

Tyler's Hope
Pushes for a cure for an Unusual Disease
By Albert Isaac

Tyler Staab's smile is infectious, his left hand held out, two fingers extended in a symbol of victory. A first glance at his photo on the "Tyler's Hope" Web page may not immediately reveal that Tyler, 9, has dystonia, a rare movement disorder that causes his muscles to contract and spasm involuntarily. A closer look reveals the awkward posture and the twisting of his limbs, as opposing muscle groups compete for control.

Up until two years ago, Tyler was by all accounts a normal young boy who enjoyed playing sports and riding his bike. But in February 2005, his parents noticed that he could not bring his arm in without it shaking uncontrollably.

His condition was misdiagnosed for months as the Staabs traveled the country searching for answers.

"It is very common for people with dystonia to go undiagnosed or be misdiagnosed," said Rick Staab, Tyler's father. "We went to Boston, New York, Houston, Wake Forest."

Then during an inpatient visit at Shands at UF, Tyler was introduced to Dr. Michael Okun who recognized the symptoms. A blood test confirmed his suspicions: primary generalized early-onset dystonia.

When the Staabs, who live in Gainesville, realized that there was little research or public awareness of this condition, they decided to do something about it. A year-and-a-half ago, Rick and his wife Michelle created Tyler's Hope for a Dystonia Cure, Inc., a foundation with a mission to advance research for a cure, discover effective treatments and to promote awareness and education about this devastating disorder.

"The reason we started the foundation is that we saw that there is very little awareness," Rick said. "Of all of the money that was going for dystonia, the majority was being spent on Parkinson's and then trickling down to dystonia. So we started looking around to see how we can help. The research shows that this is a curable condition. It's not nerve degenerative. They have come far in the last ten years. They have found the gene. And now they have the blood test. But it's like finding a needle in a haystack."

Rick said that because of the increase in awareness, the number of dystonia cases has now reached more than a half million people.

In June 2006, Tyler underwent an experimental surgical procedure known as deep brain stimulation. In two separate operations, electrodes were implanted in his brain that connect via wire leads to a device that sends electrical pulses to the areas that control his involuntary muscle contractions. While wide-awake, Tyler endured two separate brain surgeries. Tyler was one of the youngest people to have DBS, and there are concerns that

since he is still growing, the electrodes in his brain may have moved and become less effective.

Recently a Tyler's Hope golf benefit was held at the Gainesville Golf and Country Club. Hundreds of people attended the dinner the night before the tournament, a live band performed, and items were auctioned off with all proceeds going to the foundation.

Tyler was the star, stealing every scene, smiling the whole evening. At the end of the long evening, a family friend carried Tyler to the car.

The weekend event brought in \$212,000. A pair of boxing gloves autographed by Mohammad Ali were auctioned off for \$3,500 and the big-ticket item of the evening was eight passes to The Masters Golf Tournament, which included a week's stay in a 6,000-square-foot house.

"The golf tournament is definitely our premier event," Rick said.

To date, Tyler's Hope has brought in half-a-million dollars. Rick hopes to raise \$60 million, and there are plans in the works to build a research facility in conjunction with the McKnight Brain Institute at the University of Florida.

"We have the land already set up," Rick said. "And the state will match 100 percent of the money to build the building. We want to create a think tank with the best doctors in the field."

Since Rick and his wife Michelle began the foundation a year-and-a-half ago, awareness of this disorder has steadily increased. Rick said that when Tyler was diagnosed, the number of Parkinson's patients outnumbered dystonia patients 15 to 1. Within two years, that ratio had changed to 5 to 1.

"It all goes toward research for a cure," Rick said. "The awareness comes from the events and the news coverage."

To that end the Staabs have worked tirelessly promoting their cause. The Orange County Choppers, a company that designs custom motorcycles, may be helping the cause.

"They said they are going to do a chopper for us, a Tyler's Hope Gator chopper," Rick said. "And then what we are trying to work out is a way to get with University Athletic Association to raffle it off. Then we are hoping to give it away at a future Gator Growl."

In conjunction with the foundation, the Tyler's Hope Web page offers links to information about dystonia, news articles, and a diary of Tyler's trials and triumphs.

As public awareness increases, more people with dystonia contact the Staab family. Physicians tell Rick when his diary needs updating, so that they may follow Tyler's progress.

“We’ve probably met 50 other people in that same boat,” Rick said. “A lot of them have had that surgery, but not all of them.”

One woman who had the surgery is Suzie Sui Butt of Alachua, who was diagnosed with the disease at age 11. Prior to Tyler’s surgery, she met with the family and provided support and encouragement. She showed the family a pre-surgical video that revealed the now-active woman confined to a wheelchair.

Dystonia is hereditary and the Staabs have two other children. But not everyone who has the gene will get the disorder.

“Something environmental triggers this,” Rick said. “We have two younger kids with a fifty-fifty chance of getting the gene and a 30 percent chance of getting dystonia.”

At this point in time, the Staabs have no plans to have their other children tested.

“If there is a reason to test for it we will, but I think it would just worry them more,” Rick said.

For now, the family stays busy with work, caring for Tyler and promoting the cause.

“I think our biggest thing is that, in a year-and-a-half of having the foundation, the support is there, people get behind it,” Rick said. “They realize it is a curable disorder. §

For additional information visit Tyler’s Hope at: <http://tylershope.org/>

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