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Mother Knows Best

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May 6, 2009 - 7:22:06 AM

“I’ve never seen anything like this before” were the first words I remember a doctor stating the moment my son was born, as I listened to the donkey-like sound my son made. From where I was lying on the delivery table, it looked like his ribs were made of rubber and folded in half with each noisy inhalation. With every breath he took, his ribcage would collapse. Of course the doctor had never experienced this. We learned, five long, agonizing days later that it was because both of Jacob’s vocal cords were paralyzed, something so rare that the specialists at Sick Kids Hospital had not seen in over 15 years.

Until then, my only experience with doctors had been for routine check-ups and the occasional sore throat. Doctors had the answers; they diagnosed the problem and prescribed the remedy. And it usually worked. Not this time.

It wasn’t until 10 months after I heard those frightening words that Jacob was diagnosed with Pelizaeus-Merzbacher disease (PMD), a rare, neurodegenerative disease. I was at home playing with my son when the telephone rang. The doctor informed me that one of the many tests Jacob took came back positive. He had PMD. I had never heard of this disease and did not know what it meant. When I started asking questions, I was informed that there is no cure and no treatment available. According to the medical professional, our only option was to treat each new symptom as it appeared. I would not accept that this was the only option. My role as a mother was to keep my son happy, healthy, and safe. I would not sit back and wait for the disease to destroy Jacob’s body.

I lived my first year of motherhood as if I were in a bubble. While other new moms were taking their babies to music classes and various “mom and tot” programs, I was at home, isolated from the rest of the world. Because of his weak immune system, a simple cold was life-threatening for Jacob. I was not willing to risk infection by inviting other children into our home for visits or taking him for a walk in the nearby mall.

Instead, as I held him for two hours at a time for his feeding, his tiny head would get so hot it soaked through the layers of blankets that were between us. Without stopping, I was uttering the same two syllables in slow motion: Jaaaacobbbbb, Jaaaacobbbbb for hours. My biceps were burning from holding his little body as still as possible as any movement might cause him to vomit. This process was repeated every three hours. My clothes were drenched and stank from partially digested breast milk that was painfully pumped for 20 minutes, seven times a day, month after month.

Being a mother took on a new meaning for me. Yes, I held my son like any new mother, but it was different. Very different. Nothing like I thought it would be. I had to make sure I did not dislodge any of the tubes that helped him live. Yes, I fed my son like any new mother, but it was different. Instead of holding him to my breast or placing a bottle in his mouth, I had to connect him to a feeding system that dripped pumped breast milk into a tube that was inserted into his stomach, bypassing his mouth. And yes, eventually I was allowed to take him for walks in his stroller, but it was different. We walked in the halls of the hospital, stopping occasionally so I could place a suction tube in his mouth to help him breathe.

This was not the way I visualized motherhood. Seeing a healthy child was so painful for me, I felt like I would collapse in tears. When I saw a baby that was the same age as Jacob, I had to look away. I couldn’t help thinking my son should be sitting like that by now; he should be able to smile, too. When I listened to a mother complain about her child needing glasses, I wanted to scream at her and tell her to be thankful for having a child who could walk and talk.

As we were given the freedom to venture farther away from his room, I started gaining confidence in my ability to feed him by myself and was beginning to overcome my revulsion at threading a tube up his nose and down his throat for the deep suctioning he sometimes required. I was terrified. I can still feel my inexperienced hands trembling as I snaked the tube in his nose until it reached the point where it would turn, move down his throat and clear the thick mucous that was impeding his airway. I was not enjoying this part of motherhood. Not one bit.

Then, all of a sudden, I realized that I had changed. Somehow along the way, in the midst of all the feedings, appointments, and isolation, I seemed to have stopped saying that I couldn't handle it. I stopped feeling like I was going to scream every time we were told that there was nothing anyone could do. I stopped shaking every time I had to suction Jacob, and I stopped apologizing to strangers in waiting rooms for Jacob's screaming.

Eventually I stopped saying "I can't handle it." I don't know exactly when, but at some point, I realized that I can, and I had to.

It is well known that mother-bears will stop at nothing to defend their cubs. And that was me, I realized. Perhaps my child had disabilities, but still, I was a mother-bear. I had found strength and courage from reserves located somewhere deep, deep inside me. I started to question the medical professionals. I began to realize they did not have answers, and even though many were reluctant to admit it, I learned they knew little about how to help Jacob. But as time passed, as I became more comfortable with the tiny fighter who is my son, I realized that I could not depend on the doctors for the answers. Jacob is my son. I know him better than a doctor who examines him for 10 minutes, despite the plethora of degrees hanging on his office wall.

The doctors were doing their best, but I was the expert. During one of our many hospital visits, a doctor told me that he wanted to surgically remove a piece of Jacob's skin for analysis. I asked why. I wanted to know if the results would lead to a treatment or if it was simply to add more details to Jacob's voluminous medical file. At another appointment, a specialist suggested a second MRI. I weighed the potential benefits against the risk of not being able to remove the breathing tube required for the anesthetic. As my confidence grew, so did my voice. I decided that any medical test or procedure that Jacob would undergo must have the potential benefit of bringing us closer to a treatment. I would not let him suffer for the sake of gathering additional information that would be useful only in the context of academic publications about rare disorders.

Some of the professionals I've encountered have labeled me a demanding parent; others call me difficult because I don't blindly accept what they say. I know what I am. I am a mother-bear who will stop at nothing to protect her cub. I will stop at nothing to make sure Jacob has the happiest, healthiest, and safest life possible. Because frankly, that's my job.

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