

Mom Lauren Flournoy and her daughter Lillian

My *Miracle* Baby

After Helping Her Newborn Daughter Fight for Her Life, Local Mom Lauren Flournoy Lives Every Day with Hope

Written by Lauren Flournoy
Select Photography by Marisa Hugonnett

Lillian spent the first weeks of her life in intensive care at Texas Children's Hospital



The Low-Down on Turner Syndrome and CDH

Every pregnant woman I know looks in the mirror hoping to find that bump, feeling excited and ready to show it off. Mine came a little late and it grew very, very slowly. I thought this was okay, and my doctor expressed no concern. My 3D ultrasounds were beautiful, and from what I saw, she was an angel! When I reached 35 weeks, I was anxious to get another ultrasound. It had been 10 weeks since my last ultrasound. Had she grown? Had I? The image showed that she was only 4 pounds, but she had a large head and appeared ready to make her way into the world. As for me, my blood pressure was high, so I was put on hospital bed rest that day until I delivered at 37 weeks.

Uncertain Beginnings

My daughter Lillian came into the world on March 22, 2010 and I couldn't wait to see her face and bond with her. I heard a squeak from her tiny body, and I watched the nurses moving around the room. I couldn't hear what was going on, but one thing I did know - it was taking far too long, and I saw the nurse walk out of the room with my daughter.

I was in shock and was being moved from bed to bed. My only thoughts were that my baby may be leaving me and I needed to be with her. Doctors were telling me what they "thought" might be wrong. I was told I would be able to see her for five minutes and then she would be transferred to Texas Children's Hospital. She was rolled in to my room in an incubator, and I couldn't reach her or see what she looked like. Then she was gone with my mom to Texas Children's.

I was brought to my room at 2 a.m. and that's where I learned that she had a diaphragmatic hernia and that she could not breathe on her own. She qualified for a heart-lung bypass, but could only stay on it for seven to 10 days and there was only a 50/50 chance of it helping her.

My Fragile Fighter

My four-day stay in the hospital is mostly a blur. I had a blood transfusion and CAT scans and saw visitors who I can't remember because my mind was preoccupied with thoughts of Lillian. I had yet to hold the baby I had dreamed of and carried. My three sisters, mom, and best friend brought me pictures and videos of Lillian. It was those images that gave me hope, because they told me she was a fighter.

I first met Lillian when she was 4 days old. I was weak and seeing her was a challenge, because I had to stand on two step stools, but I was determined. When I climbed up and saw her for the first time, I just wanted to hold her. She was so beautiful, yet so lifeless that I was frightened for her.



Lillian was diagnosed with a congenital diaphragmatic hernia and Turner syndrome

What is Turner syndrome?

Turner syndrome is a genetic disorder that affects one in every 2,000 baby girls. Instead of having a pair of sex chromosomes, they are missing all or part of an X chromosome. The condition can cause girls to not mature sexually as they grow into adults.

What are the symptoms?

An estimated one-third suffer some sort of cardiac abnormality, 30% have kidney abnormalities, many may have a low level of thyroid hormone, and many may suffer from ear infections or hearing loss. Girls and women with TS are also at higher risk for developing celiac disease. Short stature and premature ovarian failure are also common symptoms. Girls may need estrogen replacement therapy for breast development, menstruation, and proper bone development.

What is CDH?

Congenital diaphragmatic hernias (CDH) occur in one of every 2,500 babies. CDH occurs when a child's abdominal organs move into the chest cavity through a hole in the diaphragm or because the diaphragm failed to form.

What are the symptoms?

The condition inhibits lung growth, so there is usually difficulty breathing, fast breathing, a fast heart rate, and a blue coloring of the skin. Babies may exhibit abnormal chest development, with one side being larger than the other, and an abdomen that appears caved in. (These symptoms are most evident when a baby suffers from a Bochdalek hernia, involving an opening on the back side of the diaphragm.) When the newborn suffers from a Morgagni hernia, or one where there is an opening in the front of the diaphragm, they may or may not show any symptoms.

Each case varies, so it's best to consult your child's pediatrician if your baby exhibits any of the above symptoms.

Resources: turnersyndrome.org, childrenshospital.org, and cdhsupport.org.

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Lauren held her daughter Lillian for the first time when she was 5 weeks old

Over and over, the surgeon kept stressing to me, "She may not live, if she cannot breath on her own." I knew that I needed to be strong and positive for my daughter.

– Lauren Flournoy

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With love and support from her mom, family, and doctors, Lillian is now celebrating her first birthday in March

As my sister and I stood beside my paralyzed baby, I remember her saying to me, "Talk to her, she'll recognize your voice." But what would I say? It was a feeling I could never put into words. I was utterly lost. After touching her hands and feet for an hour, the doctors began to arrive. Each one introduced himself or herself to me and then explained the role they had in saving my daughter's life.

Staying Strong for Lillian

The information the doctors began sharing with me about Lillian was overwhelming. They told me the geneticists had visited and they were waiting on the results of the testing, which were expected to be back in a week. She was missing ribs and her corpus callosum, they suspected her left lung wasn't developed, and her right lung didn't work, because her heart was on the right side of her chest. As they spoke, I looked at my sisters, who were crying. They reached for my hand. I think a few tears may have dropped, but not many from my eyes.

The genetic results came the next day, and Lillian was diagnosed with Turner syndrome, along with agenesis of the corpus callosum and a congenital diaphragmatic hernia. My sister went home and printed page after page of information about every diagnosis for me. This is what I studied as I sat day after day next to my lifeless daughter.

On day six, Lillian's blood was still not coagulating. I had first priority at the Ronald McDonald House, because of her severe condition. Thank God I chose to stay that night. Lillian had emergency surgery to take her off of the heart-lung bypass machine. Over and over, the surgeon kept stressing to me, "She may not live, if she cannot breath on her own." I knew that I needed to be strong and positive for my daughter.

