

# Kyle's Story



FOR THE FIRST HALF OF MY LIFE I HAD NO IDEA THAT I HAD FRIEDREICH'S ATAXIA. I PLAYED SPORTS AND CARRIED ON JUST LIKE OTHER KIDS. WHEN I WAS 13, WATCHING ME PLAY BASEBALL, MY DAD NOTICED THAT SOMETHING WAS WRONG. IN THE BEGINNING, MY FAMILY SIMPLY CALLED IT CLUMSINESS, BUT AS MY COORDINATION AND MUSCLE CONTROL CONTINUED TO DETERIORATE, WE STARTED LOOKING FOR ANSWERS.

NOT MANY PEOPLE KNOW ABOUT ATAXIA. VERY FEW DOCTORS HAVE EVEN HEARD OF IT. IN MY CASE, IT TOOK MORE THAN A YEAR TO FINALLY FIND SOMEONE WHO COULD GIVE MY CONDITION A NAME. FINDING A DIAGNOSIS IS DIFFICULT FOR MANY PEOPLE SUFFERING FROM THIS DISEASE. AND, AS OF TODAY, THERE IS NO TREATMENT. THIS IS WHY I WANT TO RAISE AWARENESS AND FUNDS FOR RESEARCH.

www.ridedataxia.org



National Ataxia Foundation



In association with:



A ride to educate, enable and empower

ridedataxia II  
MARCH 15-27, 2008  
SACRAMENTO  
TO LAS VEGAS





## Success Story

Last year, Kyle and his recumbent tricycle a.k.a. "the trike" were joined by his dad Mike, his Uncle Steve, fellow Ataxian David, his elementary school friend Andy and other dedicated supporters for the 2,400 mile ride from San Diego to Memphis to raise awareness and research funds for Friedreich's Ataxia. The trip was a HUGE success! Despite knee injuries, sand storms, and barefoot riding through the snow (ok, just kidding on that one), and other challenges, the team visited FA researchers and patient families along the way, and made it to Memphis on time and in good health.

The team raised more than \$40,000 and even more exciting was the uniting of the National Ataxia Foundation (NAF) and the Friedreich's Ataxia Research Alliance (FARA) for the first time ever. Both of these internationally-reaching organizations contributed matching funds creating the \$100,000 Kyle Bryant Translational Research Award. By June 2007, the grant was awarded to Dr. Nuri Gueven at Queensland Institute of Medical Research in Australia for promising Ataxia research.

## Join Our Team

The Ride Ataxia cycling team will be riding 620 miles from Sacramento to Las Vegas starting March 15 and ending on March 27. We'll average about 50 miles a day. The ride will be fully supported with vehicles, food, and accommodations. Check out our website and blog for more details about the route and itinerary. Here are the basics:

- You can join the Ride Ataxia cycling team for all or part of the ride (limit 100 riders).
- Each cyclist is required to raise at least \$125 per day of participation. Riders are, of course, asked to further support reaching the team's \$50,000 goal as much as possible.

For our awareness and fund-raising efforts, we welcome monetary contributions, media contacts, and appropriate gear, food, drink, first aid materials and accommodations for our ride. Thanks in advance for joining the Ride Ataxia support team!

## What is Friedreich's Ataxia?

Friedreich's Ataxia (FA) is a rare, genetic, neurodegenerative, multi-system, life-shortening disorder. About 1 in 50,000 people in the United States have Friedreich's Ataxia. Onset of symptoms is usually between the ages of 5 and 15, sometimes even earlier and sometimes significantly later. Organizations like NAF and FARA are supporting research that will improve the quality and length of life for those diagnosed with Friedreich's Ataxia that will lead to treatments that eliminate symptoms such as:

- Muscle weakness and loss of coordination in the arms and legs
- Vision impairment, hearing loss, and slurred speech
- Aggressive scoliosis (curvature of the spine)
- Diabetes mellitus or carbohydrate intolerance
- A serious heart condition (enlarged heart — hypertrophic cardiomyopathy)

These symptoms reflect the death of cells in certain parts of the nervous system. The mental capabilities of people coping with Friedreich's Ataxia, however, remain completely intact. The course of the disorder is progressive for most. Loss of muscle strength and control leads to motor incapacitation and the full-time use of a wheelchair usually by the late teens or early twenties. Many require surgery for their scoliosis. There are currently no treatments or cures.

Recently there have been advancements in Ataxia research that may lead to a treatment or cure very soon. We are doing our part to wipe out this disorder by raising awareness and the funds necessary to make a cure a reality.



## Donate!

TO DONATE PLEASE VISIT [WWW.RIDEATAXIA.ORG](http://WWW.RIDEATAXIA.ORG) OR SEND A CHECK MADE OUT TO "FARA" OR "NAF" WITH "KYLE BRYANT - RIDE ATAXIA" WRITTEN IN THE MEMO LINE. CHECKS SHOULD BE SENT TO:

**Ride Ataxia II**  
**P.O. Box 277466**  
**Sacramento, CA 95827**