, the kids were all out, running through the sprinkler. Of course, Zachary saw them from the window and wanted to go in the water also. Although he hated eye contact, he had a way of begging with those little eyes of his...it always made me melt. I debated, should I let him? I knew the doctor had strictly advised against it...and I could be facing needing a new cast if his got wet. I thought...I could get around that. I took two kitchen trash bags and one at a time, put them over his cast and made a couple of good knots at the top of his arm, close to the shoulder, so that the cast was "doubly" protected but not so tight as to prevent proper circulation. Then, I let him out. I made sure we moved the sprinkler several time so that the grass/mud did not get too slippery for Zachary. I kept telling him to "go slow"...and for the most part, he did. He particularly liked just standing above the sprinkler and getting wet that way as the jets of water moved back and forth. That was a huge blessing as it minimized any falls from running. Looking back, I do not know if I could do that again...that too, involved, yet, more stress. I was surprised I had not somehow died from a heart attack with everything that went on this past year.

After about ½ hour, Zachary had had enough... he wanted to go in. When I got to the garage door, while still outside, I took off his loose t-shirt and his diaper. He was completely nude. No one was around other than my twelve-year old nephew, Frank. Inside, my sister and some of the older kids had locked the door leading to the garage from inside the house. We could not get in. Frank and I started knocking on the door, saying, "Open the door".... out of nowhere, Zachary loudly chimed in with "I'm naked!". Frank and I just looked at each other in disbelief. Had we heard what we thought we had heard? Frank was the first to say, "Did he say what I think he said?". We HAD both heard it...clear as a bell. I did not know where Zachary had picked that up, obviously he must have heard it at some point in his life and he obviously knew exactly what it meant as he used the phrase in a proper context. Still more proof that Zachary knew much more than he ever let on. To this day, he has never used that particular phrase again. That night, on July 4th, I took my sister and her children, Anika and Zachary to see the fireworks over Lake Michigan. We had a perfect spot and the children all enjoyed it tremendously. Although it was not the first time Zachary had actually been taken to a fireworks display, it was the first time he actually enjoyed it and marveled at all the colors blasting in the sky.

With the warm summer nights, we decided to put a tent out for the kids. It slept six. I did not let Zachary sleep in it but he did get to play in it during the day. He was thrilled to be in there to say the least.

It would also be in July that Zachary started to actually ASK for what he wanted. Prior to that month, he had limited himself to repeating words and identifying objects. The first time I noticed him actually asking for something, Zachary and I were in the car and on our way out the driveway to the store. I heard him say, “water”. I was going to keep backing up, but then it hit me that for the first time, he was actually ASKING for something. I stopped the car and went in to get him a cup of water. I wanted to reinforce his “asking”, to let him know that if he asked for something, I would give it to him. Well, after that, he was off to the races as far as “asking”...although primarily only with one word commands.

On July 10th, Zachary said, “I want milk”. He finally started to use small sentences... primarily commands again for what he wanted. The two weeks with nine children to care for in the house went fairly well. The thing that was particularly great about that time was the fact that it forced Zachary to be in the presence of a lot of people, most of them children. My sister’s three youngest children, ages four, three and fifteen months were constantly getting “in Zachary’s face”. No matter what he played with, they wanted it too. That created a little bit of “tension” for him, but he adjusted rather well. Sure, he yelled out a scream once in a while, but, for the most part, he did ok. We explained to the children that they needed to “help Zachary play” because he was not used to playing with a lot of other kids and they were more than willing to comply. They kindly offered their toys and shared with Zachary. Zachary was not particularly big on sharing. I loved having them around to “force him” to interact. He had to start learning these skills.

July 13th was my brother-in-law’s birthday, and since his wife and children wanted to be home with him on that day, we headed out early in the morning...back to Canada, again. I visited with my in-laws and another one of my sisters for one day. That was the first time my father-in-law saw Zachary sitting at the table and feeding himself with a spoon. I could tell his grandfather was happy to finally see the progress in that with Zachary. Although my son was almost four years old, this was a skill he was only now learning and because of the broken arm, I still did not know for sure whether or not he was left handed or right handed – he always “switched hands” when eating, picking things up, etc.

Zachary was starting to say a few short phrases he had heard so many times. Things like, “How are you?” to his grandfather as he came in from outside, or “See you later”. He had told that to his grandfather as we were leaving to head back to the US. The funny thing was that he then added, “Come back soon”. Tantrums were almost non-existent. Zachary still had a tremendous need to burn excess energy though and being on the farm always provided a nice opportunity to take him for a walk. Anika showed him how to feed the horses grass. The huge draft horses were behind a fence, and still Zachary and Anika were both less afraid of them than I was. Fred, Anika, Zachary, Patches and I headed back home the next day.

My father who was in Canada, also visiting family on the same weekend, agreed to bring my eleven year old niece and her nine year old brother back to my house on his way back to home. Again, two cars followed each other. During his short visit to my house, I showed my father how Zachary could now read certain words on a chalkboard. We all cheered as Zachary read the words. Any kind of cheering became a great reinforcer for Zachary. He was so proud of himself and loved to please us by showing his new skills.

I kept my niece and nephew for most of the summer in order to help my sister. This too, proved "most challenging". To say my niece and nephew did not get along with one another was a great understatement. They fought constantly, and that added to my exhaustion. But, I had promised my sister I would keep them for the summer in order to help her out and I was not going back on my promise. As often as I could, I took the three older children swimming, almost each day. Zachary stayed at home with his dad during those outings. I took them to tourist areas, to the state fair, to as many places as possible to make their summer fun. I insisted they read two hours each day, as did Anika. I had them read a children's encyclopedia and then tested them on the material. In addition, I made them work on the computer, on educational software. They hated the fact that I forced them to read each day, but too bad, if they were spending the summer at my house, they were going to read. The girls pitched the tent I had bought Anika for her birthday on July 27th. I had given it to her early so that they could all enjoy it throughout the summer. July finally ended and August 2nd had arrived...the day Zachary's cast came off.

I had warned the doctor that Zachary did not like motors and drills and that it might be difficult to keep him still. In anticipation of that, the doctor requested the help of another man to help us get the cast off. All in all, it went fairly well. Zachary finally had his arm back. I asked the doctor, "So, he's fine now... he can do anything he used to, right?" The doctor looked at me and said, "Well, his arm is about 80% healed at this point. You'll still need to keep a really good eye on him for the next four weeks to ensure he does not fall and re-fracture it...that's a common occurrence". I could have died right then and there... another four weeks! Well, at least Zachary could now come swimming I thought... that should be safe enough. I took him swimming as often as I could. The park district had placed a big slide in the water for the summer. For Zachary, it was perfect. There was only about two feet of water at the bottom of the slide. He absolutely loved it. When he had enough with swimming, he would simply say, "All done". That was my cue to leave. The older children did not like the fact that how long they stayed at the beach depended on a four year old. Zachary had turned four on August 12th.

Even though he was only four, Fred and I both felt as though we had invested ten years worth into that child. My sister-in-law had bought him a pair of pants for his birthday. They unzipped at the knee and turned into shorts. They were loaded with pockets, something Zachary loved. They were great for holding rocks, acorns and other special items he found during our many walks. Summer finally came to an end and near the end of August I went alone to take my niece and nephew back to Canada.

September was now upon us and with that month came more progress. One morning as I was sitting having coffee, I realized that I had never actually taught Zachary "his name". _Sure, he responded to "Zachary" but he did not identify that as a "name"... I had never labeled it as such for him. Knowing it was important for him to be able to answer the question, "what's your name?", I worked on teaching him that during the month of September. I started with the question, "what's your name?" and then I would answer, "your name is Zachary, my name is mommy, the dog's name is Patches, your sister's name is Anika." Then I asked him his last name. I made a game of it, using the dog's name, I would say, "Is your name Zachary Patches?" That made him laugh. He knew it was not.

Finally, within a couple of hours, he knew his entire name, although, when asked, he still made a game of giving me the wrong answer... answering "Zachary Patches" as he burst out laughing. I then tried to teach him the concept of age. That was a more difficult one for him to grasp. I said, "How old are you?" and I answered, "Zachary is four years old".... and I followed up with "Zachary has four candles". He remembered the four candles from his birthday... he loved candles... and blowing them out. When asked when his birthday was, he knew to say August 12th. That one was easy enough to teach him. It was also in September that I noticed Zachary's toe walking had almost completely disappeared.

For the first time ever, he also picked a bouquet of wild flowers. In the past, he would pick flowers and always pull the flower part off the stem. Now, he actually picked a bunch of flowers and put them in a vase (a plastic cup) when we got home. He then set his flowers next to him as he worked on the computer. Every once in a while he still pulled the tops of the flowers off, but he was definitely learning that a bouquet was nice too. That same day that he first picked a bouquet of flowers, we had seen a little girl in the distance. When Zachary got close to her, he said, "hello", and then he simply kept walking. He had finally acknowledged another child.

In October, we worked on yet other new things... days of the week and months of the year. I had a laminated poster with the days of the week on it. I took Zachary's hand and went down each day, slowly saying each day out loud, "Sunday, Monday, Tuesday, Wednesday, Thursday, Friday, Saturday". I did that twice. Zachary repeated them as he took his hand and went down the list. He did not simply know them from the poster though. When I took the poster away and asked him, "What are the days of the week?", he rhymed them off, one at a time, in perfect order. That was all it had taken. He had an amazing memory. The next day, I figured, ok, now let us try months of the year. I thought for sure it would take at least a week to teach him those. Since I did not have a poster for the months of the year and using a calendar was not working out (he wanted to flip the pages constantly), I took a sheet of paper and put a marker in his right hand, hoping that was his preferred hand. To this day, I still did not know for sure if he is right or left-handed... he switches off. Anyway, I guided his hand as I proceeded to write the months.

