

## Margot's Story

I got pregnant with Margot when I was 36 years old. We were thrilled. We had a healthy, beautiful, "perfect" baby boy named Charlie born a year and a half prior, in March of 1999, and life was sailing along just as planned. My husband, son, dog, cat, and I had moved to the suburbs of New Jersey from Manhattan, and knew we were very lucky to live the life we did. On a beautiful day in mid-October, awaiting the results of the amniocentesis, I received a call directly from my obstetrician with a message: "Call me as soon as possible". Now, obstetricians don't generally call patients to give them good news. I could glean from his tone that things were not right. As soon as I heard his message I tried to call him back, but had to leave a message with the receptionist. I literally felt sick, was shaking uncontrollably, and had a sinking feeling in the pit of my stomach. I called my husband at work and told him that I hadn't heard from the Doc yet, but I knew something was wrong. Blah, blah, blah, the rest of the story you can surely figure out. Our lives would be forever changed with Dr. Cooperman's words: Your baby, your daughter, in your belly, has Down syndrome. God bless him, he was very encouraging. He knew several children with DS that had been developing just fine and were sweet and wonderful, thank you very much. He did go on to say that about 90 % of people who receive the diagnosis of DS decide to terminate. This shocked and saddened us. Honestly, I was stunned and did not know what to think. My mother couldn't help either, and for the only time in her life was at a loss for words or an opinion. Despite our strong Catholic faith, it was still an unfeasible and unthinkable decision.

My husband came home from work and stumbled up the driveway, crying. We just held each other, crying, and didn't say anything. Thankfully, Charlie was too young to be concerned about anything other than his Woody figure from Toy Story. The following hours were a blur, but it didn't take us more than a quick conversation to come to our obvious conclusion. This is our baby, and we will prepare and educate ourselves about Down syndrome until we were blue in the face. We would welcome her with all the joy and love that accompanies the birth of a "typical" baby, and we would only expect that kind of anticipation and response from our family and friends. To that effect, we composed a mass email a couple of days later and sent it around to everyone we knew. In it, it explained what we knew about our daughter, her condition, and how we had chosen this path for us and for her. We felt it was important that people knew where we were coming from, and wanted them to be able to react accordingly. Amazingly, over the course of the next weeks, we were bombarded with mostly happy and encouraging and compassionate responses to the news. Of course there were a pocket of loved ones that couldn't figure out why or how we would make this decision. Why *have* an amniocentesis? What kind of life would this be for you and for Charlie? Why would you want to care for a child your entire lives that is basically always going to be just that, a child? We tried not to take things to heart, but from certain people, words did sting. It took some time for us to realize that people were concerned, and uninformed, and scared. Before you are confronted with a life decision of this magnitude, you would have no idea how to handle it. When it is thrust upon you, you do only what you are capable of. As a result, I cannot judge any woman's decision to terminate a pregnancy, as much as it was not our choice. Thank God for choice!

That first, blurry, weepy, strangely joyous day, was the day I went to our big yellow pages and literally looked up Down syndrome. There is where we found Stepping Stones Parent-to-Parent, Judy Bellina, and Lee Bergman. We were so blessed to have them to connect to right away. In talking to both of them I felt grounded and encouraged and knew that if nothing else, I would be able to take solace in the fact that I would have a family that understood. Lee told me to have high expectations, and that phrase carried me through the pregnancy. I distinctly remember buying books about Down syndrome, seeing the faces and studying them intently. Maybe our daughter would be pretty like this one? Maybe she would wear glasses like this one? Maybe she would have a heart condition like this one (which she did)? Maybe she would have gorgeous blond, model-like hair, like this one? Maybe she would have more siblings surrounding her and adoring her, like this one? Maybe we would gain a new appreciation for life and "imperfection" and the true meaning of family and acceptance and unconditional love?

Margot was born 2 ½ weeks early at St. Barnabas Hospital in Livingston, on January 30<sup>th</sup>, 2001. It was a joyous day. Rather than carry on with endless anecdotes and heartwarming stories and revelatory moments, I must say that Stepping Stones truly carried us through the first 7+ years of Margot's life, not including the months in utero! We are forever grateful to have had their expertise, their compassion, their references, their vast knowledge, their staff, their connections, and their kindnesses throughout the years. Although we have moved on to a different school, they are always in our hearts and minds. Margot still talks regularly about the people there and when we drive by on our way to her ophthalmologist, she excitedly points out the Stepping Stones building! Clearly, they have impacted her as much if not more than they have impacted us. It is hard for me to even think about those years in the not-too-distant past without tearing up. I was grateful to make it through the Graduation/Stepping Out ceremony last June without dropping the video camera.

To anyone reading this who has just had baby with Down syndrome, or has just received the diagnosis of having a baby with Down syndrome, know that you now have a place in Stepping Stones that will be your rock and your guiding star for years to come. You are so lucky! Congratulations!

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