

Features



Dexter Family Attends TTTS Conference

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By Andrew Cato, ShowMe Times Sports Editor

A pair of Dexter girls attended a very exciting conference over the weekend.

Ashley and Emily Long, the identical twin daughters of Charlie and Amanda Long, are heading into their junior year at DHS. Seventeen years ago, before the twins were born, they were diagnosed with Twin to Twin Transfusion Syndrome (TTTS). Over the weekend, the girls attended The TTTS Foundation Parent and Awareness Conference, held July 27-29 in Cleveland, Ohio.

TTTS is a rare diagnosis, with (on average) less than two cases per 1,000 births according to a 2003 study by the Centers for Disease Control. The disease only affects multiple pregnancies where two or more fetuses share a single placenta. Due to the shared placenta, the identical twin fetuses can develop shared blood vessels; depending on the number, type and direction of the interconnecting blood vessels, blood can be transferred disproportionately from one twin (the “donor”) to the other (the “recipient”).

The transfusion causes the “donor” twin to have decreased blood volume, which stunts the growth of the “donor” fetus. The increased blood flow to the “recipient” twin causes the “recipient” fetus to develop more rapidly, but it can also cause undue strain to the heart, and lead to heart failure.

In early pregnancy (before 26 weeks), TTTS can cause both fetuses to die, or lead to severe disabilities. If TTTS develops after 26 weeks, the babies can usually be

delivered alive and have a greater chance of survival without disability.

The Long family's journey with the disease began in 1995, while Amanda was pregnant with the couple's second and third children. Dr. Julian E. De Lia performed Long's procedure; the Long twins were involved in the fourth procedure involving the anterior placenta.

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"I was diagnosed at 23 weeks," Amanda said. "It was a Wednesday, and on Sunday [Charlie and I] were in Milwaukee, Wis., for surgery. The girls were so severe we didn't have time to think. They made it to 37 weeks; Emily was six pounds, 10 ounces, and Ashley was seven pounds, three ounces. Emily didn't have any [amniotic] fluid around her. Dr. De Lia told me I would have miscarried within the week."

"There are people that think the surgery that we underwent was way too invasive and dangerous. It was dangerous, but so is a heart transplant! We do what we feel is right to save our babies," Amanda added. "When I was told to abort one to save the other, or just have fluid removed to help prolong my pregnancy. I looked straight at the doctor and told her God gave me two babies and I was going to deliver two babies so they better figure out another plan." Amanda pointed out that typically, with severe cases of TTTS, long-term disabilities are prevalent, but that Ashley and Emily emerged unscathed by the disease.

"The girls have no long-term disabilities," she

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noted. "I was told to count on disabilities since it was such a severe case. What they didn't understand is that God had a hand in this. Out of all of the parents I spoke with, my girls were the only ones that never spent time in the NICU. After this weekend and seeing first hand how blessed my girls were, I know it is my duty to help educate!"

The Conference featured speakers from the forefront of the TTTS field, including Dr. De Lia, as well as a fundraising walk through downtown Cleveland. Amanda said the walk was a moving experience, but noted that rectifying the lack of awareness for this disease is a critical step that needs to be taken.

“This walk was so moving. I can't even begin to describe it,” she said. “What bothers me the most is the lack of information out there about TTTS. 17 years after my girls had their surgery, women are still being told there is no hope. Doctors are giving them false information. I would have thought by now our situation would be the "norm". We lose more babies to TTTS than SIDS (Sudden Infant Death Syndrome) each year and people still don't know what [TTTS] is.”

The family returned home from a great weekend in Ohio; Emily, during the trip home, wrote the following poem:

We'll Find A Cure

*Some lose one, some lose all,
No matter what, we fight for all.
We fight for life, we fight for love,
We all have faith in God above.
We've all been there, we've all fought hard,
Some left alone, some left scarred.
We're all one, all connected,
All together, all affected.
We're all here, and we're all sure,
That soon enough, we'll find a cure!*

Photos Above:

Top: Ashley and Emily pose with Dr. Julian De Lia, the doctor that performed a life-saving procedure on the twins before they were born.

Middle: Ashley and Emily show off the signs they carried during the Official TTTS Awareness Walk for the Babies.

Bottom: Survivors and parents finish the Official TTTS Awareness Walk on Sunday. (Photos submitted by Amanda Long)

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