

## **DOING AS MUCH AS A MOM CAN**

### **LOCAL MOM'S BIKE RIDE KEEPS RARE DISEASE RESEARCH MOVING AHEAD**

*“Life is like riding a bicycle. To keep your balance, you must keep moving forward.” Albert Einstein*

**May 7, 2016 Cumming, GA-** Candy Stacks does not claim to be Einstein, but this mother of two from Cumming, Georgia knows what it takes to keep moving forward however many hurdles life puts in your way.

On Sunday, May 15<sup>th</sup> Candy will join a group of roughly 100 men, women and children at a cycling event called rideATAXIA to raise awareness and funding for a rare disease called Friedreich's Ataxia (FA). FA is a devastating neurodegenerative disease for which there is currently no treatment or cure. Candy and her husband, Jason, have two children – both diagnosed with FA.

Candy who was instrumental in bringing rideATAXIA to Atlanta this year hopes that the event will offer local FA families the support and camaraderie she found at a rideATAXIA in Philadelphia shortly after her daughter, Hannah, was diagnosed seven years ago.

At the Philly event Candy met an FA patient named Kyle Bryant. In 2007 Kyle, age 34, picked himself out of a post-diagnosis depression by riding his bike from San Diego to Memphis, Tennessee – an unlikely task for someone with compromised muscles, coordination and energy. Kyle completed that ride in 59 days alongside his dad, his mother driving a support RV behind them. With that journey and many others since Kyle and his parents sent a message to FA families everywhere that together the improbable is possible.

Candy Stacks got that message loud and clear.

The Stacks' daughter Hannah was diagnosed at the age of six. The disease progressed rapidly. With the help of an aide who takes notes and helps Hannah navigate her wheelchair around the building, Hannah is a star student at Liberty Middle School. “She's very smart – and takes all advanced classes,” Candy said with pride.

While FA is a genetic disease and siblings have a 25% chance of sharing the diagnosis, the Stacks held off getting their younger son, Austin, tested.

“With no cure and no treatment, we decided to wait until we saw any signs,” Candy explained.

Those signs came around Austin's fifth birthday when his parents noticed marked unsteadiness on his feet. The progression of the disease has been slower than it was with his sister. “He's clumsy,” Candy says, but he's still very active.” Austin participates in sports. He has bruises from his many falls, but he always gets back up. Like moms everywhere, bumps and bruises aside, Candy just wants to see her son run around as far and as long as he can.

When asked if she has been training for the Atlanta Bike Race, Candy is quick to point out that rideATAXIA is in fact - not a 'race.' The scenic ride offers distances for all abilities with an 8 mile trail ride and 25 and 50 mile road routes followed by lunch catered by Outback Steakhouse. Candy says, "More than anything it is a gathering of people affected directly or indirectly by this disease— people who want to do something, anything, to encourage and to remind their kids, their friends, their spouse, themselves, that even when doctors tell you there is nothing to be done – you can still do something."

So next Saturday the Stacks family: Candy and Hannah, Jason and Austin will get on their bikes and start pedaling. "I don't know how far Hannah will go on her trike," said Candy, her voice trailing off. "But we'll have her do as much as she can."

*While there is no cure for Friedreich's Ataxia, hope is on the horizon with significant research and clinical drug trials currently taking place. For those living with FA, however, time is of the essence to at least find a treatment to slow the progression of this disease. rideATAXIA Atlanta benefits the nonprofit organization- the Friedreich's Ataxia Research Alliance (FARA). Your support can make this possible. To participate in rideATAXIA Atlanta or to lend your support please visit [rideataxia.org/atlanta](http://rideataxia.org/atlanta)*

#### **About Friedreich's Ataxia Research Alliance**

The Friedreich's Ataxia Research Alliance (FARA) is a national, public, 501©(3), non-profit, tax-exempt organization dedicated to curing Friedreich's ataxia (FA) through research. FARA grants and activities provide support for basic and translational FA research, pharmaceutical/ biotech drug development, clinical trials, and scientific conferences. FARA also serves as a catalyst, between the public and scientific community, to create worldwide exchanges of information that drive medical advances. For more information about FARA, visit them online at [www.curefa.org](http://www.curefa.org).