I wrote January in one color, February in another...and so on...all the way through December. I knew Zachary was a visual learner and thus, I wanted him to have the months written out in front of him to help him learn them. I then read the months over with him a few times. Each time I said one he repeated it. In no time, he took his hand and pointed to each month as he read each one down the page. I then took the sheet away to see if he remembered them. The first time through, he forgot a couple, but in no time, he knew them all, once again, in perfect order. It had only taken him a couple of hours to learn the months of the year.

In October, I, myself, also came to understand something else quite clearly. I had purchased fifty coloring pencils and a dozen various colored markers for Zachary. Zachary had never shown any interest in coloring. That was a skill I now wanted to show him. Try as I may though, he still showed no interest. All he wanted to do was play with the pencils and markers on the floor, and, yes, sometimes on the walls or kitchen cabinets too. I had been careful to buy only washable markers and the pencil came off easily enough. With everything we had gone through as a family in the last year, if there was one thing I had learned it was not to get too attached to material possessions and not to "sweat the small stuff". After an hour or so of trying to get Zachary interested in the task of coloring, I gave up. I went into our home office to talk to Fred. I was so discouraged. I explained to Fred how Zachary simply wanted to "play with the pencils", scattering them all over the floor, aligning them by placing all "pointed tips" together and all "bottoms" perfectly next to one another.

As I said that, it was like I was hit by a bolt of lightning. Every time I had tried to introduce a new learning tool, be it flash cards, books, marbles for counting... anything, Zachary always needed time to "play" and "touch" them first. He used to stack all the flash cards rather than show any interest in what was on them, same thing for the books. A stack of books, or flipping through all the pages had always been more interesting than what the books actually had in them. The same had been true for computer programs. If there was an "arrow" to go forward (as in a "book" on computer where you had to turn the pages with a mouse click), he liked to "turn all the pages" instead of stopping to see what was on them.

I now knew that for each new thing I introduced as a tool, I had to give Zachary the time to get acquainted with it by allowing him to touch or play with the new item until the "newness" had disappeared. So, that night, when I went to bed I told Fred (who was always up before me) to give Zachary the pencils to play with first thing in the morning. It took three or four days before I could actually sit down and use pencils "as pencils" rather than "toys" or things that were "nice to scatter, align, or touch". I now saw how this would definitely be another reason any intelligence testing of autistic children could be so difficult and misleading, at least for Zachary. Anything new first had to be made "familiar" to Zachary before he even considered using it "appropriately". He went through an almost "ritualistic" familiarization process...stacking, spinning or aligning new things best he could. That had, in a way, also been true with his toys. New puzzles could not be used as puzzles until the pieces had first been "stacked" one on top of the other, then scattered. Flash cards could not be read until they had been stacked one on top of the other, then scattered. New cars could not be used as toy cars until they had been flipped over, and the wheels spun endlessly. **Everything went through some kind of ritualistic familiarization process**. Once the "newness" was gone, the new tool introduced could be used for its intended purpose.

After a few days of letting Zachary play with the pencils, I finally noticed he spent very little time with them any more. The physical newness of the pencils was gone. I then sat him down at a table, put a pencil in his hand and started to make letters. The newness was now in the actual tool and how it was used, the various colors they made, etc. I could now ask Zachary for a specific pencil color and he gave it to me. I used it to color. Then, I asked him to pick another one, not telling him what color to take. As he selected one, he told me the color and handed it to me. Soon, I was giving him the pencil, instructing and assisting him as to how to hold it properly in his hand (we alternated because I still did not know for sure which hand he preferred) and helping him color in the coloring book. Finally, the task was interesting in and of itself and he enjoyed it.

With the beauty of fall colors, the walks outside increased and became more and more enjoyable as I pointed out the various colors on the trees. On one day, while out for a car ride, an absolutely gorgeous rainbow appeared over Lake Michigan. Zachary had always been told about rainbows, but, in the past, when I had tried to show him one, he never really seemed to see it. This one was different. There was no missing it. As we came down a big hill toward the lake, there it was, right in front of him...a perfect rainbow...one end of the arch to the other, over Lake Michigan, and the various color spectrums were quite thick. This was no tiny rainbow. It was huge and it was gorgeous. When Zachary saw it, his eyes just opened up. "A rainbow..." I said. He finally understood what a rainbow was and that these things actually existed in real life. I tried to explain to him how it was there because the sun was shinning on the raindrops in the sky. I did not know if he grasped that, but I did not care. He had finally seen a rainbow!

In October, we also noticed that <u>Zachary now enjoyed more fascinating videos</u>. He no longer limited himself to videos that "labeled things". He now enjoyed <u>videos that had storylines</u>. He started selecting the videos for his viewing pleasure by himself, or telling us which one to put in when he noticed the one we had in our hands was not the one he wanted to watch. He loved Walt Disney's "Winnie the Pooh" series, "Tarzan", "Jungle Book" and so on. He laughed at funny scenes and it was great to hear his laughter. On October 11th, Zachary looked me directly in the eyes and said, "it's ok, it's ok...", kind of like it was ok to look me in the eye. He still had a hard time with eye contact, but he was improving and slowly there was a little more of it. I practiced eye contact by saying, "look in mommy's eyes" and if he did, I praised him. We did everything we could to encourage eye contact and spark his interest. Since he liked circles, I asked him to look at the circles in my eyes. Eye contact was still difficult though, no doubt about it.

We continued to find new games. One of his favorites was the "**<u>non-sense color game</u>**". In this game, we called out something out of the ordinary and tried to "out-do" the other person's "non-sense color item". For example, I called out something like "purple cat", Zachary answered "green dog", I called "orange turkey", he called "pink horse", and so on. Although this may seem ridiculous, what it did was actually stimulate Zachary's imagination by prompting him to imagine those items. I knew most autistic children had a very difficult time with "pretend" or "imaginary" play and this was one fun way I found to stimulate him to imagine the unexpected or "non-ordinary" and develop his creativity. In a funny way, <u>it helped take the "order" out of his world by allowing the unusual to come in.</u>

Another game we played was based on Fox Video's <u>Dr. Seuss' Green Eggs and Ham</u>. I used the "<u>would you, could you eat them</u>" concept to teach Zachary more words. I said, "would you, could you...<u>on a telephone pole</u>" as I pointed to a telephone pole, he answered with "would you, could you...<u>on a tractor</u>" and on and on we went... "on a quad-motto, on a skateboard", etc., etc., etc. for close to half an hour at times. It was <u>another way to stimulate his imagination and increase his vocabulary at the same time</u>.

With the use of more words and the newly found communication skills, Zachary was now asking for what he wanted more often. When he was hungry, he came around and said, "spaghetti", or "ice cream, or "cookie", "cup cake", "bacon and cocos" ("coco" being a slang for "eggs" in

French) - all casein and gluten free items, of course. I found that if we did not respond right away to his demands, he used more words. For example, Anika had once locked herself in her bedroom to work on a craft. She did not want Zachary coming in for fear that he would destroy her artwork. Zachary came knocking at her door and yelled, “open door”. She did not answer. From the office next to Anika’s room, I then heard, “open the door”...and then, “open this door, Anika”. Fred and I just looked at each other and laughed.

With November, came another interesting development. For the first time ever, Zachary used slang. Fred had been trying to put a video on for him. As he fast forwarded through all the previews at the beginning, blocking Zachary’s view, Zachary said, “Whatchya doin’ ?” Zachary also started to “correct” us now also. After lunch one day, I told him I had to wash his spaghetti face. He chimed in, “spaghetti and ice cream face”. He was right, he had eaten both, as was clearly evident from his smirky little face. I simply responded, “yes, spaghetti and ice cream face”.

Zachary also understood the concept of danger now. When he saw a car coming, he rushed to my side. When he practiced “walking on logs” in the backyard (a few trees left in four foot sections that were downed for the fence installation), he said to himself, “be careful...”, he understood that fire was dangerous also, although he loved candles. I had a small candle I lit for him once in a while. I allowed him to admire it in the dark but was always careful to say, “Don’t touch- just look”. The first time I did that, his eyes just glowed and he had a smile from ear to ear. Of course, blowing it out was fun, too. But, again, I made a point to say, “hot wax” as I showed him the melted wax in the candle.

Everything has a lesson in it... every walk, every trip, every video...everything. In November, I taught him that after lunch, you put your dishes in the sink and now, he often did it without a reminder. When he ate a banana, he now automatically threw the peel in the trash. I still did not like to give him too many bananas though because I still found they increase hand flapping and the “push your forehead along the floor” behavior. I was beginning to work on sequencing with him....”eat your spaghetti first, then ice cream”.

He still had a hard time with the concept of same or different. He seems to do ok with it at times, but not always. He could easily help me unload the dishwasher and put all the big spoons together, the little spoons together and so on, but when asked to show me which two items were the same or which one was different in a book, he did not seem to do that well. So, I was not 100% sure he really knew that concept at this point. Of course, he may very well understand but just be playing his “wrong answer game” again. I was not sure on this one. He understood the concept that five cents equals five pennies. He was starting to understand basic addition and subtraction also. I still tried to come up with new games whenever I could. One of the latest was my “attack roll”.

Zachary had always loved to throw my folded laundry on the floor if I failed to put it away as soon as it was folded. I started having him help me fold dish towels. One time, I noticed him "rolling up the towel". I took it and started "attacking him" with it. As we played, I called it "my attack roll". He thought that was hilarious. Now, I fold the towel in two, and he often makes the roll himself.

