

Twin-to-Twin Transfusion Syndrome: Golf Hope Raises Awareness of this Serious Disorder

By Lori Chandler Pruitt



Twins William Grady and Aiden Harvey are doing well today.

Last year, Casey and Ebru Middlebrooks became very familiar with fetal distress syndromes when their twin boys were born with TTTS, or Twin-to-Twin Transfusion Syndrome.

In TTTS, twins share a common placenta and connecting blood vessels. One baby pumps too much blood to the other baby. The baby who receives too much blood is at risk for heart failure; and the baby who receives too little can suffer from kidney failure, anemia and is often much smaller.

Ebru was diagnosed with TTTS at 18 weeks and was sent to Cincinnati Children's Hospital, where doctors performed life-saving surgery. "Without this surgery, the fatality rate is 96 percent for both fetuses," Casey says. "The survival rate when surgery is performed is 92 percent for one baby and 64 percent for both to survive. The doctors

weren't sure the smaller twin would survive, but by God's grace both are doing well today."

After the surgery came bed rest and a few hospital stays to prevent premature labor, but twins William Grady and Aiden Harvey were delivered at 35 weeks and came home from the hospital about a month later. "After a lot of prayer and good doctor care our boys are now doing great," Casey says. "The experience was very taxing, but our faith was strong and kept us positive. My wife was a rock during the whole event. She did everything possible to ensure our babies stayed safe and alive."

The couple wants to help other families, raise awareness about fetal distress syndromes and show that there is hope and treatments available, so they have partnered with the Fetal Hope Foundation for a non-profit Golf Hope Charity Tournament and Family Fun Day, to be held June 29 at Pine Tree Country Club in Irondale. All proceeds will go to the Fetal Hope Foundation.

This first Golf Hope tournament is a four-person scramble and the cost is \$150 a person. Entry fee includes a goody bag stuffed with great items, lunch, all tournament contests including a chance to win a free car from Benchmark Chrysler Jeep Dodge for a hole-in-one on a predetermined par 3, and other door prizes.

"We're hoping to raise at least \$10,000 for the Fetal Hope

Foundation," Casey says. "Our goal is to help other families and show there is hope and treatments available, and that the Fetal Hope Foundation can offer advice, emotional support and financial assistance to those in need."

The tournament also will include a Family Fun Day, with balloons, face painting, party inflatables, character mascots, activities and more. Many groups, including Birmingham Mothers of Multiples (BAMOM) and the U.S. Army will be on hand to help. Admission to the Family Fun Day is free, but everyone is asked to bring a canned item for the United Way Community Food Bank.

"Families that have undergone fetal distress are especially encouraged to come out and share their stories," Casey says.

Lori Chandler Pruitt is associate editor of Birmingham Parent.

Golf Hope Charity Golf Tournament & Family Fun Day

June 29, 2009

Pine Tree Country Club, Irondale

Golf registration begins 11 a.m.; play begins at 1 p.m.

Registration available online at www.golfhope.com

Family Fun Day begins at noon www.fetalhope.org.