Madison's SMA Story

Madison was born both happy and healthy. For six months, everything was perfect. And then I noticed she wasn’t using her baby walker or bouncing in her bouncy seat anymore. She had stopped bearing weight on my lap when I stood her up—nor was she able to hold a crawling position. I brought Madison to the pediatrician, who told me she was just delayed, maybe even a little lazy. This didn’t sit well with me, or ease my mind in any way, shape, or form. I hadn’t acquired years of experience as a mother of three for nothing! Not to mention, I had been a single mom for five years! A month later, I went back to that practice and asked to see a different pediatrician. She considered my concerns and guessed Madison’s leg might have been dislocated. What? Wouldn’t she have been in pain? How would I have not known about something like that? Well, go figure, the x-rays came back fine; in fact, the orthopedic doctor we were referred to noted that Madison had good posture when sitting. The problem, he guessed, might be as simple as me holding her too much. He assured me that she would be walking by twelve months and wouldn’t need to see us back again.

Well, as fate would have it… One night, still frustrated and feeling helpless as Madison appeared to be getting weaker, I tripped while carrying her and fell to the floor. We were fine, but Madison did bump her head, so I took that opportunity to get in front of a new set of doctors in the ER! The CT scans came back normal, but I insisted that they take a look at her legs. The doctor, though in doubt, complied. The results showed Madison had lost all the reflexes in her feet and knees. This terrified me. What did it mean? We were told to go ahead and make an appointment with a pediatric neurologist.

We were now five months into looking for answers and hoping for the best. Madison was just shy of a year old. We met with a pediatric neurologist and emphasized how weak she was getting; how she wasn’t hitting the normal developmental milestones. They sent us for blood work that day, with the expectation to have the results in two weeks. The office called asking us to come in two days before Madison’s first birthday. My parents, Aaron’s parents—we all went. While I knew it might not be good news, I had no idea what to expect. “Unfortunately, my suspicions were correct and your daughter has spinal muscular atrophy, type 1. There is nothing you can do for her. This is a fatal disease and she won’t live to see her 2nd birthday.” Seeing the incredulous look on my face, she handed me a memorial card of her last patient with SMA to prove what she’d said was true. I left her office with nothing but a phone number for HOSPICE! Numb and not knowing what to do with myself or what to say to my parents, I left. I drove home slowly, barely able to see through the tears. Aaron and I had driven separately; I got home to find him in the backyard, crying his eyes out. My older children, Katie and Zach, knew something was wrong, and I didn’t know what to tell them. Do I tell them their baby sister is dying? Do I support my husband? Or do I spend what precious time I have left with Madison holding her? I couldn’t stop looking at her, trying to memorize her features, as if at any moment she’d breathe her last breath.

Over the days that followed, I felt like we were racing the clock, losing time and sleep, as Madison steadily lost more and more of her muscle function. As a family, we were crumbling. The stress was getting to us. I couldn't go back to work. We were desperate find someone with knowledge of SMA. Our search led us to Dr Mary Schroth in Madison, Wisconsin where we flew to get a seven-hour crash course in how to keep Madison as healthy as possible. We learned that with supportive care, I could help my daughter. We added a pulmonologist, an ENT doctor, a physical therapist, speech and occupational therapist to Madison's healthcare team and flew back home feeling like we had a chance at hope. We became a team. We worked together to educate our family and find new Doctors at home.

Around this same time, we attended our first SMA conference and finally met other SMA families. Needless to say, the positivity was overwhelming. Over the span of a few days, we learned so much—about caring for Madison and utilizing support. We met kids just like Madison, laughing and goofing off in their wheelchairs. I could see my daughter in their smiles and love of life. I wanted her to have friends like that closer to home. It was after listening to parent advocates who ran chapters in different states that I felt inspired to start a chapter in Florida in 2009. I had to be a part of making a difference in the world of SMA, do my part, and start educating about the importance of research. I started Fundraising like crazy for research and separately for Madison's medical bills.

Our family had evolved and we felt like we had a pretty good handle on SMA; and yet, we still felt powerless against the detrimental effects SMA had on Madison's little body. Year after year, she grew weaker and weaker, never crawling, walking, or standing. We tried to get her into clinical trials but were rejected. I always held onto the hope that, one day, treatment would become available in her lifetime that could possibly provide hope for living with SMA. That day came on December 23, 2016, when SPINRAZA was FDA-approved as the first drug to treat SMA—our Christmas gift! We had kept up with its progress in clinical trials, waiting what felt like forever for its approval. We would wait another few months for our insurance company to write a policy and approve SPINRAZA for Madison. But then we were denied, and it broke us. No, not when we had tasted hope. This was my daughter's life—something that mattered to me more than my own. We had come too far not to give this everything we had. The cost was $750K for the first year of treatment so we needed to wait four months to get the insurance decision overturned and Madison would finally get treatment!! After a year on treatment, she called me into the room to show me something. "Look mom," she says, and I watch as my brave girl bends over in her chair, touches her toes, and straightens back up all on her own. Just a small thing, but so huge for Madison! I see her brush her own hair, wash her face, scratch the top of her head, and brush her teeth. I have a unique perspective as her mom; I'm witnessing important achievements and GAINS!!

There are days when it feels like we've taken two steps back—when Madison needs more support from us than the day before. It's frustrating as much as it is disappointing. Such is life with SMA. We can't let those bad days rule our life. The trick is finding a balance—taking advantage of the good days; making memories to hold onto forever; showing Madison why pushing through our challenges is so worth it in the end. I have photos of Madison participating in all kinds of activities like swimming with dolphins, ice skating, riding rollercoasters, and making speeches about SMA in front of her classmates. My daughter is not as fragile as she looks. Believe it or not, her lifetime goal is to swim with sharks! We'll see about that! She's been telling me more lately, "Mom, I got this." And you know what? I'm okay with taking a step back; in fact, it's my joy to give her the space she needs and wants to grow into herself. I feel so fortunate just being able to say that. We've come a long way, Madison and I. People often ask me how I've managed to stay standing considering our circumstances. "You're so strong,"

They say. "How do you do it?" Well, that's easy. It's Madison. My daughter—the strongest, most fearless person I've ever known—has been my inspiration since the beginning. At the end of the day, I need her way more than she needs me.