Zachary also started to converse a little in late November. When his sister told him, "get up Zachary" one morning, he replied, "I want to sleep". Whenever I encouraged him with something new, I always sang my little song, "you can do it, you can do it, you can do it....I know you can do it, yes, I know you can do it".... when trying new things, Zachary would sing it to himself, "You can do it, You can do it, You can do it"...at times, even using the correct pronoun, "I can do it, I can do it, I can do it...". Slowly, we were making progress.

Each month, each day, had its ups and downs. With steps backwards came steps forward. Some weeks were much harder than others. We were now in November of 2001 as I completed this book. I noticed slightly better use of pronouns this month. If he fell and hurt himself, he usually said, "are you ok?" or "are you alright?...much as I would have said to him. Once, after he fell, I heard him say, "I'm alright". He was finally also learning how to dress himself now. I had made him too dependent in that regard, never forcing him to do it. I simply got tired of doing that for him. So, now, we practiced that, too. As he sat on the floor, I gently threw him his pants and told him to put them on using both hands. I did the same thing with his socks. He still hated doing it by himself, but, if he tried, he could. He knew how to put his hat and mittens on as well. Boots were still a little hard for him, as was his shirt, but that was coming along too. Although he can not actually put the two sides of a zipper together, he was always eager to zip one up. He still hated wearing anything but sweatpants. At this point, this fell in the "not that big a deal to me" category although I would have to work with "different clothes" this year.

Zachary had indeed made great progress in the last year and a half. He rarely had tantrums. His little fits did not last that long any more. He still was not potty trained although he would do a "big boy pee-pee" standing up if I took him to the bathroom. He still never asked to go by himself although he certainly felt the discomfort of a poopy diaper, so I was hoping potty training would occur soon. I was making him lift up his training pants too, another thing he hated to do. I had not worried too much about potty training in a while though...I figured when he was ready, it would come. In the grand scheme of things, it would not matter if he learned to do a specific task at four or five as long as he learned it. He still liked certain repetitive movements, like filling and emptying a jar with sand (more than normal), and spinning on occasion, although usually for short periods only.

I found that when he got stressed out, he still needed his "de-stressers" as I called them, toys he could spin a little, his carousel or a ceiling fan he could watch go around, and videos on shapes, colors, numbers or the alphabet. He needed those a little each day to calm down when things got to be too much. Although he very much still had his days, each month brought new progress. Zachary had mastered many software programs for his age group and was doing quite well on programs made for children up to age six.

When asked to put letters in the proper place to spell words (up to four letters), he could easily do it. He now recognized a ton of words and could read them. These included an entire flash card set. Specific words I knew he could read were: cap, nap, lap, map, tap, well, tell, bell, fell, sell, bed, red, fed, led, fan, can, ran, van, man, pan, cold, gold, fold, hold, sold, kite, bite, duck, luck, suck, bus, us, fish, wish, dish, cat, hat, bat, sat, fat, rat, goat, coat, boat, box, fox, sox, pool, tool, fool, cool, moon, spoon, noon, loon, cow, now, how, star, car, far, bar, jar, book, cook, took, look, hook, net, get, jet, let, pet, jam, ham, dam, ram, sun, run, bun, fun, pig, wig, big, fig, dig, zoo, moo, boo, too, top, hop, cop, pop, mop, log, fog, dog, hog, jog, nest, best, pest, rest, ball, call, hall, tall, wall, fall, dad, mad, sad, had, bad, tent, bent, sent, rent, went, tree, see, bee, free, rain, pain, gain, train, rug, bug, dug, hug, mug, pot, hot, lot, not, got, jeep, deep, keep, weep, band, hand, sand, land, hill, pill, will, fill, boy, toy, joy, make, lake, bake, cake, take, rock, clock, sock, block, lock, kiss, miss, nut, hut, but, mom, feet, foot, teeth, go, Zachary, bumblebee (one of his favorite words), water, wave, video, stop, yellow, lemon, orange, potato, tomato, carrot, milk, on, off, shut, under, open, animals, alligator, muffin, Panasonic (the brand name on one of our televisions), all the days of the week and months of the year, and much more. If he knew the phonics, he could pretty well decipher the word.

What I once considered his greatest problems, his lack of flexibility and need for order were now also much better. On November 21st, after coloring a few pictures with me, I let him stack his coloring pencils, only this time, like ends were not all together...they were mixed and they did not have to be perfectly aligned. The pen caps did not have to match the same colored pen. He purposely mixed them, putting a blue cap on a yellow pen, a green cap on an orange pen and so on. The thing I found so difficult with Zachary was that in so many cases, he would do something and then later, he would refuse to do it again. For example, I have never heard him say, “I’m naked” except for that one day in July. He has never said, “hello” to another child since September. It was almost as if he figured he knew “this task” so there was no need to repeat it. It was hard to explain, because it was not with everything that he was like that.

I found that for most of the day, each day, he did rather well, but when 5:00 p.m. rolled around, that was when things got really difficult... almost each day. When he got tired, that was it...he became impossible and it still gets very draining on all of us very fast. A bath, some play or a movie often helped, but every day, that was usually “the time”. Trips to the store helped keep him entertained although he was still quite sensitive to certain sounds (i.e., P.A. systems, humming of freezers and lights in grocery stores, etc.). Often, he had his hands on both ears as we went through stores. I found that when distracted though, he was better able to tolerate those “background noises”. He did not stare at lights the way he once used to. That behavior disappeared months ago. I often wondered if he was going through some kind of seizure when he used to do that. I did not know.

I still used a vaporizer to help reduce congestion/facilitate breathing when he slept during the dry months of November through March and put a vaporizing rub on his chest to further help when I saw he was somewhat congested. I rarely used any medicine other than a very occasional Tylenol or Dimetapp (maybe twice a year). I had a tremendous fear of antibiotics given that I believed they destroyed the healthy bacteria in the intestines. I preferred to try home remedies first. So far, I had been lucky. I kept him away from other children who were sick and made sure he got his supplements to keep his system strong. Zachary has not been on an antibiotic in close to two years. He was finally communicating more too!

CHAPTER 15

A Small Setback...But Back On Track!

Toward the end of November, as I literally prepared the final touches for this book, I noticed Zachary had a few behaviors again that previously had almost completely gone. These included a little more spinning of truck wheels than had been "usual". He was down to spinning for only ten or twenty seconds, and now, thirty seconds to a few minutes of spinning occurred. He plucked plastic flowers off the Christmas tree and pulled the "flower" off the stem again, he wanted the lights off (that one was one of the more pronounced things to "come back"). He was a little more sensitive to certain noises again, the sensitivity to food textures had come back (he began to spit bananas out again unless cut in small pieces) and he now refused to eat his rice spaghetti noodles. These behaviors troubled me. I had even seen him do his "finger face spinning" once or twice. Again, most of these behaviors were by no means "severe" again, and in most cases, it had taken me quite a while to even notice they had intensified somewhat...but they had and it was just noticeable "enough".

I thought and thought...what had been different – nothing it seemed...at least not in the last two or three months. But, upon thinking further, it hit me. In the past, I had given Zachary rice noodles with sea salt, organic black pepper and a little safflower oil spread. But, then, I decided to "test" giving him a teaspoon or two of spaghetti sauce mixed in with his noodles. I had given him rice spaghetti perhaps two or three times a week in the last three months – a food he absolutely loved – <u>that in itself should have tipped me off to the fact that there was something wrong</u>. But, I had let my guard down...I had not seen a "reaction" when I first gave him the "sauce" back in September. <u>It had taken three months for some of these behaviors to "come back" though only mildly – but still, there was a change that was now "noticeable"</u>.

I could stop the unwanted behaviors simply enough with a distraction but, regardless, it bothered me tremendously – they were after all a step backwards. The spaghetti sauce had to be the culprit. It contained "spices" that must have contained gluten – it was either that or the slow accumulation of phenols from the tomatoes. It was one of the two – I just knew it. The next time I tried to give Zachary rice noodles, with only sea salt, organic black pepper and nothing else, as I had done in the past, he went to the refrigerator and said, "jar", meaning he wanted his teaspoon of "sauce". When I refused to put it on there, he refused to eat it. That was as good a confirmation as I needed – absolutely no more sauce for him – not even three to five teaspoons a week. <u>I had let my guard down. Not seeing an impact right away, I thought the reintroduction of this food had gone well, but I was obviously wrong</u>.

Zachary could still not tolerate even a small amount of gluten or tomatoes. The ingredients in the sauce were listed as follows: tomato puree (water, tomato paste), diced tomatoes, corn syrup, beef vegetable oil (contains one or more of the following: corn, cottonseed, canola), salt, spices (oregano, basil, and other spices), onion powder, dehydrated garlic, citric acid, dehydrated parsley, spice extract. I included this listing in the hopes of further helping scientists who may find value in this book as one of my primary reasons for writing it was also to provide data to further the scientific study of autism. I had been very strict with Zachary's diet, and yet, he was obviously still impacted by even minute amounts of "bad foods" even after eighteen months. That was ok, I would simply get back on track.

I had hoped Zachary's gut had been healed enough to start introducing such products, but obviously not. It certainly would have been nice to end my book without this chapter, however, Zachary's "small reversal" had been sent to me as a reminder not to let my guard down. I saw how it could literally take months to see the impact of even just a little "bad food" for Zachary. As such, I had to include his minor "setback" also. I felt like a fool for having broken his diet with this one product, but throughout all of this, I had always battled with the question of "when" to try "regular foods" again. Bananas and apples he now tolerated a little, but processed foods were obviously still going to have to be "out".

