

After surgery, Ellie had to wear a corrective helmet for several months



# My Child's Tragic Diagnosis

A Sugar Land Mom Shares Her Story

Written by Ingrid Karazincir Photos by Joey Thomas

**O**n February 5, 2008, my husband and I welcomed our new baby girl, Elise (Ellie) Cassandra into the world. She weighed in at six and a half pounds, with ample curly brown hair and dark eyes. She became a blessed joy in our lives and a best friend to her sister, Emily.

## A Mother's Intuition

Ellie was always a good sleeper and eater, rarely crying or fussing about anything. After a couple of months, I noticed something different about her. Her head was not shaped like other babies' heads. It was very narrow and came out too far in the forehead and back of the head, like a football. With her curly locks and big smiles, not even her pediatrician, Dr. Raymond Kahn, saw the problem at first. When she was four months old, I persisted and Dr. Kahn ordered an x-ray. With that evidence, we were then directed to a pediatric plastic surgeon, Dr. John Teichgraeber MD, in the Houston Medical Center, who then ordered an MRI.

## The Diagnosis

We were devastated to find out she had a condition called Craniosynostosis, specifically, Scaphocephaly. This is when the head is shaped like a football and involves premature closing of the sutures, or soft spots, on the baby's head. This would lead to continued growth in this shape and most likely psychological problems and learning disabilities. This condition is more common with babies who were born prematurely, which she was, by about four weeks. The only solution was surgery.

## Preparing for Surgery

We made an appointment for the end of August for the surgery. We were as prepared as parents could be for their little baby to go into a very serious procedure. We did research, took time off, and flew my parents in to help out with Emily while we would be back and forth from the hospital. When the day came to bring our little baby in, my heart was in my throat. We sat in a small room with her,

where we dressed her in a miniature hospital gown and let her crawl around on the toddler-sized bed with rails. Of all days, she decided to make things even more difficult for us. She grabbed the rails and pulled herself to a standing position for the first time. I couldn't hold back the tears. She looked at us with such pride and excitement, not knowing what was to come. Soon the nurses came and took her from my arms to prepare her for surgery. She went to them so eagerly, smiling and cooing. It broke my heart.

We wrung our hands and paced the waiting room for hours, when finally the doctor came out and said all went well. We went in to see her, and that may have been the hardest moment. Her head was wrapped thickly in gauze, still sleeping in her little hospital bed. We sat there for only a few minutes when her eyes slowly opened, blood shot and hazy. She began crying immediately when she saw us. We tried to touch her, hold her little hand, but she had so many tubes in her and blankets wrapping her, it was hard to give her the comfort she needed. There was no way to explain to her what was going on. I felt so guilty, like I betrayed my little girl by letting them do this to her. Only we knew it was in her best interest, which was no comfort to anyone at that time.

### Sleepless Nights

Soon we got to her room in the NICU and stayed the first night there. My husband took the night shifts and I stayed as much as I could during the day. We knew Emily was sure to be scared and confused at only three years old, so I tried to be there for her as well. Neither of us slept for the five days Ellie stayed in the hospital. I



Ellie suffered from a condition that caused a premature closing of her soft spot

always made sure the nurses were on top of the medications, as she would start crying so much when she was in pain. After two days, the doctor removed the gauze, and she was much happier to be able to move and roll over more easily.



The Karazincir's are grateful for their doctors and the support received from family and friends



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Big sister Emily was only three when Ellie had her surgery



### CRANIOSYNOSTOSIS WARNING SIGNS

These signs may not be noticeable at birth, but they will become apparent within the first few months of your baby's life according to MayoClinic.com. Please see your pediatrician if your newborn has these symptoms.

- ~ Unusual head shape
- ~ Abnormal feeling soft spot
- ~ Early disappearance of soft spot
- ~ Slow head growth
- ~ A raised, hard ridge along the head

The scar was not easy to look at, going from ear to ear, and her beautiful curly locks had been shaved across that section. As the swelling drained from her head, her eyes became very swollen, making her look like she'd been in a fight. It was very hard to see our baby like that. When my parents brought Emily to visit and everyone gasped, my father simply said, "Yeah, but you should've seen the other guy!" It definitely helped diffuse the moment.

### The Road to Recovery

After wearing a corrective helmet for several months, she is doing well. Today she is a beautiful, smart, and advanced toddler. She started walking by 10 months old and is very sociable with everyone she meets, though she continues to be very reserved about going to people. I'm sure it will take some time for her to trust again, but she is doing incredibly well and her head is just perfect.

### Follow Your Instincts

For parents who may face the same issue, the best advice I could give is to follow your instincts. Dr. Teichgraeber performs a much less intrusive surgery if this syndrome is caught as early as a month or two. If I had persisted when I first noticed it, the whole situation would have been half the heartbreak. If you notice anything unusual with your little one, be sure to voice your concerns to your doctor right away.

We want to thank the doctors for their work and our families and friends for their ongoing love and support. Now that Ellie is one year old, she is doing better than we could have imagined. **SLM**

*INGRID KARAZINCIR is a Sugar Land area freelance writer and the mother of two beautiful girls, one-year-old Elise and three-year-old Emily.*

If you have a touching story to share with other Sugar Land families, email editor@sugarlandmagazine.com.