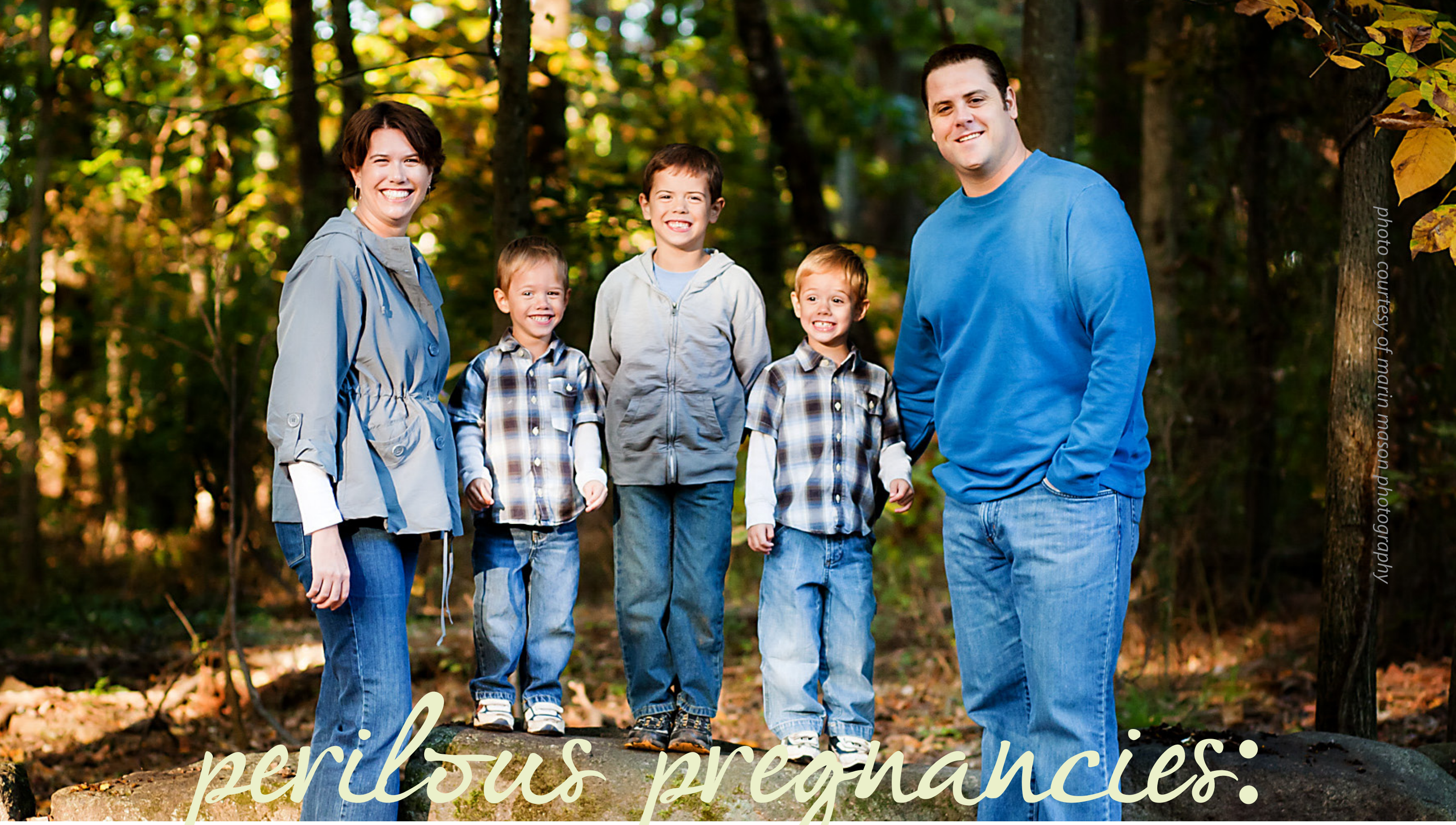

photo courtesy of marin mason photography

perilous pregnancies: three families' journey to hope

by talitha a. mcguinness

Learning of a twin pregnancy brings so much excitement, and especially uncertainty with the journey for the next nine months and beyond, yet it also brings with it its own set of anxiety. Multiple births are at higher risk of a number of things including prematurity, yet no mom expects to learn that her baby has an intrauterine fetal syndrome, some of which are more common amongst multiple birth pregnancies. With literally hundreds of fetal syndromes known within the fetal/maternal realm and being researched today, most still have no known cause, and even more unnerving, are still beyond the mother's control. The only resounding comfort is that the mother does nothing to cause it.