God Works Miracles

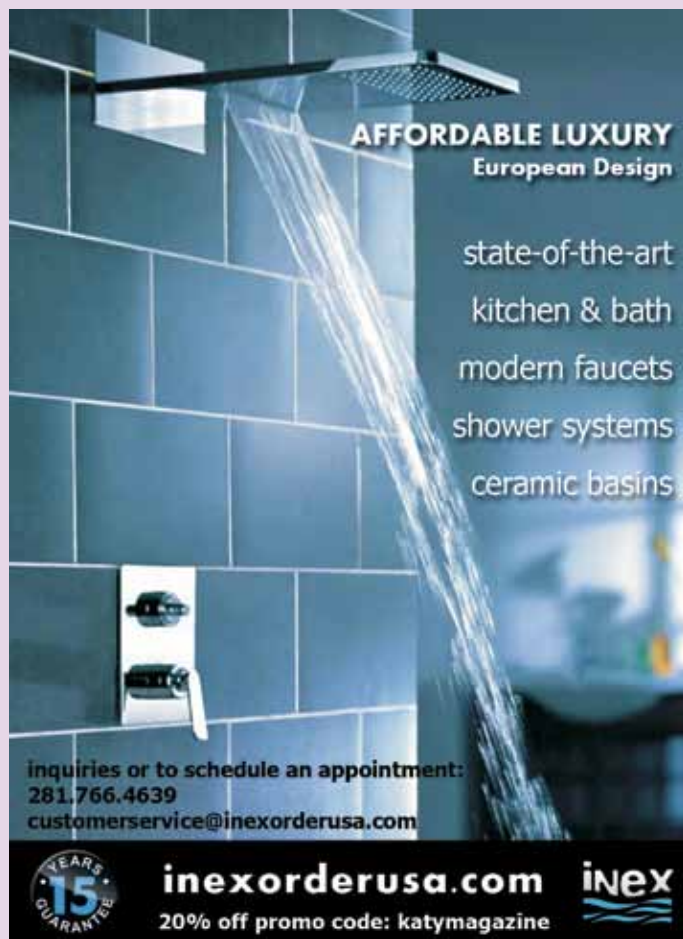
I said my goodbyes, kissed her hand, kissed my fingers, and placed them on her face. I left to rest and wait at Ronald McDonald House with my mom. The hours rolled by slowly. Finally, I called the nurse's station to check on Lillian. I rushed to her room, and there she was – without a huge contraption attached to her. God works miracles! When I actually kissed her for the first time, I had complete faith that she would continue to fight.

When Lillian was 3 weeks old, she had surgery to repair her diaphragmatic hernia. She had her first taste of breast milk when she was a month old through a tube down her throat. I held my baby for the first time when she was 5 weeks old, and she was released to come home at 8 weeks with a nasal gastric tube to feed her and oxygen. After one month at home, she was released from the oxygen.

On the Path to a Healthy Future

Lillian is now almost a year old. She eats baby food with her mouth, but still drinks milk through her nasal gastric tube. We go to therapy twice a week to work on her sucking and motor skills. Our weeks are full of appointments at the medical center and they will continue until she is 18. There is a strange comfort in driving to the hospital and knowing that I'll see the nurses and doctors who saved her life and cheered her on. In 18 years, it will be a bittersweet goodbye. **KM**

EDITOR'S NOTE: Katy Magazine would like to thank Lauren and Lillian for sharing their story of hope and strength. Visit laurenandlillian.blogspot.com.

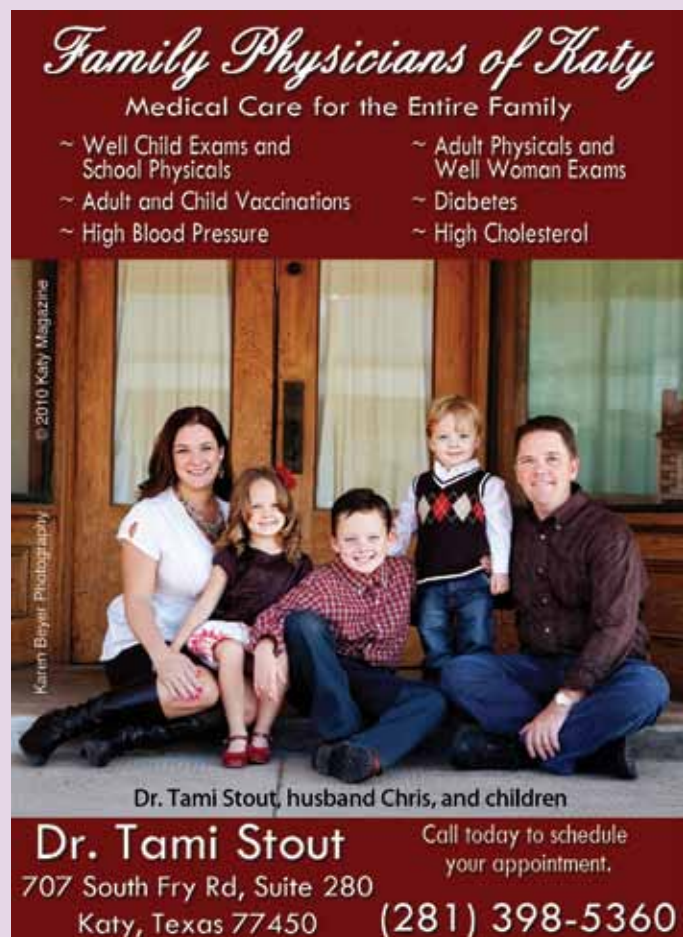


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