

No Time for Sorry

by Melissa Arceneaux

In my 20's a doctor told me that I'd probably never conceive a child. An unplanned pregnancy at age 37 was the greatest surprise I've ever been given. Giving birth to a beautiful baby girl... well that was just icing on the cake.

My Ariel was a sweet and cuddly baby from the start with the softest hair curling around her big beautiful eyes. She was a delight as a baby and grew quickly into a quiet and very organized little toddler.

On Ariel's 2nd birthday I did what all good parents do and took her for her regular checkup. Little did I know, the visit would be anything but normal.

"YOUR DAUGHTER IS AUTISTIC" the doctor said to me in a cold, clinical tone. My head spun and I doubled over grabbing my stomach as though I had been punched in the gut.

I sat back up, overwhelmed, knee deep in grief. I couldn't be in denial since the doctor's diagnosis had been so clear. Anger seemed too easy and well, there was nothing to bargain for.

"Your daughter is autistic," he'd said bluntly. I had no choice but to plunge head first into acceptance.

I left the office and drove to Barnes and Noble. I stacked books around me as high as a mountain. For weeks, I barely ate. I barely drank. Hell I barely even went to the bathroom.. and when I did I just sat there reading. I read and read, day after day, week after week, trying to connect every dot in an effort to understand my child's diagnosis.

Things were good. Ariel and I were on a roll. And then one day ugly showed up at the playground. Ariel was 3 and the playground was crowded so there wasn't a free swing anywhere. Ariel paced back and forth behind an occupied swing and I could sense her frustration growing.

Two mothers nearby muttered just loud enough for me to hear them. "Why is that kid "stalking" my child's swing?" I rushed up to them to quickly explain that "My daughter is autistic". I wanted to nip this in the bud before they began to judge her against the world's so called "norm." I hate the world's norm and honestly don't even think the world's norm exists anymore anyway.

"I'm so sorry" the mother in the expensive yellow tennis skirt said. "It must be soooo difficult for you." She looked like she could cry, almost like she was acting how she thought she should act, like some weird role in a script. The other mother just nodded, her lips turned down. I was so caught off guard I simply lifted Ariel into my arms and mumbled a few random words before heading to the car with my heart racing and tears in my eyes.

I buckled Ariel in and plopped in the front seat, still muttering under my breath. I began to notice that for the very first time on this journey I felt angry. While looking in my rearview mirror at my precious child I asked myself "What are THEY so damn "sorry" about?" My cheeks were flushed and I moved in closer to the mirror so I could have a talk with myself. The tears steadily rolled down my cheeks as I asked myself "Did you miss a memo, Melissa? Are you SUPPOSED to be "sorry" -- and feel BAD that your beautiful Ariel is different?"

The tears continued to cascade down my face as I drove home, but of course my Ariel didn't notice. All of the sudden my front seat passengers were fear, doubt and insecurity. It was eerie. They were talking to me, making me question everything I knew about myself. They were challenging me to abandon the person I had become - the mama warrior rising up to fight for everything

my child deserves. They wanted me to abandon the fight. My first instinct was to explain myself to fear. After all, fear and I had been friends most of my life. But then I realized that I do not have the time or inclination to explain myself to anyone. Speaking to the empty seat, I stated "I do NOT have TIME to be "sorry" during my baby girl's fight to fit into this world.

That night I engaged in the "normal" routine of cooking dinner and washing the dishes. I got Ariel ready for bed and read to her. I remember going to bed extra early and praying for a world where differences can be embraced. A world where patience replaces pity and awareness replaces sorrow. A world where a fistful of compassion is reserved for those with children who appear "normal" but who face unknown struggles, minute by minute ...

My Ariel is almost 10 year old now. The years have been loaded with "playground" incidents but we take each day as a rewarding and challenging adventure. On our good days, we are so strong and alive that I can feel autism buckling under the power of our alliance against it. And then there are days when autism has my baby girl in its grasp and I'm worn out. I am exhausted navigating the different worlds I live in - work, social groups, family - and facing the daily choice of pretending that

everything is ok and the problem has been solved... when it simply has not.

I was recently asked "Have you given any thought to what happens to Ariel when you are gone?" My old enemy fear assaulted me in that moment, smothering me like a blanket, and robbing me of my voice. I stood frozen remembering how boldly I have lived my life. In a flash I realized that I can't live with the fear of wondering what will happen to my child as she grows and the world does not grow with her. I realized that I had to forge ahead and challenge the world to join our fight for compassion and understanding.

That fear is why I struggled with telling my story. That same fear is exactly why I HAD to tell my story... the story of what life is like with my wonderful daughter who loves art and water slides and who loves without judgement as she lights up every room she enters.

I fear that if we look too weak you will pity us. I fear that if we look too strong you will think we don't need you... we do. We need all of you.

I will conquer my fear by embracing what Ariel has taught me about life. She has taught me that embarrassment is nothing more than a chance to learn. She has taught me to never underestimate

anything or anyone. She has taught me to love without boundaries.

She has taught me that we will never have time to be sorry.