

# Ellie's Story

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## Our Pregnancy

September 22, 2004: With our 17-month-old son Sam in tow and anxious to get a glimpse of baby number two, we headed to our OB/GYN with excitement. It was time for our routine 20-week ultrasound and we had one main question—girl or boy?

The ultrasound technician was quiet and thorough. She wanted to show our doctor pictures of our baby's heart because she thought the chambers looked asymmetrical. My mind started racing. I recalled that while pregnant with Sam, he had some irregular heart beats which turned out to be nothing. Though this was of some comfort to me, I couldn't help thinking that we might not be so lucky this time.

## The Diagnosis

When our OB came in, I asked, "It may be nothing, right?"

His eyes grew serious as he looked at me. "I'm sorry, but it is something this time."

The doctor thought our baby might have heart disease, but only a fetal echocardiogram would determine the diagnosis. Over the next twelve hours we searched the internet, learning about congenital heart defects. I still hoped it was a mistake. I wondered what I did to cause this, as many parents do when faced with a child's illness.

The next day our fears solidified when we learned our baby had one of the most severe heart defects possible, called Hypoplastic Left Heart Syndrome (HLHS). The disease would make it difficult for Ellie's heart to pump blood throughout her body. We also learned Ellie had a restrictive atrial septum, making her initial recovery from surgery at birth very difficult and carrying a 50% mortality.

We were given three devastating options. We could provide "comfort care" at birth and Ellie would die after a few days, we could abort her, or perform at least three open heart surgeries before the age of two. I kept thinking "these are ALL terrible options." But we had no other choice.

Ultimately, we decided all we could do was find the best surgeon and forge ahead. While searching out hospitals, we learned about an experimental fetal intervention being preformed on unborn babies in Boston for the treatment of HLHS.

## The Fetal Intervention

After talking with the cardiologist at Boston Children's Hospital and learning the risks were minimal, we agreed to the procedure. The team of nine doctors was able to successfully dilate Ellie's aortic valve. Two days later, we left—not knowing how well Ellie's heart would grow but praying that the operation had helped her.

Choosing the fetal intervention gave us hope. This hope was an enormous help for Dan and I through out the rest of the pregnancy. We felt we were doing something proactive to help our baby instead of watching her suffer day after day.

### Ellie's Birthday

For the rest of the pregnancy, we had a monthly fetal echocardiogram. Each time, we saw that the left side of Ellie's heart was slowly growing and starting to pump more effectively. Cautiously optimistic, we awaited her birth at 37 weeks. While concerned about how our 20-month-old son would handle the trip, we decided to head to Boston for the birth because we knew the doctors there were best equipped to help Ellie and her heart. The birth was thrilling and normal at the same time, with all the doctors on hand in case intervention was needed.

After birth, Ellie spent three weeks in the hospital fighting a urinary tract infection and proving that her left ventricle could do its big job of pumping blood out to the entire body. When she was three weeks old, we headed home after no cardiac intervention! We felt like we escaped a bullet or won the lottery. Our baby was doing well and we were told she would thrive and develop. Yet we knew she would be followed closely and was likely to need further treatment in the future.

The impact of the hospital stay has forever left a mark on us. I remember the other children we saw near Ellie's bed side. Some were heading home with "fixed" hearts and annual check-ups. We learned that statistically these children should live a long life. Others had an uncertain future because they were the pioneers in the treatment of their condition.

At about four months, Ellie started to have periods of labored breathing, refusing to eat much of the time. An echocardiogram showed her left heart chamber all balled up and not pumping well. We went back to Boston for open heart surgery that we hoped would help. The surgeon, Dr. Del Nido, shaved out the scar tissue in Ellie's left ventricle to help it pump more efficiently. The operation worked and as her heart healed over the next year, she continued to show improvement.

Ellie learned to sit up, crawl, then walk—milestones expected by parents of healthy children that we could not take for granted with our little girl. As Ellie grew, a delightful personality emerged. She was energetic, liked to be tickled, stand on her head looking through her legs saying, "Hi," dress up in hats and glasses and laugh hysterically. Ellie was enamored by her big brother, Sam, who gave her little attention until she started walking and then became her best buddy. Once she learned to talk Ellie's vocabulary exploded. The gusto with which she spoke still brings me happiness.

### Our Lives Changed in an Instant

On a warm July night in 2006, Dan and I had a heart-to-heart talk outside after the kids were in bed. We had been contemplating having another child, both admitting we worried that if Ellie's heart defect would some day take her, we didn't want Sam to be by himself. That night, I realized admitting Ellie might not outlive us was not something we had ever wanted to say out-loud. But as we recalled the events of the past two years, we were surprised at how much we

loved our lives with Sam and Ellie. We decided we were ready for a third and last child—(and welcomed Ellie’s little brother, Joey, in June 2007!)

The next morning, Dan took the kids to his parents’ farm to give me a break. Before they left, Ellie gave me an unusually long tummy-to-tummy hug, while I was lying on the couch. I sat really still, thinking, “I am going to enjoy this for as long as I can.” She looked up at me with knowing eyes, almost as though she knew our time together might not last and wanted to say, “Mom... I love you. It’s OK.”

At around 2:45 p.m., I got a call from Dan, “Brita, Ellie is gone.”

“What... what does that mean? Tell me you’re kidding, right? This can’t be true. Don’t say that.”

“I’m holding my daughter in my arms...she is gone.”

I rushed to the farm but was too late; Ellie had been killed instantly by a truck in a back-over accident. After all we had been through, I could not believe this was happening; but it was, and there was nothing anyone could do about it. Though I had once believed I might be ready for it, I know now that nothing can really prepare you for the nightmare of a child’s death.

### Ellie’s Legacy

Two years have passed, and in those two years Ellie’s father and I have thought long and hard about how best to honor her memory and all that she meant to us. We have long had a dream of raising awareness about the incidence of congenital heart defects and the life-saving fetal intervention treatments available for HLHS. We share this dream with friends Jessica and Erik Lindberg, whom we met through Children’s Hospital in Boston. They are parents of Ethan, who continues to pave the way for other children born with this condition.

Ellie’s story, so precious to our hearts, is also traumatic. Yet we hope you will remember Ellie by the way she lived, fighting the odds as a pioneer in the treatment of congenital heart defects. Amazingly, there are many more kids out there just like her and we hope that our story inspires you to help. We can make a real difference in the lives of many families. The financial strain of caring for a chronically ill child can be enormous and, at the very least, difficult. Our dream is to help these families carry that burden.

People say kids are resilient, and the children we saw in Boston are a testament to that fact. They will play with IVs in their feet, pulling their feeding tubes and oxygen tanks along with them as they head to the play room. It is to children like these—and to Ellie—that our work, and this web site, is dedicated.

We love you Ellie-Belly!

Mama, Daddy, “Brober” Sam, and baby Joey