

# Our Story Could Be Yours

By Sigrid & Bill Hirschhorn

The story that I will be sharing with you is truly only the tip of the iceberg because what lies underneath the surface is that which so many of us must struggle with every day of our lives, yet still learn to survive.

I want you to know also that, even after all of these years having dealt with our daughter, we still get emotional over the many issues we face, mainly because of the future she will never realize.

Our story began 24 -1/2 years ago with the birth of our second daughter, Samantha, who was born healthy and developed normally (even following in her older sister Jessica's footsteps - Jessica had been identified early on as developmentally advanced and was later confirmed as being gifted). That is until a flu-like illness required Samantha to be hospitalized around the age of 2 and dealt us all another deck of cards.

Over a span of several years we very gradually became aware of an alarming and ever increasing delay between Samantha's developmental age and her chronological age. She talked less and less and eventually just stopped talking, her walk became stiff and ataxic and she often fell. She seemed quite frustrated, unable to explain what was going on with her, often breaking down in tears. During this time period numerous medical tests and consultations were conducted, but they only provided us with more questions. She was labeled as having a degenerative neurological condition of unknown origin. In other words - no one had a clue.

By the age of 9 Samantha could no longer stand or walk on her own and required a wheelchair. Being non-ambulatory further compromised her condition and eventually resulted in severe kyphosis, scoliosis, hip displasia, and muscle atrophy.

Over time Samantha's spasticity has increased in her extremities and she still continues to decline in that area. Doctors have added spastic quadriplegia to her diagnosis. Her swallowing muscles have likewise been affected and she presently eats only pureed food by mouth and takes her liquids via a syringe - like device. Feeding her usually takes around 45 minutes to an hour, as she eats very slowly and we need to be careful to avoid reflux. Samantha is considered to be medically fragile.

We started out almost 25 years ago harboring all of the dreams and hopes one has with a healthy baby and now we have a young adult who is non-verbal, non-ambulatory, in diapers, needs to be fed, and requires total care for all daily living skills. How can I possibly convey the psychological, emotional, physical, social, and financial toll this situation takes on a family?

I have sacrificed my teaching career for almost a quarter century now in order to care for and advocate for our daughter, meaning that I could not contribute financially to my family nor earn a pension to follow me into my senior years. I know for certain that, unfortunately, I am not alone in this circumstance. Many parents have given up their careers to do the same and the cost is exponential in countless ways.

Samantha spent 13 wonderful, productive years at Elwyn, an approved private school in Media, PA which serves the special-needs community. Here a committed team of professionals arranged programming to best meet all of Samantha's social, physical, and emotional needs providing such things as aquatic therapy, physical therapy, field trips, musical presentations and best of all, friends.

At age 21 in 2005 Samantha aged out of Elwyn and overnight, to our dismay and disbelief, her quality of life changed dramatically. For about 4-5 years prior to graduation, while Samantha was still in school I did my research, continued to attend yearly IEP meetings, initiated modifications when necessary, and met with prospective placement personnel while making arrangements for her transition after Elwyn. This was all documented at the IEP meetings. I was consistently reassured by my then supports coordinator at MHMR that I had all of my ducks in a row and that with Samantha's consolidated waiver, she should be set to go. I even enrolled at Villanova full-time and became a certified paralegal in order to better understand the legislative infrastructure and governmental rhetoric involved in the special-needs arena.

Imagine my surprise and frustration when I found out in June 2005 that someone, somewhere along the line, had dropped the ball and no one had noticed - not even with all of the documentation that had taken place. Samantha did not have a consolidated waiver after all! Not only could I not accept the 5 days per week day -program that had been meticulously arranged previously, but without this funding the most I could expect was 2 days a month, and that came with restrictions. Samantha has remained at home with us since graduation.

Adding to this unfortunate news was the development of serious health issues for my husband, Bill (age 66), also in 2005. My husband had 2 cataract surgeries that resulted in severe eye infections, which happens rarely, and ultimately was rendered legally blind. This was followed by 2 strokes that same year, which, along with his visual limitations cause balance and general mobility difficulties. Because of his health issues, Bill, the breadwinner of the family, was downsized to half- time. He works from home with my assistance and the help of various adaptive technologies on his computer and still his performance reviews note that he exceeds expectations.

By default, I am now the designated driver and caregiver for both my husband and our adult daughter.

The frightening truth for us is that if something happens to me, then our entire family structure will fall apart. Because of his continuing health issues, my husband will be retiring in December of this year after 40 years in the pharmaceutical industry and in academia. That means I lose my health insurance. He will then go on Medicare and Samantha already has Medicaid, but I, the person who needs to stay healthy in order to keep the family together, will lose my insurance coverage. There seems to be no safety net for me, nor for the many others in similar circumstances.

Neither of us could have imagined the challenges the future held.

I would like to share a saying that seems to fit the occasion and also reflects what all families who face special challenges in their lives feel. "Courage doesn't always roar. Sometimes courage is the little voice at the end of the day that says I'll try again tomorrow."

What we would like for you to take away from our message is the recognition that there needs to be a better understanding and a more compassionate approach to addressing the problems that we and so many others like us face in life, because except for the Grace of God...OUR STORY COULD BE YOURS!