When the Tyrells *(pictured above)* decided to add to their family, mom Jenna had no idea she would see two babies during her 10-week ultrasound. Like many new and expectant moms of twins, she was also quickly introduced to lingo never before heard.

At 16 weeks, there was obvious size discrepancy and fluid levels were different, but not enough to fall within the Twin-to-Twin Transfusion Syndrome (TTTS) category. TTTS is a rare disease that affects twins who share a placenta. The disease affects both babies because of sharing nutrition and blood flow through select vessels across the placenta. While one twin, known as the donor, is in jeopardy from anemia among other issues, the other twin (the recipient), likewise suffers due to the strain with which it is presented in trying to maintain for both babies.

"We were introduced to [Selective] Intrauterine Growth Restriction (SIUGR), something we would deal with throughout the entire pregnancy," said Jenna. "I was offered to terminate Baby B, but it was not something [we] could consider. At the time, surgery wasn't commonly used for SIUGR, but we were ready to go to Florida to see Dr. Quintero, the Specialist that would perform fetal surgery if the fluid levels reached a certain point on each twin."

SIUGR occurs when there is unequal sharing of the placenta. Because this factor may result in poor nourishment of only one of the twins, resulting in subsequent poor overall fetal growth, it is coined "selective".

With the likely help of unofficial bedrest at 20 weeks, the Tyrells never got to the point of requiring fetal surgery. Baby B continued to grow, but was 50% smaller than Baby A for most of the pregnancy.

Jenna saw the Perinatologist at least once a week. "I was on the phone with my family and friends after visits, and my husband was a rock star. If he was as scared as I, he never let me see it."

luke and ethan today

As it turned out, Jenna delivered the boys one day shy of 34 weeks during a scheduled cesarean section, as the survivor rate with IUGR significantly starts to decline after week 34. Luke and Ethan Tyrell were born on July 18, 2007, with nearly one month's stay in the NICU. They both had some gross motor delays that required physical therapy, but were caught up by age 2 and have not needed additional help since. The Tyrells say that life today is completely normal, chaotic and crazy.

If ever diagnosed, Jenna strongly recommends finding someone experiencing the same journey. "I met a woman in Texas through the Fetal Hope Foundation who was dealing with IUGR at the same time as me. We became very close, despite our distance. She was one of the first people I called after each appointment, [as] no one really understands quite like other twin moms do."

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The Carreres learned of their twin pregnancy at an elective 10-week ultrasound. In retrospect, had they waited until a later scan, they more than likely would have lost one or both of their babies due to TTTS.

After their 18 week scan and an answer they did not understand, the doctor said the words 'Twin-to-Twin Transfusion Syndrome' and their lives changed forever.

"He gave very little hope and I was actually the one who brought up laser surgery, as I had read about it in a nursing journal," said mom Elizabeth. "The doctor agreed to a referral, but was not optimistic. We left feeling totally alone and devastated."

adelaide and genevieve at 5 weeks

While more than 800,000 families each year receive the news of a fetal syndrome, the Carreres did their own research and found Dr. Quintero and the Fetal Hope Foundation who were a constant support throughout the entire pregnancy.

Elizabeth said, "We felt strongly that the laser surgery was the only way to cure our babies and give them the best possible outcome. For us, there was really no other choice."

After having intrauterine surgery, Elizabeth spent the summer on bedrest. She had weekly appointments, yet at 23 weeks, there was bad news. Something was wrong with Baby B's heart.

"[Baby B's] right ventricle was basically not working. Our goal was to get them as big as possible for Baby B's anticipated open heart surgery shortly after birth."

The girls were born Adelaide and Genevieve Carrere on September 5, 2007, at 35 weeks.

"The delivery was a STAT c-section and the babies were rushed to the NICU. Adelaide stayed for two weeks without complications, but Genevieve was transferred to the Cardian ICU at St Joseph's Hospital. However, her surgery was delayed because she was too ill to survive the procedure. Her lungs were the biggest problem, so by the time she was able to breathe on her own, her heart started doing better," said Elizabeth.

"We were humbled to see the hand of God in her healing. Our girls just turned 5 and they are happy, healthy and thriving.”

In 2010, the family welcomed a baby boy to the mix. Elizabeth says that the girls know their story well, as it is such a part of who they are as a family.

