July 15, 2012

When the opportunity arose for me to write this letter, my daughter, Reily, was about 9 months old. I could not bring myself to sit down and type out my thoughts and feelings about having a daughter with Down syndrome. I suppose it was just too emotional. Now, almost two years later, I am ready. I will try to keep this short, yet express my feelings honestly.

When Reily was born, the diagnosis was totally unexpected. We had been to the doctor and gone to one of the best hospitals in Baltimore for thee different ultrasounds that all said our baby was completely typical and we had nothing to worry ourselves over. Reily was born two weeks early and we were told nothing until the morning after she was born. Then doctor’s told us they saw some signs of Down syndrome, but not many so they took some blood. We were to take Reily home and wait for the DNA results. Two weeks later, we were sitting in the doctor’s office, the color of the office walls were a gray-blue color, I remember thinking how much I like the color. The doctor entered and showed us Reily’s karyotype. As a former science teacher, I taught about karyotype s and Down syndrome so I knew exactly what I was looking at before the doctor even spoke. We left the office and I cried. I cried and cried, now looking back I still know why I cried, but at least I now know I did not have to cry for the loss of a “normal” child.

I called my mother when we received the diagnosis and I said, “She has Down syndrome” followed by, “she is never going to graduate from high school, she will never get married, she will never move out of my house”, all my greatest fears for my daughter spilled out of my mouth in less than three seconds. My mom listened and she tried to reassure me that everything was going to be fine, that my life was not over because I had a daughter with Down syndrome. My thoughts were all about the things I thought my daughter would not be able to do instead of the many things she will do. In an instant, I came to believe all of these things about my daughter and she was only a few weeks old. Within a few short months, I met other families who had children with Down syndrome, I learned more about Down syndrome and I learned from my daughter. She will graduate from high school, she may get married someday and she will move out of my house. Yes, I cried and cried again, because now I do not think I ever want her to move out!

Reily was born in April, by May I had purchased every book possible (I spent $100s, so if you want to borrow something, let me know, I am sure I own it), had her enrolled in the infants and toddlers program receiving all kinds of services, had read everything I could possibly read or view online, but the greatest “gift” I ever received was from a woman I have still never met, four letters and a book of pictures. This complete stranger knew my brother and one day my brother handed me a red box. It was shortly after my birthday so I thought it was a regular gift. I went to open it and he said, not right now, you may want to wait until you are home. I remember opening the box and seeing the zebra print tissue paper that held the most precious gift. I read the first letter, it was written by the grandmother of a little girl with Down syndrome. It was filled with joy. One line read, “Special children are gift given to special parents. I am sure there will come the time when just like us you will just see your beautiful daughter, the Down syndrome won’t even be an issue, she is just your sweet loving daughter”. The second letter was from the little girl’s older brother, he was 11 at the time he wrote it. The letter was only about five sentences but said so much more. He started with the sentence, “living with [my sister] is great, it gives a different experience and a little spice to your life”. He wrote about how much he loves his sister; he helps her and would not trade her for any other sister in the world. This letter especially touched my heart because Reily has an older brother. Another fear of mine was how this would affect his life. The next letter was from the little girl’s aunt. She wrote about the day her niece was born and said, “I had all the same feelings of joy and excitement just like all the other births in our family”. She wrote something else in this letter that made my heart feel so much better; “I had a good friend ask me if I would want to take it all away and have her born without Down syndrome and my answer was a very quick no. Down syndrome is not who [she] is but it will always be a part of her and who she has become and what we have been through. To take that away we would lose some of her and some of our family’s strength”. The final letter was from the little girl’s mother. She wrote a lot about her daughter and herself. She wrote, “She makes us laugh. She makes us cry. She still needs love, attention, hugs and kisses. She is a normal child. She gets cranky, she throws fits. She laughs, she plays, she loves water, Elmo, and Dora.” Her words I have found are true. Reily fits this description too. Reily does everything other children do; it sometimes just takes her a little longer. The pictures included in the box were beautiful. Of course I cried while I looked at the pictures, but what made me chuckle and realize life goes on was the very last picture. It was of the woman and her three siblings. Her brother was wearing a t-shirt that must have said something she did not like. She blacked out the writing with a marker. I thank her for this little gesture, not for crossing out something rude on a t-shirt but showing me how other things in life will mean more then Down syndrome and life really does get back to “normal”. I feel this today, as my world no longer revolves around Down syndrome. I am confident you will find this to be true for you as well. The box is still in my closet where I see it every day.

The greatest advice I was ever given was “love your child, she may not be typical compared to other children, but she is normal and she will prove that she can do whatever she chooses with no limitations”. This is so true. I wish I could take back all of the tears over my lost “normal” child, because Reily is my greatest gift. If you ever have the opportunity to meet Reily, you will see all of the potential your child also contains. Reily will make you fall in love with her from the first moment.

Congratulations on the birth of your new baby. He or she will be loved by many and will bring a joyful and emotional life that you may never have dreamed possible.

-Wendy (Reily’s Mama)

