

Sarah Van Orden's Story

by Tom Van Orden



Morquio Syndrome, MPS IV A. A name that might as well described a type of flora that existed on a Icelandic tundra in our knowledge. That was 9 years ago and as most of have learned there really is nothing beautiful about it. Our daughter Sarah was diagnosed in April of 2002 by a skin biopsy after many months of run around from the medical testing industry. It would turn out to be the beginning of a very trying as well as fulfilling experience.

Sarah's early life started out typical for the most part with the normal ear infections, colds etc. I think it was about after a year we started to notice her chest was oddly shaped. While at a doctor's visit Ruth asked our pediatrician about it and he replied with music to any parents ears that she was just oddly shaped and would surely grow into it. We never really pressed it any further as he was a older doctor and worked with Ruth at the local hospital. He was nice enough to not charge any of the nurses he worked with and always cared for the children with love and compassion. But we always kept the thought of her oddly shaped chest in the back of our mind.

November 1998 found us relocating to Lancaster Pa. On a routine visit to our new

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pediatrician he found that Sarah had stopped growing totally. He spent a lot of time taking measurements and making calculations and said he was sure that there was something wrong with Sarah but he was not qualified to make a diagnosis. He referred us to DuPont Children's Hospital in Wilmington DE and directed us that though we would wait 3 months we needed to see Dr. Charles Scott. On our first consultation with Dr. Scott he gave Sarah a very thorough exam with x-rays and concluded that she was showing signs of multiple types of dwarfism. Many months later

Sarah's diagnosis was confirmed by skin biopsy which the lab technician happily stayed late to get us the results after all we had been through.

Since her diagnosis Sarah has multiple surgeries. She has endured 2 neck fusions, leg straightening, and hip surgery as she had no hip sockets, and a few minor procedures. The worst 2 being the hip spica experience and her second neck fusion ended her with a halo for 4 months. Despite all that she has been through she is a amazing happy thirteen year old that just wants to be treated normal by her peers. She participates in therapeutic horseback riding, performed in the school chorus , and hopes to take after her sister and join the high school band next year. The one thing that has made a huge difference in Sarah's life is the fact that we have had going to physical therapy since she was diagnosed. Sarah has learned to walk a total of five times in her



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life. The first time she learned on her own but the all the other times she learned due to the tireless efforts of the therapist at Schreiber Pediatric Rehab Center and the staff in the Rehab Dept. at DuPont Children's Hospital. She is an inspiration for countless people whose lives she has touched.

The good things to come out of Sarah's situation are it has made us all more accepting people. Her siblings know that all people are not created the same and they accept people for who they are. They have found compassion for people no matter what their situation in life. They would never mock anyone for being different in any way. They also have matured to understand what is really important in life. When Sarah came home with her hip spica cast Ruth and I were at the end of our rope. We had slept very little in a week after caring for Sarah in the hospital. The kids picked up on this and offered to do night shift duty so Ruth and I could get a decent night's sleep. 7 restful hours later we awoke to a stack of dirty bedpans but we were rested and recharged to take care of Sarah. That is something that we as parents will NEVER forget. They still help her when she needs it though in order to keep Sarah's life typical we make her tow the line with chores. Unloading the bottom drawer of the dishwasher or dumping the bathroom garbage usually results in a groan and a grimace.

The best thing has been that it has made our whole family closer. Not just the 5 of us but the



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WHOLE family. We are fortunate that when we need help people flock in from NJ or as far away as CO. Her sister recently left to attend Penn State and it was very hard for the sisters to go their separate ways. Her brother bypassed the going to college track as he said “I don’t want to miss a day of Sarah’s life”. Having a child with special needs can be very taxing on a marriage. It has brought Ruth and I closer than ever. We have the rule that when we are dealing with a major crisis one of us has to be strong at all times. One minute I may be curled up in a fetal position sobbing but 5 minutes later we switch. We depend on each other at all times of our life. I am very fortunate that Ruth is a RN and totally understands the clinical aspects of Sarah’s care and I handle the brawn. We have built a bathroom and many things in the house to make Sarah more independent. They were projects the whole family pitched in with.

The one thing that we have learned is that life holds no guarantees. We live it to the fullest, and above all remember it could always be worse.