The following week, I tried making "my own" spaghetti sauce for Zachary. I simply took five or six organically grown tomatoes, boiled them in water until cooked, put them in a blender (after removing the outer peels), strained them to remove all the "seeds" and then gave Zachary bout five teaspoons on his rice noodles. It was very "liquidy"...much less potent than anything he would have had from a store bought brand. I added a little sea salt and organic black pepper. Zachary started to eat the noodles, then he stopped (actually a good sign in my book). I then picked up the bowl and fed him a spoon at a time. He ate pretty well all of it. That night, I found him a little more restless than usual – he banged his legs again to "get rid of the extra energy" and settle down for the night but other than that, he seemed ok. The jury was still out on "tomato tolerance" (tomatoes were high in phenols). I needed more "observations" to come to any definite "in" or "out" conclusions. I would give it two or three weeks.

I knew we could quickly get back on track and minimize negative behaviors again if they really surfaced...at least I knew for sure there was no gluten there and so any adverse reaction would have to be due to the tomatoes. I looked at it as a part of the learning process. It certainly did not take away from the fact that Zachary had made huge progress in the last year and a half – and that was much more noticeable to everyone who knew him than this small setback.

I guess it was better for me to find out now and include it in my book than to have perhaps several hundred parents with children on casein and gluten free diets make the same mistake. There was a blessing in everything – perhaps that was it! Within a few days, I noticed Zachary's behaviors (from the store bought sauce) were subsiding again, and that was good. The bottom line was...I still very much had my son back!

Like everything, each day still had its struggles. Would I say Zachary was 100% cured? Absolutely not! But I knew that he has come a very long way in eighteen months and that he was well on his way to a normal life. I had my son back, a little boy who laughed and played, pretended and learned, and continued to amaze me each and every day...a little boy who now returned my precious butterfly kisses of so long ago. He was my "best boy", as I always told him as I blasted him with kisses. I figured he was probably around the age of two and a half socially but more near the age of six in cognitive functioning, and that averaged to right around four, exactly where he should be. I knew that was a different way of looking at things, but the last eighteen months had been anything but "usual" or "ordinary". I knew the social skills would only get better with time. I was happy with having a son I knew could later function well in this world...and that meant Anika would have a better life also...knowing my children both benefited from Zachary's difficult gluten and casein free diet and the low phenols as well - that in itself had been worth this tremendous effort. I knew Zachary was not perfect and he may never be completely "recovered", but that was ok because as my mother used to say, "perfection is not of this world".

CHAPTER 16

The Revelation...ORDER! ORDER! ORDER!

I had actually completed the initial editing of my book on paper on November 28th, 2001. That night, I went to bed, thinking that on the following day, the 29th, I was going to input all my changes into the computer and basically consider my book completed. Little did I know that the best was yet to come!

Prior to going to bed that night, I said my prayers as I always do. This time, I asked God to "make sure I included everything I needed to include in this book, because I would only have one chance to tell Zachary's story". At 2:00 a.m., that same night, God gave me the answer to the puzzle...bits and pieces of it had been there all along, throughout my book, everywhere in Zachary's behavior, but I had been unable to put it all together until just then. I had not recognized how the pieces were all part of the whole...the underlying problem.

It had always bothered me that almost every book I had read on autism stated that a routine was critical for these children. I wondered how my experience could have been so different than that of so many others. With all of our trips, our moves, etc., life had been much less than "routine" for Zachary and he strived on seeing new things. New stores were never stressful in and of themselves. Visits to see relatives were never stressful in and of themselves. A new home had been adjusted to literally overnight. What was I missing? At 2:00 a.m. that morning, God gave me the answer!

What had always caused Zachary stress and frustration was **a lack of order** – **that was different from a lack of "routine"**. It hit me like a ton of bricks. It now all made sense to me – and so, with my new "last minute" insight, came my need to write yet another chapter...The Revelation!

So many of Zachary's behaviors and frustrations could be attributed in some way to the need for order. I was sure it was this part of the brain that was being so impacted in autistic children. From my readings, **autistic children were consistently strong or weak in similar areas. The things Zachary always did well with were not those things that were part of a routine (he had none), but those that had order!**

It explained why he mastered the alphabet so quickly....each letter was followed by another, specific letter... there was order!

It explained why he had mastered phonics so quickly...each letter made a specific sound. Each letter or letter combination always had the same sound...there was order!

It explained why he had learned to read so easily...it was simply a matter of putting the sounds all together and saying them... as long as he knew the sound, Zachary could read the word.... there was order!

It explained why Zachary could easily pick out words that started with a specific letter while playing his educational games on the computer....there was order there!.....but, it also explained why he had difficulty picking out words that either ended with a specific letter or had a specific letter in the middle....that would not have “order” to it since you read from left to right! To him, the order was gone!

It explained why he loved to count and by the age of four could easily count to 100...each number was followed by a specific number...there was order! It explained why I had had difficulty showing him how to count by twos, fives and tens...the order was not as obvious to him...he was still young, but I was sure once he saw the order, that would come quickly too!

It explained why Zachary loved shapes....they never changed...they were always the same...a hexagon always had six sides, a triangle always had three....Zachary had easily mastered all his shapes, including star, heart, circle, triangle, square, rectangle, oval, pentagon, hexagon, octagon, trapezoid....each was a constant that never changed... there was order there!

It explained why Zachary had a difficult time learning colors...these were a little more abstract...there were variations within one color... sky blue, navy blue, royal blue, turquoise...this was a little more difficult to grasp...the order was not as obvious or perfect as it had been for so many other things!

It explained why Zachary had no problem learning a whole slew of opposites...up always went with down, black with white, on with off, over with under, forward with backward, go with stop, big with small, and so on...one always went with the same opposite...there was order there!

It explained why the concept of seasons had been so easily grasped, spring was followed by summer, which was followed by fall, which was followed by winter and so on...there was order there!

It explained why he had mastered the days of the week in a matter of minutes... each day had a specific name and was followed by another, specific day...it never changed... there was order there!

It explained why he had mastered the months of the year in just two hours...each month had a specific name and was followed by another, specific month...it never changed...there was order there!

It explained why the concept of birthday was also easily learned...the date was always the same...there was order there!

It explained why the concept of name was also easily learned...it was always the same...each person had a name that never changed... there was order there!

It explained why Zachary could answer any question that had to do with labeling objects. Each object had a specific name and that never changed...there was order there!

It explained why he enjoyed puzzles...and why he got so upset if I put a red circle where the blue circle should go, or yellow square where the purple square should go...there had to be order there!

It explained why he learned songs so quickly... each word in a song was followed by a specific word...there was order there!

It explained why Zachary talked in “commands”...certain words always went together...things like “open the door” or “I want ____” always produced a specific outcome...there was order there!

It explained why Zachary had said to his grandfather, “see you later”... and then he added out of nowhere... “come back soon”...those two phrases together were part of a logoff procedure for one of his computer games...to him they went together...there was order there!

It explained why when Zachary pretended to be on the phone, he simply said, “hello... goodbye” but nothing in between...he was imitating one of his “opposites” video...those two things always went together...there was order there!

It explained why Zachary tried to put the chunks of snow back on the snow bank...where they belonged...there was order there!

It explained why Zachary pulled the tops off flowers and then made a pile of “flowers” and a pile of “stems”...there was order there!

It explained why Zachary aligned pencils tips at one end, bottoms at the other...why he aligned, stacked and grouped just about everything that was similar in shape, size and function ...there was order there!

It explained why brushing his teeth or cutting his hair was ok as long as I counted out loud while I did it...it brought order to a process!

It explained why rewinding a movie and seeing it go “backwards” on the television frustrated him...it went against normal order of going forward!

It explained why the credits after a movie were more interesting than the movie itself... they consisted of orderly text that went from the bottom to top of the screen, in a constant order...the movie had no order and thus, was of no interest. If he had seen a movie at least once, then it was more enjoyable. He could anticipate the outcome... there was order there!

It explained why any change in direction, left, right, backward, sideways, (in a car, on a walk, in a store, etc.) was so frustrating to Zachary...it went against normal “forward” order.

It explained why my son would have surely drowned at the end of the dock as he faced away from shore had his father not seen him in time... there could be no “going back” to shore...normal order meant going forward.

It explained Zachary's campfire dances and his constant need to go in one direction or the other... there was order there!

It explained why rides at the fair were more interesting than animals...animals ran around randomly, whereas the rides went in a constant, specific pattern...there was order there!
It explained why Zachary could not see the elephant for the squirrel twirling a nut three feet in front of us at the zoo...he was literally captivated by the twirling motion...there was order there!

It explained why Zachary always liked to wear the same type of clothing... sweatpants and a shirt... there was order there!

It explained why Zachary had such a hard time with the concept of same or different... he did not know what to make of the "different object"...there was a lack of order there!

It explained why Zachary had difficulty with conversation... for the most part, conversation was random, except for communication via labeling things or the giving of commands... these forms of communication had order as opposed to actual conversation which did not...conversation lacked order!

It explained why Zachary loved to spin objects...spinning caused something to move in a predictable direction, one way or the other...there was order there!

It explained why, when frustrated, if Zachary could not find something to spin, he reverted to "pretending" to be spinning with a finger or to some object that provided order and as such, it explained non-sense language...his walking around the house saying words that appeared to be totally out of context...such as "green truck", "circle, square, triangle"...the reciting of all shapes, the alphabet with associated words for each letter, etc., prior to going to bed...there was order there! Zachary used to go around the house and say, "circle, triangle, square" , or "circle, circle, circle, etc...", or "green truck" (had wheels and he loved to spin wheels... but also something concrete that "made sense"), or "fan", or "carousel", ...they were all things that I had perceived as "non-sense language", something so characteristic of autistic children, yet, now that I understood Zachary's need for order, I understood this too...to him, these were not "non-sense" words, these were things that in his world....had order. Whenever he used these "non-sense" words, I now knew that he was giving himself an "order fix" as I came to call it. He did this when he was stressed out, or simply after a period of time when we had been watching a movie or doing something else that had basically no order to it.

