

Life is like a Rainbow....

You need both the sun and the rain to make it's colors appear.

Everyone wants their life to be full of rainbows...but how often does that really happen? When you're having a baby, you have so many dreams before your precious bundle even arrives, but when you have a baby that might not be what you expected; it's hard to think there will ever be any happiness in your 'perfect' little world.

At least that's how I felt, or so I believed.

In May, 2002...I had a beautiful baby girl named Alexis Lynn, the perfect addition to our family. Alexis has an older brother, only 20 months older named Johnny. Everything had been uneventful...no problems in the pregnancy, I was 9 days past my due date, so I was induced. Nothing really seemed to be a problem; I was induced when I had my son too. When Alexis was born, she had the most beautiful blonde hair...one huge difference since my son had black hair. But I noticed something else different about her; it was something in her eyes. I was tired, after all, it was 1:30 am, I didn't think anything of it, and they whisked her away to be cleaned up and weighed.

The next morning, I was waiting for the nurse to bring her in to me...instead, it was her pediatrician, the hospital pediatrician, not my own. She very blatantly said, "I just got done checking your daughter and I think she has Down syndrome, do you know what that is?" I was dumbfounded....I was all alone, looking at this stranger hearing words that really weren't making any sense. Was this a sick joke..I had an AFP, that was normal, I was only 31 years old, all my ultrasounds were fine...what the heck is she talking about? Then I think she started rattling off 'markers' the nurses noticed, by that time I was hysterical and she ran out of the room. That was a great reaction from a professional.

The next day was just as surreal, now there was a Cardiologist in my room...thank goodness this time my parents, sister and brother in law were with me, he started explaining how children with Down syndrome had a 50% chance of having a heart defect called Complete Atrioventricular Canal, well, my daughter was in the 50% that were born with it. She would need to have open heart surgery at around 4 months old. We were just devastated..how can this happen to my beautiful baby girl?

While I was still in the hospital, my sister was home making phone calls, getting all kinds of information about Early Intervention, looking up statistics online and she made the initial call to Stepping Stones for me. I really couldn't pick up the phone at all, I didn't want to talk to anyone, about anything, and I certainly couldn't say the words "my daughter has Down syndrome."

In the weeks that followed, we started with evaluations for Early Intervention, I still couldn't bring myself to call Stepping Stones. By the time Alexis was 7 weeks old, she was in heart failure, and her surgery had to be done now instead of when we planned. When Alexis was 8 weeks old, we were at NYU dressed in scrubs carrying her onto the operating room table. I remember about 15 pairs of eyes just looking at me all of them saying "she'll be ok." Would she?

After six hours of surgery, she was in the PICU at the hospital. She was doing so well, she was already off the respirator. We knew the first 24 hours were critical, after that we figured she was free and clear. We were wrong, really wrong. Long story short, Alexis had a stroke & seizure and needed to go back on the respirator. She had a fever that no one could figure out where it was coming from. My husband and I were told there was a possibility Alexis' heart was infected and she may need a transplant, but because Alexis had Down syndrome, it was unlikely she would be eligible for one. Her prognosis was 'hopeful' she would survive the next 48 hours.

It was at this time when I thought I may lose my daughter that I finally realized Down syndrome was not a big deal after all. I remember making a 'deal' with God, if He let her survive, I would do anything to make sure she would be given every opportunity available to learn and grow to the best of her ability. She made it through those 48 hours. The doctor found out it wasn't her heart that was infected, but a urinary tract infection, and although she suffered many more complications, she fought and survived. After 32 days in intensive care, she came home.

There were so many doctor appointments, medications, and even special formula, but Alexis was alive, and I had a promise to keep. In October 2002, we finally got the approval to start Early Intervention and I made the call to Judy at Stepping Stones. Alexis' first day at Stepping Stones was October 31, 2002, her first Halloween.

It was so cute to see all the children in their costumes, parading around, and yet I cried driving all the way home that day. Maybe it was the reality of the unknown staring me in the face. What did her future really hold? Would she walk, talk, would she have the ability to learn...I didn't know. Only time would tell how she would function. We continued at Stepping Stones twice a week...meeting with the therapists who assured me she'll meet her milestones in her own time. I met with parents of older children, who seemed to take things one day at a time. I realized, we all had our own struggles, but we all worked through them. The other parents seemed so strong, so positive, and so confident. I wanted to be like that. That is what I wanted for the sake of my daughter and our family. My daughter had one MOM, if I didn't fight for her, if I didn't push her, if I didn't make sure she received the best of everything, no one else would. Stepping Stones taught me how to be this strong,

positive, confident person. The therapists had answers to most of my questions. Alexis learned how to walk and to talk...in her own time, but she did it.

We stayed in Stepping Stones for 3 years. For the three years we attended, there were mostly girls in her group and only one boy. All different families coming together in one place because of a very special bond, our children who happened to be born with Down syndrome. We still see each other at birthday parties, send Christmas cards to each other, I made life long friends at Stepping Stones. I always say *I* needed Stepping Stones just as much as Alexis did.

Alexis is six years old now. She is in 1st grade at a school in our district, she is in a Language Learning Disabled class for part of the day, and Mainstreamed for all her specials, lunch, recess and homeroom. She is doing better than most would have ever expected. She is writing her name, adding, she even has Spelling tests, although she needs a lot of help with it, we'll continue to work on it. She wasn't supposed to be in that school or that program, but I fought to send her there, and I'm proud to say I won because I knew it would be the best placement for Alexis, it is her Least Restrictive Environment. I'm her MOM, the only one she'll ever have and if I don't fight for her best interest, no one will. That is my mantra, I thank Stepping Stones for giving me the confidence I needed, for the strength to fight for what I believe in, for teaching me that Awareness = Acceptance, and if I want society to accept my daughter for who she is, it is my job to make them aware of her abilities. There is no such thing as a 'perfect' little world, and once you realize that, the world can be a wonderful place to live.

My daughter has Down syndrome. I can say it now, but it doesn't define her. I focus on her abilities, not her disabilities. That is how I want others to see Alexis. She is funny, beautiful, caring, helpful, compassionate, and she's a fighter. She's made it through the rain and seen the sun...and her life is absolutely my Rainbow.

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