“The girls have seen the in-utero pictures from my surgery and could point out their tiny body parts at a young age. We have also had the opportunity to introduce Dr. Quintero to our girls on two different occasions and continue to be so grateful for his many gifts.”

the carrere family

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On a different front were Ethan and Angela Stowell, who in 2011, were ecstatic to learn of their first pregnancy. However, at an early scan the Stowells discovered that they were expecting twins, and quite possibly, identical boys.

“Everything looked fine until we went to our anatomy scan and Baby B was found to be smaller. It was not significant enough for intervention, but we were referred to Eastside Fetal Maternal Medicine for further monitoring,” including weekly scans for the next six weeks.

During one of the scans, Baby B was diagnosed with SIUGR. His amniotic levels were lower, but at around the 24 week mark, the levels were evening out. The doctors were optimistic that the boys were healthy and that Angela would make it to 30 weeks before seeing issues with SIUGR.

However, at 25 weeks, conditions worsened. While SIUGR was always present and they never received a diagnosis of TTTS, the tell-tale signs were present during an ultrasound.

Angela said, “The ultrasound showed Baby B as the recipient. His amniotic level had jumped up to 10 cm and his bladder was huge. Baby A had little fluid around him and no bladder showing.”

The plan was to be re-scanned on Monday to see if things had reversed, and where intrauterine surgery might come into play.

“That Sunday I started to feel ‘off’. I wasn’t feeling the babies move as much...I think I knew that something was really wrong,” said Angela.

During Monday’s scan, the sonographer immediately said “I’m sorry, Angela. There are no heartbeats.”

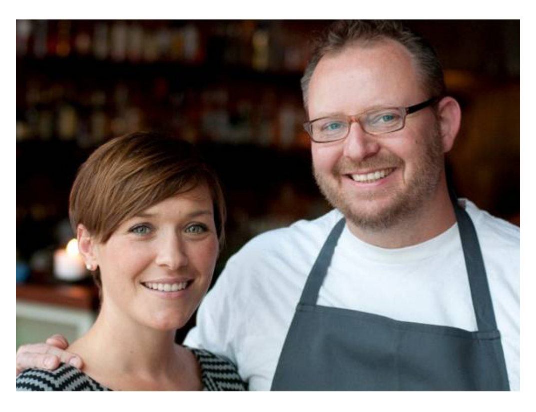
“Everything after that was a blur. We felt like, at 25 weeks, we were so close to the end.”

On July 20, 2011, Angela was induced and delivered two beautiful boys, Nathaniel Hudson and Gabriel Charles. “We spent time holding them, cried a lot, and said goodbye.”

Ethan and Angela received an outpouring of support from among their family, friends and peers within the restaurant business. In the months that followed, they wanted to make sense of their sons’ deaths and to redirect their grief toward something to help others.

Angela said, “We got involved with the Fetal Hope Foundation and drew upon our restaurant peers to put on Eat. Run. Hope., a 5K and Feast that would bring the community together. The race was a huge success and we are looking forward to this event every year as a way to spread awareness about TTTS, and as a way to honor our sons.” ◆

****Note - the Stowells recently delivered a baby boy, Adrian Charles (Charles after his angel brother, Gabriel Charles). Their next child will have the middle name of Hudson - after angel brother, Nathanael Hudson. It will be their way of telling their living children about their brothers.*



angela and ethan

photo courtesy of geoffrey smith

a trusted resource

If you or someone you know is ever in a situation where there is a diagnosis of a fetal syndrome like TTTS, SIUGR, or a number of other syndromes, the Fetal Hope Foundation is a trusted resource for helping families during one of the toughest times in the pregnancy.

Together with a Medical Advisory Board comprised of top fetal physicians around the U.S., Fetal Hope serves as a liaison in getting accurate information on diagnoses, treatment options, prenatal and post-operative care, etc. into the hands of the families who need it most. Through its online repository of fetal syndrome information, along with its unique forums, family matching, bereavement counseling resources, and Travel Grant program, Fetal Hope is poised to help parents through the entire process in saving their babies' lives.

Founded by families who also experienced fetal syndromes, Fetal Hope arms parents with information in becoming the best advocate for their unborn babies. Want to help? November is National Donation Drive month. Donate as little as $10, set up an online recurring donation, or even your own fundraising page to help other families when in need. To learn more, visit www.fetalhope.org.