It explained the echolia... the constant repetition of words in an effort to bring about some type of order.

It explained why Zachary's de-stressers were usually things that spun, ceiling fans, his carousel, etc....they went "one way" or "the other"... there was order there!

It explained why Zachary **physically had to remove himself** from situations that had no order to reduce his frustration level...and why he often positioned himself **in a way that his "line of sight" could not see the "disorder"** all about...there had to be order!

It explained why certain social skills were easier to learn than others...dirty dishes went in the sink, banana peels in the trash...there was order there!

It explained why Zachary had to put the "clean clothes together with the dirty clothes"...they belonged together...it explained why the piles of clean, folded laundry were all thrown on the floor, together… not in these funny little stacks that mom had made...he, not I, had brought order to the laundry...his pile had created order!

It explained why Zachary pulled all the labels off my food cans, the stickers off my appliances, a bandage off a wound on his finger, the plastic caps off my metal door stoppers, and so many more such behaviors...these things "did not belong", they were not part of the "normal" order!

It explained why Zachary never "mixed" objects such as rocks and acorns. You could have one or the other in a pocket, not both...that would have lacked order!

It explained why "turning pages" on computer "book programs" was more fun than "reading the book"...turning pages had an order to it...pages in and of themselves did not...they lacked order!

It explained why, one night, as I laid next to Zachary in bed he went into what seemed like "neural overdrive", as I had described it to Fred. Zachary was on his back, and before he could settle down for the night, it was as though he "had to order" his world before going to sleep. It was when learning phonics and how to read words – he went through the alphabet, "A is for apple, B is for bed and so on...all the way through the letter Z" and then he started over using new words for each letter. It was as though he was "ordering" his world – an activity that usually happened as we slept – but he was performing this function while still awake. He could not calm down for the night until this had been done. Upon seeing Zachary do this, I had commented to Fred that Zachary indeed seemed to be "ordering" his world before going to sleep and I had added that, "it was the wierdest thing I had ever seen".

It explained why social breakthroughs were those that had "order". For example, when Zachary acknowledged the "1,2,3 lady" at the park who called out numbers as she pushed her child in the swing, it was because she had brought "order" by counting.

It explained why certain social situations were less difficult than others...the family was a "familiar" environment and interaction with family members was usually preferred to a strange social situation that lacked any order. It was easier to play with a predictable sibling than an unknown child at the park. Familiarity with family members brought predictability to situations whereas there existed no "stored reference" or base knowledge/ "ordering system" for an unknown child or social situation. The order of family dynamics was more predictable and thus more "orderly".

It explained why some "pretend" behaviors came more easily than others. For example, Zachary could easily meow like a cat, but he did not like anything out of order, such as hearing me bark while pretending to be a butterfly...that brought out his frustration...that lacked order!

It explained why Zachary had such a difficult time with potty training...that was more or less a "random" thing...it lacked order! Perhaps I could now "train" Zachary with the help of an alarm clock, showing him to "go to the bathroom at specific times".

It explained why Zachary had to go through a ritualistic familiarization process with everything that was new and involved "grouping"... he had to "create order" before he could use new tools for what they were meant to be...tools...not things you "ordered".

It explained why routines seemed to "work" for these children – that brought a sense of order to situations where none may have existed previously. Routines created a "point of reference" or "databank" to draw from in the future. It brought "forced order" to specific tasks. Routines were actually reinforcing "order" and thus, <u>perhaps doing just the opposite of what was necessary</u>... to break the need for order.

I was convinced that breaking the intense need for order was key! I had already accidentally fallen upon this with a few things we already did... the non-sense color game (i.e., pink horse, purple cat, etc.), our activities at the park when walking forward, walking backward, walking sideways, etc. With Zachary, I was finally starting to see the need for constant order subside. He no longer had to align all his coloring pencils tip-to-tip and bottom-to-bottom. He no longer had to put the red pen cap cover on the red pen...it was ok to put it on the blue pen. It had been a good thing to let him pick dandelions for over an hour...to come to the conclusion by himself that you could never "complete the task"...as had been the case for the chunks of snow and the snow bank. He had realized by himself that nothing "bad" had happened when the task was not perfectly completed.

Although there could indeed be more at play in terms of actual senses, it could potentially also explain why new foods could at times be difficult to introduce...again, there was no "databank" to draw from, no "reference point" as to whether or not the food was good or bad and therefore, they were physically approached with caution.

Granted, there were many behaviors that "order" could not explain such as the impact on senses in general (sensitivity to light, sound, etc.), but <u>the fact remained that the need for order did explain so much! I was certain the impact on actual senses could certainly be explained by the problem with casein and gluten and possibly phenols as well...and now, I knew exactly what part of the brain was also impacted by these things...that part of the brain that dealt with ordering. For concrete things grouping was more critical. For abstract things, it was less obvious in Zachary's behavior...but it was there...that was how I came to see that a barking butterfly was "not acceptable"...it was not part of the "normal" order of things.</u>

<u>As I thought more about the whole issue of senses, a thought came to my mind. Could it be that it was not the "senses" themselves that were affected by casein, gluten and possibly phenols but</u>

rather that part of the brain that "ordered" sensory information. As I thought about this, I certainly did see it as a possibility. For example, I had once read that fluorescent lights really seemed to bother autistic children. Someone once told me that fluorescent lights "flicked 60 times or so per second" (I can not remember if that was the actual number of times, but that does not matter). Was Zachary trying to "order" that flicking of the fluorescent lights? I did not know, but it certainly was an interesting possibility. I had to leave that one up to scientific study!

I was excited about finding still **new teaching methods** for Zachary – methods that had to "**break the inappropriate need for complete order**"...and that meant, for most situations, breaking "routine", something I saw as an artificial "order" , but an order none the less that just reinforced the child's need for order...the very source of the problem!

I decided to spend the next two days testing my theory...that **the need for complete order was the root of the frustration** for so many of these children.

I had always been a very tidy person... now, I would leave the housework and let the house become a disaster area in order to see the impact on Zachary. I let the house go for the entire day...I did not pick up a single thing that Zachary or someone else had "misplaced". The next morning, I got up and looked around. The house looked like a tornado had passed through it. I could not see any change in Zachary's immediate stress level. I was more stressed out than he was. I told Fred that I could no longer take it and I started to clean the house.

I began in the bathroom just off the master bedroom. I looked at my counter. I always had the soap dispenser on the right, the fluoride and mouth rinse on the left. They were not exactly in their correct places...I adjusted them. As I did that, I thought, "these bottles could be flipped over on their side and Zachary would not come in here and put them in the correct position".... he would not care about these. Hum!

Then I worked my way to the front entrance. The shoes and boots were all over the place. I started to order them. As I did that, I thought, "Hum, Zachary has never ordered the shoes and boots". I wondered why.

I then turned to my living room... that was the worst area in the house. I began picking things up. Everything, it seemed had been thrown on the floor and left there as Zachary had gone through his toy bin. There were plastic Easter eggs, wooden blocks, the bows Anika had put on chairs to decorate for Christmas (Zachary had pulled them off the chairs), there were puzzle pieces, train tracks, pencils, crumpled window clings, flowers off the Christmas tree, there were trucks, and other one of a kind objects. As I began to pick them up, again, it hit me like a ton of bricks...I was literally picking up my puzzle pieces...there they were... in front of me... scattered about the floor.

Those things which caused Zachary frustration were not one of a kind items like stuffed animals or trucks, etc... the items that caused him frustration were primarily those that **required grouping of some kind... they were similar in shape, texture, and function… parts of a group – parts of a whole!**

One of a kind Christmas ornaments were still on the tree. The plastic flowers I had placed in the tree, however, had been taken off the tree and the flowers pulled from the stems. The puzzle pieces were similar objects that Zachary grouped. His pencils were similar objects that he grouped/aligned. The wooden blocks were similar in shape, texture and in function. The only window clings Zachary had removed, although of various sizes, were all window clings of snowflakes...they were all similar and thus should be grouped. Last year, all window clings had been removed (although they were all similarly flat and similar in function too). This year, Zachary had been more discriminating...only the snowflake window clings were crumpled on the floor. It all made sense. Boots and shoes were different enough in shape and size that they were not perceived as "similar" and thus Zachary never cared to "group them". It had always been the same with one of a kind objects like stuffed animals...they were never similar enough that he perceived them as belonging together. **Pencils, blocks, train tracks, snowflakes, puzzle pieces, Easter eggs, Christmas bows... all these things, however, were similar and therefore, had to be perfectly grouped for Zachary's world to be in "order".**

I decided to test my theory. I put everything away except for the Easter eggs. The eggs consisted of two "shell" pieces and they were of various colors. At the moment, all the eggs were apart...only shells laid on the floor. I decided to sit down and start putting them together. Almost immediately, Zachary went into a fit. I would have thought the mixing of colors would have upset him (it has done so slightly in the past but the "newness" of color had disappeared), but that was not what triggered his frustration. He was upset to see whole eggs verses shell parts...he only wanted to have shell parts, no "whole eggs". As I worked at putting the eggs together, his frustration grew more and more intense. He was now next to me, pulling the eggs apart. He got especially upset if I took the ones he had just pulled apart again, and put them back together. Seeing that he could not keep up to me, he quickly got up and started stepping on the eggs to pull them apart faster. He was very upset. I let him pull them all apart.

