



Complex Child E-Magazine

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Looking Normal by Cristy Balcells

For six months we have been fighting with our insurance company in order to get our daughter Eva a wheelchair. She turned four in April, and all of a sudden we left the world of overgrown baby items and crossed over into the land of special needs and durable medical equipment. Eva has Leigh's disease, a form of mitochondrial disease, that affects her muscles and neurologic system such that she cannot walk or talk. Sounds terrible, right? In reality, once we got over the diagnosis, we find so much joy in Eva. For a little one who doesn't walk or talk, she has more personality and charisma than many adults that we know.

Dealing with insurance for basics like formula or durable medical equipment (i.e., a wheelchair, a feeding seat, a way to take a bath) for a parent who already has her hands full working, running a family and caring for her dependent special needs child is the definition of stress. I have a Pavlovian response when I see an envelope in the mailbox from the insurance carrier.

Meanwhile, in January we finally got Eva's wheelchair. I must say, it's fantastic! The degree of support and size are perfect for her. At the time of delivery, the vendor commented, "This must be so hard for you...putting your daughter in a wheelchair." Are you kidding? I'm ecstatic. She weighs 40 pounds, and finally she feels comfortable. I've come a long way.

So, right away I pack up my kids and away we go to the mall (early, before the crowds). My kids have a blast pushing Eva up and down the mall at a racewalk speed. Eva is loving it. We are having more fun than Disneyland. We even have ice cream and hot dogs!

However, I can't help but notice that people are giving me sympathetic looks, or a sad smile. One woman even stuck out her bottom lip--really! We traveled into the Disney store (Eva loves princesses) and well-meaning mothers coveted their children and cleared the aisle. Keep in mind Eva looks pretty normal. While we were happy, jubilant in fact, to be out with Eva and her new wheels, I was taken aback by the sympathy and interpretation that our daughter was somehow less fortunate by her position. I sensed that people were afraid to interact with us.

As I mulled this over during the rest of the weekend, I started to think about how much we depend on appearance in order to estimate one's ability. That's probably the Achilles

heel of mitochondrial disease. When one “looks normal,” how can you really be dealing with a disease or disability? I’ve been out with Eva plenty of times in a stroller and we never got a second glance, even during the times when I really needed extra help (boarding an airplane, for example). Putting her in a wheelchair changed everything.

Many adults and kids with Mito can walk...some of the time. Or they can talk...until they run out of energy. Have we moved beyond discriminating against people with disabilities to a point now where we as a society have taken a hands-off approach instead? For fear of discrimination, the aisles will clear when the wheelchair enters. How do we, the community of people with all kinds of abilities and special needs--visible and invisible--teach our neighbors to embrace us instead?

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