

## **My Story**

### **Deborah Arcoleo**

I had a picture-perfect pregnancy with my second child. Despite the fact that I was 36 I had no concerns; I was active and healthy. I had had several Level 2 ultrasounds, but no amniocentesis - I was concerned with the risks of the procedure and couldn't imagine that I would change the course of my pregnancy in any way depending on the outcome. I am, by nature, a non-interventionist when it comes to all things medical.

When Emily was born, she was slightly blue and they laid her on my chest and had me put an oxygen wand up by her nose. As I looked into her face for the first time, I thought I detected an "odd" look, but then again, many newborns aren't the most beautiful in their first few minutes. Then the midwife gently told me that they wanted to take Emily to the NICU to make sure her oxygenation was OK and that they also suspected she might have Down syndrome.

I can vividly recall, almost 13 years later, what went through my mind. No fairy tale wedding, no prom, no college . . . all the things I was going to miss out on. Would I even be able to continue in my career? Would I have to become a full-time caregiver? Is she OK physically? Is she in any danger?

I was devastated. Within the hour, Emily was diagnosed with pulmonary hypertension and a heart defect, requiring her to remain in the NICU for the next two weeks. During that time, I was so concerned about her health and getting her home safely that I didn't give Down syndrome a thought. We got some brochures from the hospital's social worker and began to do some internet research. And we reached out to friends and family to see who we knew who might know a family or two we could talk to. I remembered meeting Chris Singer during a business meeting years before and it was through Chris that I was introduced to Stepping Stones. Emily started her early intervention there at 3 months and remained until she was 6 and ready for kindergarten in our local school district.

I have learned a lot in the intervening 12 1/2 years and I wouldn't trade any of it for a "normal" child. Emily is healthy, happy and a constant source of joy and amusement - everything we could want! And I have made so many wonderful friends among the community of parents with kids with DS, friendships I truly