A few minutes later, I came back, and started over. Again, he was quite upset. Then, I made a game of it. When I had a "whole egg", I started to blow it across the floor. He thought that was fun and so now, the exercise was not as upsetting to him. I only put some eggs "back together", not all of them. I did not want to create "complete order". After I blew a "whole egg" across the floor, Zachary would pick it up and put it in a small wicker basket. Then I tried to put some "egg shells" or "halves" in the basket as well. Again, that stressed him out totally. Only "whole eggs" could go in the basket. He now tried to assemble those eggs I had left "unassembled" in order to place them in the basket as "wholes" just like the others. I walked away and let him work at that a little. He could not put them all back together though...he took the basket of assembled eggs into the kitchen and played with them there, leaving the unassembled shells in the living room – out of sight...that was less upsetting to him.

When he left his basket in the kitchen to move to another activity, I took his basket of assembled eggs back into the living room. I took some shells and some "whole eggs" and mixed them up in the basket. I also left some of each on the floor. Again, Zachary came by and got very stressed out. He took all the eggs out of the basket, threw the basket on the floor and walked away. Once again, I put some whole eggs in the basket mixed with eggshells and left some of each on the floor also. Again, he came by and emptied the basket... again, I did it... over and over, until he gave up and left the eggs (whole and partial) in the basket as well as on the floor. For the rest of the day, he paid practically no attention to the eggs on the floor. After a while though, he assembled all of them again and put them in his basket. I figured he had had enough for the day and so I let him be.

I tested the "need for order" in other ways. <u>I knew groupings were a problem for Zachary.</u> I could now focus my energies and attack that specific problem. I suspected the need for order impacted him in other ways also. I pretended to be a duck. I started flapping my wings and saying, "Zachary, look, I'm a duck...quack...quack...quack...". When I knew that he had seen me "as a duck", I continued flapping my wings, only now, I began to bark. Again, almost immediately Zachary showed frustration. He started to "butt me" with his head and said, "broken dog". As soon as I stopped the duck-dog thing, he was fine. Seeing he was a little frustrated, I decided it was time for a break. I laid down on the carpet in the living room. Zachary had no "de-stressers" around...nothing to spin. He therefore decided to make up an activity to give himself an "order fix" as I called it. While I laid on the floor, he went to my feet and started to walk on my legs...he started on my ankles, and worked his way toward my head. By the time he got to my chest area, I had pushed him off of me. At that time, I did not realize exactly what he was doing...I thought he just wanted to play. He went right back to my feet and started walking on me again... he insisted on going past my neck and head...almost to the point of breaking my glasses. When he got to my neck area, I had pulled him down. He fought with me to "get passed my head" and keep going in "that straight line" in order to complete the task. He put one knee on each side of my head and then went over my face and above my head. Now, he had completed a task that had some "order" to it in his mind and he was fine and went on with his activities. I decided break was over and I tried something else. I played the horse. Zachary was on my back in no time. I gave him a ride around the house, at first making the sound of a horse. I then continued with the horseback ride, only now, I was meowing like a cat.

Zachary enjoyed the ride, but there was still frustration there... as we moved around the house, he kept saying, "oh, dear... oh, dear... oh, dear...". After I "faked death" to get him off, he started walking around the room, in no particular order, but now, he was talking to himself. He started saying things like, "a fan, a fan, a fan" and "a match...a fire...a candle", "hat, mat..."...he was going through an "order fix" again... each time he got stressed out, he looked for some semblance of "order" to bring his world back to a "stress free environment". I then took three long key chains that I could wrap around my neck... I had obtained these at the fair earlier in the summer. The key chains were very similar… there was one for "army", one for "navy" and one for "Michigan National Guard". My daughter had picked them all up at the fair for free because she thought they were so cool. The key chain holders fit around my neck like necklaces and went about down to my belly button. They varied in color but were similar in shape, size and function. I then added a smaller pink beaded necklace on a pink shoelace that my daughter had made for me when she was four years old. It was strikingly different from the other three objects around my neck. It looked very different, and hung at a different level on my chest. Upon seeing the "different" object/necklace, Zachary immediately made a motion to remove it. I said, "no" and he stopped. You could tell it still bothered him, but not tremendously. I went into the office to talk with Fred.

I was lying on my back on the bed in the office as I spoke with Fred. Zachary came in. He wanted up on the bed with me. My knees were bent and up in the air so that my feet were flat on the bed as I laid there on my back. Zachary perceived this as a lack of "order", he started to push down on one of my knees to lay my leg flat on the bed. He then tried to do the same thing to the second leg. As he worked on the second knee, I put the first one back up. Again, he became very frustrated, his need for "order" mandated that I should have both legs flat on the bed. As I lay there I told Fred, "see, I can turn his frustration on and off like a switch now"... it was so true. The need for order was the huge source of frustration for Zachary. Now that I knew that, I could work on that area specifically. Life had just gotten 100% easier. I did not have all these "unknown causes" of frustration any more...I knew exactly how to set him off and on...just like a switch and I spent pretty well the entire day doing it as I started to address his issues. It was absolutely amazing... and the beautiful thing was, that it was so simple.

Knowing what the problem was made it easy to tackle. I could now control Zachary's behavior completely. I spoke to my sister-in-law about all of this. I told her how "odd" I looked based on the fact that I had all these "wierd things on me" (three key chains around my neck along with my pink beaded necklaces, various color rubber bands around my watch, a hole in my pants at the leg...all things that did not belong). We joked how if someone came to the door that person would surely think, "what is with this woman...she is so "not together"". I wore the key chains and beaded necklace all day... and Zachary noticed...but, overall, he adjusted. When I made the comment as to breaking the order of what we had on, my sister-in-law made the comment that her son had once been very upset one time when she showed up in the kitchen with her bathrobe. She was usually dressed for the day when she got up for breakfast. Andrew had found that to be very stressful...to see the "order of appropriate clothing" broken...he was physically trying to push his mother back into her bedroom for her to change prior to breakfast.

I continued to test my theory of "order" throughout the day. I gave Zachary a wicker basket and a ton of stuff to put into it… here the order would be either "in or out". I gave him so much stuff that he could barely fit it all in the basket. He would scrunch it down to make it fit, but usually, something fell out. I wanted to force him to have to leave something behind. Also, I would attempt to "take" something from his basket. As I did that, his hands went down tightly over it. I still managed to take something out, saying, "it's ok, it's ok.... I'll give it back to you after I show daddy". I then took the object and went over and pretended to show Fred something. Zachary was very stressed out over this. I brought the object back to Zachary...but, then, I took another one. This time I placed it on the refrigerator. That was again, very stressful and frustrating for him. Eventually, I gave it back. For the next hour or so, Zachary played with the basket and the objects I had given him. The more time went on, the more he could leave behind as he moved with his basket around the house.

That was another thing I had noticed... the frustration level and need to "group" were higher when the objects were new or the process or task was new. Once they had been around for a while, it was less frustrating to Zachary if I took one away...often, he felt no stress whatsoever. "**Newness**" of the object, process or task definitely played a role also. That explained why new coloring pencils had to be played with, touched, aligned, etc. for four days before I could even begin to show him how to "use them as pencils". Zachary was going through his "ritualistic" order creation/familiarization process. I did further testing.

I went to work again with the Easter eggs...this time, I added coins, a small bank, and a jar, in addition to the wicker basket in which he kept his eggs the day before. I gave Zachary too many coins to fit in the bank. I had a jar of coins in my kitchen and had taken about two thirds of them out of the jar and dumped them onto the floor. At first they were pretty much in one area, but not mixed with the eggs (wholes or shells) that were on the floor. When I noticed that, I mixed the coins among the whole eggs and eggshells that were on the floor. Zachary had not been as stressed out about the fact that there were eggshells and whole eggs on the floor... he was getting "used" to that. Coins brought in a whole new aspect though. First, I let him fill up the bank...he put as many coins as he could in there. It was packed and he could barely add another coin, try as he may. I then sat next to him on the floor. I took several coins and slowly started putting them in an eggshell, then made a "whole egg". Zachary went ballistic! He started to scream and cry and attempted to pull the "money eggs" apart. To say he was upset would be a serious understatement. As I did this (mixed the coins and eggs together in a whole egg), I said, "it's ok, it's ok, it's ok" to ease his frustration. The more I did it though, the more his frustration surfaced. "It's ok" was quickly becoming a coping mechanism for Zachary as I tested my theories. He started saying these words himself. Seeing how upset he was, I walked away to let him calm down. Later, I went back and started over.

I would constantly break the normal order of things Zachary had "rearranged" while I was gone. I mixed coins and eggs (whole and partial) together, filling some eggs with coins, taking coins out of his basket but not completely (where he would put them after the bank was full). The fact that I knew breaking order increased his frustration level made it all so easy now. I could literally "turn him on and off like a switch". He got upset again as I sat down next to him and started over... putting the coins in the eggs had really upset him, again. He frantically tried to put the coins in the bank... but it was full. Each time he put some in the wicker basket, I dumped them out **<u>partially</u>**. I then took a "broken egg" and held it out in front of him to see if he would put coins in it by himself. As I did this, again, I said, "it's ok, it's ok". He repeated, "it's ok", but he pushed my hand away, he refused to put the coins in the egg. I walked away for a few minutes, again, then came back and tried once more.

