

My Son is My Greatest Teacher

By Marcy White

I had no idea how my safe and insular world would be tossed, shaken and dropped unceremoniously on its head with the first breath of my first child in May 2002.

It was Jacob's birth and early struggle for life that led me to my unequivocal vocation, the one I never thought I would have. It wasn't a dramatic shift, despite what you might expect. Instead, the realization gnawed at my brain like a persistent cat that wants a head rub. As I watched Jacob fight for his life and baffle the medical professionals who were at a loss to explain his illness, I knew I had to stand up and advocate for my little boy.

As Jacob was closing in on his first year, we received a shattering diagnosis. Jacob had Pelizaeus-Merzbacher disease (PMD), an incurable and rare neurodegenerative disease. Jacob's prognosis was grim. The doctors told me that he would never speak or sit independently. His symptoms would worsen as he aged.

Once the shock wore off, I determined to do whatever was humanly possible to find a cure for this horrible disease. I was not ready to sit on the sidelines and watch as PMD slowly ravaged my son's body. He deserved more. And as his mother, I was not going to let anything or anyone stop me from giving him the best chance at a full and happy life.

The first handful of years after Jacob's birth were unbelievably difficult. In addition to learning how to be a first time mother, I had to learn how to care for a severely disabled child. I had to familiarize myself with this new and scary world. I spent a lot of time learning, I did not have much wisdom or experience to share.

As my son grew, I earned a "PhD in Jacob" and gained confidence in my ability to care and advocate for him. I began to trust my instincts and learn when to push for what Jacob needed, and when it was okay to let some things go.

Four significant realizations included:

1. Despite wanting to, I can't do it alone and have learned to let others help with Jacob's care.
2. I learned patience and to appreciate the small things that I used to take for granted. Jacob's first smile came when he was almost a year old. He learned to communicate yes/no when he was about four years old. And his first words, with the help of a specially designed iPod were "I want a great big hug." He was eight years old.
3. I learned how to take what life threw at me and how to cope with it. If Jacob could find reasons to smile, then I could too. There were many, many times when I said "I can't do this" but as Jacob got older and I settled into my new normal I noticed that I *can* do this. There are still times when I think I can't keep going but these thoughts comes less frequently. I know that I can and I will keep going.
4. I realized that I learn important, practical and relevant things from other parents. They are my best source of information, as they have traveled this road before me. Whether it's an everyday concern as it relates to my daughters, such as a good way to get them to eat more vegetables, or something more obscure such as which positions are most comfortable for a child with severe scoliosis, they are a great resource.

I wrote [The Boy Who Can: The Jacob Trossman Story](#) with the desire that other parents facing challenging situations can gain hope and strength and know they are not alone.

Many people have children or siblings with special needs. Even more people have cousins, friends or colleagues with children who have special needs. I wrote the book for these people to get a glimpse into what our lives are really like. And more importantly, how they can still maintain their friendships with families like mine despite our dramatically different lives.

And finally, I would love for medical professionals, caregivers, educators and policy makers to fully comprehend what raising a child with special needs entails. Despite their best intentions, there is so much more to our lives than the small window that they see at the hospital, clinic or class room. I want them to know that their action or in-action can have a real impact on us.

The following are some small ways people can make a difference in the lives of children like my son, and their parents:

1. Don't forget that the person in the wheelchair is more than simply a body in a chair. He has thoughts and feelings.
2. Bend down and talk to the child at their level.
3. Don't be scared. Children will sense your hesitation.
4. You won't catch their disability, you can come close to chat.
5. If you see someone struggling pushing a wheelchair, hold the door or elevator for them.
6. Empathize with what it's like to be a person who cannot speak or move but who understands conversations around them. And don't ignore or stare!
7. Notice their abilities, not their disabilities.
8. Most of all, treat them just like you treat anyone else their age and gender.

Marcy White BSc, MSW, MBA, enjoyed a career in the investment industry that was sidelined with the birth of her son in 2002. Her academic degrees did not prepare her for caring for Jacob who was born with Pelizaeus-Merzbacher disease (PMD). Since Jacob's diagnosis at 10-months-old, Marcy has become an advocate for her son and furthering

PMD research to help find a cure. Marcy has recently published her first book, [The Boy Who Can: The Jacob Trossman Story](#) and has written many articles about Jacob that have appeared in various news and parenting publications. She co-founded curepmd.com to educate people about PMD and fund research into finding a treatment. Marcy lives in Toronto with her husband, Andrew, and their three children, Jacob, Sierra and Jamie.

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