

A Mother's Prayer. . .a child's full recovery from autism!

Last Father's Day the Sunday paper arrived with the biggest Father's Day gift for my husband. His family was featured on the front page of the paper with the headline "Autism Battled in Different Ways – Grafton family's son recovers." Yes, we had come a long way. . .and not just the 3000 miles from California to Massachusetts.

When our son, Daniel, was diagnosed with autism at the age of 18 months it set in motion the biggest life change of our lives. It now meant we were the parents of a child who was potentially facing a lifelong disability. Worse, no one had answers on how to help our child at least to be healthy. He was losing weight, had chronic diarrhea and was so immune suppressed he caught every cold or flu that came along. A mother's prayer for her child must move heaven and earth. In my case I prayed as though my son's life depended on it. But I also worked as though my son's life depended on me to get good at finding out how to help him.

Thank god for the internet arriving at a time when it was needed most. My use of Google knew no bounds when I surfed the internet for anything that would lead me to the next tidbit of information. Finally I googled "Diet help for autism" since my son's diarrhea was so bad it had to be associated with his autism in some way. That search led me to starting a diet known commonly as the gluten/casein free diet. Translation is no wheat, dairy or anything with gluten. Within a week of taking my son off dairy I noticed an immediate change in his demeanor. Yet the wheat and gluten portion was slow for me to get good at; until my son regressed further into autism. My motivation shifted to be more militant on the diet. The angst of starting the diet was troublesome. My life was already stressful enough and adding one more thing might send me over the edge. Besides I was unconvinced he would actually benefit. And yet he did.

We continued with behavior therapies which helped but still something was missing in our quest to help Daniel to be healthy. While consulting with a leading allergy/immunologist in Orange County, California, he did the unthinkable. He referred us to another immunologist who actually was doing "out of the box" treatments for kids with autism. The treatments are known as IVIG, immunoglobulin. It is a blood product of human immune system and commonly used for patients who are so immune suppressed they would die without these infusions. But the application of IVIG is now being tested with a variety of disorders, including autism and even Alzheimers.

We knew instinctively IVIG represented a viable chance for a normal life for our son. I hear from families who are understandably concerned about the blood component to this treatment and ask me about why we took the risk. Perhaps it was because the risk for us was really the lifetime of autism versus a chance at normal. Daniel began treatments when he was 2-1/2 years old. At that time he was the youngest recipient for IVIG to treat autism related immune dysfunction. His immunologist, Dr. Sudhir Gupta of University California Irvine, thought he would be a good candidate for the treatment based on his lab results.

Once started the impact was almost immediate. He was happy even goofy one day after his first infusion. The second infusion was much the same. And then he hit the fourth infusion and autism walls came crumbling down. He was non-verbal when we started. By the fourth infusion he was full sentences, albeit the kind of sentences only a mother could understand. But, hey, he was talking. By the eighth infusion his autism doctor (known commonly as a DAN doctor) declared Daniel to be on the road to recovery. At the twelfth infusion Dr. Gupta was smiling from ear to ear as he proudly declared him to be one of his “recovery” kids. Yet, we were uncertain we were out of the woods so we continued with the IVIG infusions for seven more months.

The true test came when we met with his regular pediatrician for his four year check up. He observed Daniel, spoke to him, asked him questions and me as well. He knew all about what we had been doing and compared them to what he had done for his own children who were also on the autism spectrum. Finally he pronounced that Daniel no longer fit the profile for autism and would not qualify for the diagnosis at that moment. He was beaming, extolling my virtues as a mother and said he had never seen anything like it. So, in essence, Daniel had recovered from autism.

Even after losing the diagnosis we continued to work on other issues that beset Daniel’s medical condition, including a colonoscopy to fully address his chronic diarrhea. We ended up flying from California to New York to one of the only gastroenterologists who has an understanding of the gut issues children with autism face. It was determined Daniel had a form of colitis commonly associated with autism. Medication was started and within a month our prize “normal” poop arrived.

The following year we determined Daniel would benefit from a sound therapy called Tomatis to work on how he processed sound. The symptoms he displayed in the classroom were similar to ADD, yet I knew it was more than inattention. It was the inability to even understand what was being said. He did not have a hearing loss, but a sound understanding loss. The therapy worked wonders and allowed him to make great gains in language, vocabulary and processing speed.

We have also tackled his orthopedic issues with physical therapy, specialized gymnastics and even horseback riding. All of which helped him.

Parents who have a child diagnosed with autism today face the same concerns and angst about their child’s future. Families are decimated first by the diagnosis and then the lack of information and myths that still persist. . .most particularly the myth that autism cannot be treated. Gratefully the families whose children are diagnosed today are now supported in ways not available in the not too distant past. In fact my role now is as a mentor to the next generation of families who are just beginning their autism journey. It is a role which I did not choose as part of my life plan. But I will never take for granted the gift of my son’s recovery and it’s ultimate purpose of giving back. My mentoring the next parent has now reached into the hundreds. The quest is that they will find HOPE, understanding and perseverance to help their child reach their fullest potential.

Today, my son is eight and one of the top students in his second grade class. He has decided already who he intends to marry, wants four kids, plans to live on a farm with a dog named Spot. Oh, and I get to come babysit. It will be my pleasure.

The most beautiful moment that sticks out in my mind the most was the Christmas following his start of IVIG. I believe he had just had his twelfth infusion. On Christmas morning Daniel wrapped his arms around my neck and said “Mewwy Kwismas, mommy. I wuv you.” A prayer of thanks from a mother whose child has come back to her must move the oceans. Because I sure cried enough tears of joy to fill an ocean at that moment.

As I write this article I am filled with so much I’d like to pass along to the reader who is facing autism. So in the next set of articles I will be sharing a bit more on the variety of treatments that are making a difference in the lives and well being of children with autism. My son’s recovery is actually not as unique as one would think. I personally know eight other families with recovered kids. The one thing we have in common is that we caught the disease early (before three) and implemented a variety of treatments tackling the disease from all angles. I will begin writing about some of these treatments, therapies and even protocols that are being used by families. The goal is that someone reading this will wonder enough to do what I did. . .GOOGLE IT.