Zachary could no longer put the coins in the bank, I had put the jar away after taking a few more coins and saying it was "mommy's milk money" (that upset him, but just a little since **there were already some coins in the jar**). Labeling it as "mommy's milk money" helped to make it easier for him to cope. Coins were scattered all over the floor, intermixed with broken eggs and whole eggs. On his own, Zachary picked up one of the shell bottoms and put some coins in it. He then tried to close the other piece of the egg to make a "whole egg" with coins inside of it...a "money egg". He actually did it. I praised and hugged him! It was now ok to have an egg with coins in it. He shook it to make noise and rolled it along the floor a little. But then, he laid down, his egg about a foot away, in front of him, and he admired it – taking in his "creation". This was another small step forward. I was thrilled. He tried to spin the egg, I then said, "don't spin"... he slowed down his spinning and stopped completely within less than a minute. He then experimented with trying to sit the egg up on one of its ends. That did not work, so he tried to spin it again. I let him spin a little. I knew it probably would not last very long. Sure enough, he stopped spinning again fairly soon and broke the egg open. The coins fell out. He started to put them back in. A task that had caused him so much frustration ten minutes earlier, he now did on his own. This was just too simple!

Understanding the need for order and the need to teach him how to break fanatical order made it so simple. I could work with Zachary between my tasks/activities...as he sat on the floor, learning to cope with his change in order, I could go along and do what I needed to do. Whenever I heard him say, "oh, dear...oh, dear...oh, dear..." or "it's ok...it's ok...it's ok", I would reinforce by saying "it's ok" myself to help him ease the frustration. Zachary had had enough though. He put his forehead on the floor, and bunched himself up in a little ball. As soon as he did that, I picked him up, and told him again, "it's ok, it's ok". Then I kissed and hugged him and told him he did a good job putting coins in the egg.

I put a video in the VCR – one with a storyline – a Winnie the Pooh video. It had not been re-wound. I re-wound it – letting the story flash "backwards" on the television screen. Of course, Zachary's frustration came out again. I let the tape run backwards and as I did, I said, "it's ok...going backwards". I said that a few times. Then I said, "almost done"... that further helped him deal with the frustration. Finally, the tape was re-wound. That "training" had been completed.

Zachary started to watch the movie as I prepared his breakfast. I gave him a cup of rice milk with his calcium and magnesium supplements in it to help calm him down. Not a peep. He was now perfectly happy. Within ten minutes though, Zachary went back to the area on the floor where I had scattered the coins, eggs, bank and basket. I had secretly added the "coin jar that was **partially filled**" back as he had watched television. He noticed after a little while that the jar was there again. He now went over and started to put all the scattered coins in the jar. I let him do that. He also "cracked" the "money eggs" and put that money in the jar as well. I let him do that, since I wanted him to relax. Anika was up by then... she went over and put coins in the eggs again. Needless to say, Zachary got very upset with her. I wanted him to calm down so I asked Anika to leave him alone. Zachary picked up another whole egg from among the scattered eggs (whole and partial) on the floor. This particular egg did not have coins in it – he simply tossed it to the side, without breaking it!

He proceeded to put all the coins in the jar... then, he emptied the jar and scattered the coins with his hands. I took the jar, put some coins in it as I said, "this is mommy's milk money" and, again, put that jar away. Zachary got up, picked up his basket and gave himself another "order fix". He started turning himself round and round. I forced him to stop by holding on to his arms. He got so upset that I had interrupted his "order fix" that he bit me – he had only done that one before – a very, very long time ago! He got a small slap on the butt for that. I knew I was on track though. He threw himself on the floor. I hugged him and again said, "it's ok, it's ok". He calmed down. As encouraged as I was with my results, it was still hard for me to see how frustrated and upset Zachary could get. As I hugged him, I realized that "as easy as this seemed to me", that was most likely because I had had some basic training in behavior therapy. This was yet another double-edged sword.

I strongly felt I needed to crack open the books again and refresh my training in behavior therapy. I would not need an expensive program for Zachary. I knew I could do this on my own, but, I wanted to make sure I would not harm my son... and I saw how this could so easily be done if his "therapy" was not properly done.

If I was to assume the role of "therapist", at home, I had to completely understand "my impact" as far as how Zachary was affected by this new approach. I knew I could "break" Zachary's fanatical need for order – I just wanted to make sure I did it in a loving and lasting way and that, in the process, I was completely aware of exactly what I was doing and the impact that had on my son. I had to brush up on the basics of behavior therapy again – and focus on rewards – not punishments – to me, that was critical! Zachary was not an animal to be manipulated – he was my son and I wanted the best for him. I had never agreed with "punishment" in behavior modification. If it took me slightly longer to "get Zachary to accomplish a task", then so be it - I would only push so much! Zachary had gone through so much in the last year and a half. Indeed, if things had been hard on the rest of the family members, Fred was right – I could not even begin to imagine how difficult all this had been for Zachary himself – **<u>living in constant frustration because no one "had understood"</u>**. But, now, I did understand, and I understood the source of his frustration. Knowing **Zachary's problem had to do with inability to "break order", and with partialities, the "non-whole", "the incomplete".** I knew I could now, at least focus my energies. I knew the enemy – and this was one battle, I was once again preparing to win – without further hurting Zachary in the process. Patience and understanding... patience and understanding... patience and understanding! That was what Zachary needed and that was what he would get! I was determined to stick to "positive reinforcers" and avoid "punishment" at all cost!

Now that I finally understood the source of Zachary's frustration, my own stress level had gone down tremendously. I was better able to cope and deal with my son each day. It gave me new found energy. Zachary was always so willing to help, to please. Like all children, he was so precious!

I knew I could make this a good experience for both of us. Sure, there would be frustrations, but at least now, they would be much more controlled. I could remain in control of the situation and show Zachary that it was indeed "ok", that we would learn to "break order" together!

I was lucky. I did not have to attack all order – only "inappropriate need for order" and specifically, "grouping" and "partialities". That was the worse thing for Zachary. I would teach my son to deal with everyday frustrations, the "real world". Zachary was fine with the "normal" order of things... a dog barked and both he and I were fine with that. I would make a game of enhancing his creativity though by using things such as my barking butterfly. The true challenge would come in minimizing his "order fixes"... if anything, that would be the hard part. But, my energies could now be very focused and I was excited to say the least.

I could now expand our "non-sense color game" to include verbs as well. Instead of "green bear", I could now say, "a green bear is walking down the street with a yellow hat". I would make sure I minimized routine and kept it only to actual "I'm teaching you math, reading, etc." type activities. I could start leaving clean clothes on the bed, with a basket of dirty laundry near by and start to actually show Zachary why they did not go together... that some clothes "smelled good" and other clothes "smelled bad or had stains" and I could show him how to put the "dirty clothes" in the washing machine to make them "smell good". I could continue to "un-do" what he ordered or grouped to make him familiar with the disorderliness of things.

All I had to do was break order... like my sister-in-law had said, that could be as simple as switching chairs at dinner time, changing who wore what hat or mittens to go outside, etc. When he spoke in non-sense language, I just had to distract him with something else. When he said, "fan" for example, to get an "order fix", I would immediately take his attention away from "fan" and say, "yes, that is something we use to keep the house cool". I knew I could not say something like, "yes, a fan turns to keep us cool", because that would put the focus on "turning" and give him his "order fix". I could be creative though...I now knew what to do and that was 90% of the battle. If Zachary said, "green truck", I could say, "yes, green trucks take food to the store". I would slowly have to deal with each and every one of his "order fix" behaviors... verbal, motor, etc. Whenever he went for that "order fix", I would have to distract him with something "fun". If he spun himself, I could put myself in his path and give him a horseback ride, something he now liked. If I thought about it enough, I could certainly come up with something to attack all his "order fixes". **The key was simply to break the need for complete order and to allow for the "in between"!**

My "working" with Zachary had just taken on a whole new dimension, but that was ok...because I now knew the enemy and that made life 100% easier.

So, there I had it... the key to my son's frustrations**. For concrete objects he could touch, grouping of like items in shape, size and function was critical to Zachary. One of a kind things like a stuffed animal, etc., those objects did not bother him because they were not part of a group "per se"... to be considered part of a group, they would have to be all similar in shape, size and function. For more abstract things, they had to follow convention...for example, a dog could not meow...that lacked order in the "normal" world.** Zachary had to stay on the gluten free and casein free diet. I knew that helped him tremendously with all the problems he had as far as his senses (sensitivity to light, sound, touch, smell, taste) and it kept him in "this world" as opposed to his being in a "drug induced state" as a result of the casein and gluten. "**Saving Zachary" had just become a two step approach: 1) a casein and gluten free diet that was also low in phenols and 2) behavior therapy to deal with inappropriate/ fanatical "need for order".** Zachary had been on his casein and gluten free diet for over a year and a half. If only I had figured this out sooner...I could have worked on "the need for order" as soon as I saw he understood ...when he was no longer in his "drug-induced state". That was not to be. But, I could **now** start my own home "behavior therapy", and the best part was that I could do this with everyday objects in my house.

