

Ellie's Story from a Dad's Perspective

Ellie had three older brothers before she came along, they were 12, 10, and 7 years old. As you can imagine, after learning we were having a girl, we were elated. We painted her soon-to-be room pink, and had a bunch of girl's things all picked out. We were eagerly awaiting our little princess; our family was complete. As a father, I had dreams of her first date, high school prom, walking her down the aisle, and more – I am going to have a little girl!

Something was different this time. We were at Ann's doctor, and she said to head over the hospital now. Our baby girl was coming today. After three normal deliveries, I knew something was wrong because the nurses were hovering looking at the vitals. Ellie's heartrate was a concern, and they swept us in for an emergency C-section.

Whoooooosh! I was spinning, and things moved so fast. When I heard Ellie cry, I was grateful – I could breathe again. Then, I noticed something. She had flip-flop toes...you know extra spacing between her big toe and the next one. Also, the back of her neck seemed to have extra skin. Hmmm? I didn't say anything, I just was happy to have our healthy girl.

When the doctor said "Down syndrome," both shoes dropped! This wasn't what I expected, planned for, or frankly what I felt I deserved. Down what?! I knew about it, but didn't know it. We were in denial until the karyotyping came back as trisomy 21. ...Ellie has Down syndrome. That changes everything!

Ellie had open-heart surgery at four-months old. The surgery went very well, but I was a mess. As a man, I wanted control and I didn't have it. I struggled with how to best support my wife during all of this, and in hind-sight could have been a much better husband and father.

Fast forward since May of 2004...

Heart surgery has been the only medical challenge for Ellie. Her Atrioventricular (AV) Canal Defect repair was excellent, she hasn't had any other typical Down syndrome issues.

Ellie is perfect! I wouldn't change a thing; she's more than I deserve, and is God's little angel in our lives. Ellie is a joy to everyone who meets her. She has taught us that God is good all the time, and we are blessed to be parents of a child with Down syndrome.