I was convinced that breaking the inappropriate need for order would be the key to having Zachary function in society. Society would indeed have difficulty accepting this. After all, **"routine" had so long been advocated as "the key"...but it was not "the key" and I knew that! "Breaking order" and "allowing for the in between or partial" was the "key". Routines were indeed a double-edged sword. You needed some order to teach educational materials, however, routines provided "more order" and "forced order" to a child who already had too much order and thus, provided that "comfort level" via "order" just reinforcing exactly what Zachary and other autistic children probably should not have**. That, I truly believed was why so many autistic children did so well with **"routines"....they provided "ORDER"! The fact that I could now literally turn Zachary's frustrations "on and off like a switch" told me I was on the right track**. No routine could ever do that the way I had. A routine was simply an "ordered, artificial state". I had to break the order in order for Zachary to truly function in "the real world"... a place of randomness, a place lacking in order in so many ways. **Knowing what I now know about "routines" (and how they provide order) and the need to "break order" as the key to behavior therapy in the treatment of autism, please keep in mind that the books listed in my "suggested reading", at the end of this book, do emphasize "routine" and I honestly believed that this was not the best alternative. That was very different from saying that "behavior therapy" played no part. I now knew that behavior therapy was indeed critical for these children...but not in providing "routine"... rather in "breaking inappropriate need for order". There was probably not a single behavior therapy book out there in print today that will tell you that...and that was another reason why I had to put this out over the Internet and give it away...for parents of autistic children, this was just too important to wait! Behavior therapy had to take on a new focus... I honestly, honestly believed that. And I could now see how behavior therapy, also, had become a critical piece to helping these children "break order".**

That would be my plan of attack this year. Life had been so much easier over the past few days simply because I now knew what to look for. For Zachary, and I suspected many other children with autism, there was definitely a difference among a) order, b) routine and c) randomness and that impacted how they behaved given the situation dynamics for each of those types of situations. I was now convinced, also, that role playing was necessary to set for Zachary a point of reference to draw from, a "databank" for situations he was not familiar with. The simple fact that I could turn Zachary's frustration on and off like a switch told me I was on the right track and that God had given me the key to my puzzle... the need for ORDER! ORDER! ORDER! It explained so much!

CHAPTER 17

SAVED!

As we started out our long and difficult journey a year and a half ago, none of us knew where it would lead. With each passing day, each new trial, each new frustration, there were many days where Fred, Anika and I all wondered if we would make it just through the next ten minutes. Exhaustion, discouragement and the thought of simply "giving up" were battles we fought almost daily. It was as a result of this that Fred and I began to do something we had not done in probably ten years...we started to read and study the Bible (one with notes at the bottom to help explain some of the passages since given our situation, we did not have time to "try to figure it all out for ourselves"). In its pages, we found strength, encouragement, hope, determination, comfort, understanding, patience, persistence, never-ending love, and life. I now saw how although my son was not perfect right now, one day, he would be, and he would be for all of eternity. I just had to get through this lifetime and that was how I began to live, one day at a time, with the complete knowledge that Zachary would eventually be perfect, forever.

In God's perfect Word, I found so much I had not seen before, so much in the book of Revelation I had never been taught. Unfortunately, like so many others, I had no relationship with God. From now on, that would be different. God had given me Zachary for a reason, and I saw that now... it was to bring me back to Him.

As our family healed from the scars of autism and the internal death we, as parents, had felt inside upon learning of Zachary's condition, it would be Fred and I who would experience a re-birth as we worked so hard to "save Zachary". It was as a result of this new found life and hope that I wanted to share our story with other parents facing autism, to give them hope and help. One night, I had another dream, and with it, I awoke in the morning and felt an intense need to write this book, to share our story...freely. I had no desire to make money from the writing of this book. It was just a voice inside me telling me to "write the book...write the book... write the book... and give it away". So, I wrote the book and will give it away to help other parents and researchers in the field of autism. God literally waited "until the book had been written" to give me the final piece of the puzzle – the best chapter of all, the chapter that explained everything and put it all together- just as in the Bible – "The Revelation".

Little did we realize, upon setting out to "Save Zachary" that it would be Zachary who would help "save us" as his condition pushed us toward Christ for answers and strength. Zachary's favorite movie had always been Pixar/Walt Disney's Toy Story. In the words of Zachary's favorite animated character from that movie, Buzz Lightyear, our autistic son would, indirectly, help take us "to infinity and beyond"!

"Make Me A Blessing..."

There is a hymn written by Ira B. Wilson, entitled "Make Me A Blessing".... that hymn truly expresses what I hope my story will become for families with autistic or special needs children. I truly believe that "The Revelation" I received after I thought I had completed my work, came from God Himself after I prayed to include "everything I needed to" in this book. I know God, Himself, gave me that breakthrough so that I could pass it on freely to other families. Because of the answers God gave me, **I can now understand Zachary's behavioral problems...and, consequently, I literally have the capability to "turn his frustrations on and off" like a switch**.

If your family was blessed by the information within these pages and you, also, want to be a blessing to someone, I ask that you do so by providing funds to an organization that is devoted to providing God's Word in other countries. God gave me the answer to my puzzle so that I could pass it on freely to others, and I know that. I now have my life back - in more ways than one. Americans are truly blessed by God. We can purchase a Bible on almost any street corner. However, that is not so in many parts of the world.

There are people around the world who must hand write all the pages of a Bible "to have their own copy of God's Word". It is a very time consuming effort. As such, any money from "my story", any funds people want to provide, I request be given to this organization whose work I value tremendously as they are helping to send Bibles around the world, in various languages, for those who want them. **The best way to thank me for this work, is by sending a gift to this organization. A $4.00 gift provides a complete Bible; a $1.50 gift provides the "New Testament" section of the Bible only. Please help be a blessing to others and take the time to do so now**.

May God bless each and every one of you who reads this book as well as the many children whose lives I hope it will impact!

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THE END

Suggested Reading Materials

THE HOLY BIBLE...If there is one book I recommend for anyone dealing with autism, this is it! I strongly recommend a "study Bible"... one that has notations in it to help you understand God's Word. I found that to be critical to understanding so much I had never understood about the word of God. Also, for those of you who are not yet familiar with the Bible or have not picked it up in a while, I strongly suggest starting with the New Testament. That part of the Bible is about the life of Christ (his life, death and the period after his resurrection) and it is much easier to read and understand. It also includes my favorite book in the Bible, the Book of Revelation, a book on end times prophesy that is so critical to understanding God's plan for man. The Old Testament (first part of the Bible) deals with prophesy prior to the coming of Christ and is a little more "tedious" reading.

The Bible I used has ISBN 0-8407-0645-6 – A King James Study Bible from Thomas Nelson). It is by far the best study Bible I have seen. I know many will argue that the King James version does not include 15 books that are in the Bible used by Catholics or other religions (the Apocrypha). The Apocrypha is not in the King James Version because these 15 books were never quoted by Christ as authoritative Scripture and were never declared as inspired or authoritative Scripture until the Council of Trent in A.D. 1546. The fact is, that the New Testament is the same whether or not you are Catholic, Protestant, etc. and the best study Bible I have found is this one. It has taught me a great deal about end times prophesy and has literally "put the whole Bible together" for me. It is well worth the expense!

Cohen, Shirley. 1998. *Targeting Autism: What We Know, Did not Know, and Can Do To Help Young Children With Autism and Related Disorders*. Berkeley: University of California Press. (ISBN 0-520-21309-2)

*Duncan, Mary. 1995. *Boron, Phenols and Health: Clues to the Mysteries of ADD, Alzheimer's, Asthma*. Alkimos, Australia. Park Printing Company. (ISBN 0-646-26612-8)

Hamilton, Lynn, M. 2000. *Facing Autism*. Colorado Springs: Waterbrook Press. (ISBN 1-57856-262-7)

Hart, Charles, A. 1993. *A Parent's Guide To Autism*. New York: Pocket Books.(ISBN 0-671-75099-2)

Kaufman, Barry, N. 1994. *Son Rise: The Miracle Continues*. Tiburon, CA. H.J. Dramer, Inc. (ISBN 0-915811-61-8)

Lewis, Lisa. 1998. *Special Diets For Special Kids.* Arlington, TX: Future Horizons, Inc. (ISBN 1-885477-44-9).

Maurice, Catherine. 1993. *Let Me Hear Your Voice: A Family's Triumph Over Autism*. New York: Ballantine Books. (ISBN 0-449-90664-7)

Rapp, Doris, 1991. *Is This Your Child*? New York: William Morrow and Company. (ISBN 0-688-11907-7)

Seroussi, Karyn. 2000. *Unraveling the Mystery of Autism and Pervasive Developmental Disorder and Pervasive Developmental Disorder*. New York: Simon & Schuster. (ISBN 0-684-83164-3)

Shaw, William. 1998. *Biological Treatments for Autism and PDD*. Overland Park, KS: (No Publisher Listed). (ISBN 0-9661238-0-8)

Zand, Janet, Walton, Rachel, Rountree, Bob. 1994. *Smart Medicine For A Healthier Child: A Practical A-to-Z Reference To Natural and Conventional Treatments for Infants & Children*. New York: Avery Publishing Group. (ISBN 0-89529-545-8)

I chose not to follow Behavior Modification Techniques during the first year and a half of Zachary's treatment. I did read up on that subject prior to embarking on this "journey to Save Zachary". I included the best of those books I had read at the time for those who wish to further investigate that option. There were several more, but I found these to be the best...at the time of my reading them!

Koegel, Robert, L., Kern Koegel, Lynn. 1995. *Teaching Children With Autism: Strategies For Initiating Positive Interactions and Improving Learning Opportunities*. Baltimore: Paul H. Brookes Publishing Co. (ISBN 1-55766-180-4)

Lovaas, Ivar, O. 1981. *Teaching Developmentally Disabled Children: The ME Book*. Austin: PRO-ED, Inc. (ISBN 0-936104-78-3)

Maurice, Catherine, Green, Gina, Luce, Stephen C. 1996. *Behavioral Intervention For Young Children With Autism: A Manual for Parents and Professionals*. Austin: PRO-ED, Inc. (ISBN 0-89079-683-1)

*This book (*Boron, Phenols and Health: Clues to the Mysteries of ADD, Alzheimer's, Asthma.*) is not available in the US. To obtain it, you need to send $18.00 US to: Alkimos Australia, 26 Trian Road, Carabooda, Western Australia, Australia 6033. Although I was able to get some "bits and pieces" from this book, I find you need to have a good background in chemistry to thoroughly understand it and that was something I did not have...yet, research does seem to show a link between phenols, ADD/autism.