

Kyle Bryant on his recumbent tricycle on the American River Parkway, where he is training for June's Race Across America

cause & effect



The Ride of His Life

A local man with a rare neuromuscular disease embarks on a bike competition across the U.S. as he races against time to help find a cure

by **Kyle Bryant**
as told to
Elyssa Lee

I WAS ALWAYS A REALLY ACTIVE KID. For as long as I can remember, I played sports—basketball, baseball and football. My family went camping and hiking. We lived in Lake of the Pines, a subdivision near Auburn that surrounds a lake, and my parents had a boat when I was growing up, so we used to always go out and go water skiing and kneeboarding. I distinctly remember wanting to be a professional kneeboarder. We used to go to Marine World and they'd have those shows where the [performers] do back flips and stuff on the water. I wanted to be one of those guys. In high school I was on the ski team. I was also on the golf team. I absolutely loved playing golf.

Then when I was about 16—I'm 28 now—I was playing baseball, and my dad, who coached my baseball teams, noticed that my skills were going downhill. I mean, I guess we all noticed, but he pointed it out. My throws started going off target and I was unable to run for the fly ball in the outfield. And also in football, I'd always performed well, but by my freshman year, I was the slowest guy on the team.

There would also be little things like I would lose my balance walking on the bleachers at a basketball game. I remember trying to get to my seat at the top and having to put my arms on people's shoulders to make sure I didn't fall or step on somebody. I've always been kind of clumsy—when I was a little kid, my mom couldn't let me go outside without putting my shoes on because I would inevitably stub my toe—but all these things added up to the fact that there was probably something else wrong, something more than just clumsiness. We were starting to get scared that this could be serious. So my parents and I started looking for answers.

We would go see doctors and they'd run these tests like putting little electrodes on my scalp and sending tiny electro shocks to my feet to test the amount of time it took for those to get to my feet from my brain. Or they'd have me do stuff like walk down the hall heel to toe like I was walking a tightrope. And I wouldn't be able to do it—I'd have to hold on to the wall. Or they would have me hold one hand out in front. When I did, it would shake a little and my fingers would move a little involuntarily. And the doctors saw the symptoms, but didn't have any reason why this was going on. They'd go, "I don't think anything is [really] wrong."

We were in and out of different doctors' offices almost every two weeks for a year. At one point, I remember feeling like, "I don't care what it is, just tell me so I can deal with it."

We finally found a doctor, a specialist in San Francisco who dealt with neurological diseases. He had seen [my symptoms] before and thought he knew what I had. There was a blood test for it, so I took the blood test.

A week later, the test results came to my house. I remember coming home from a friend's house. I arrived at the door and saw my parents looking at the test results at the kitchen table. I sat down and they said, "Yup, the doctor was right. It's Friedreich's ataxia."

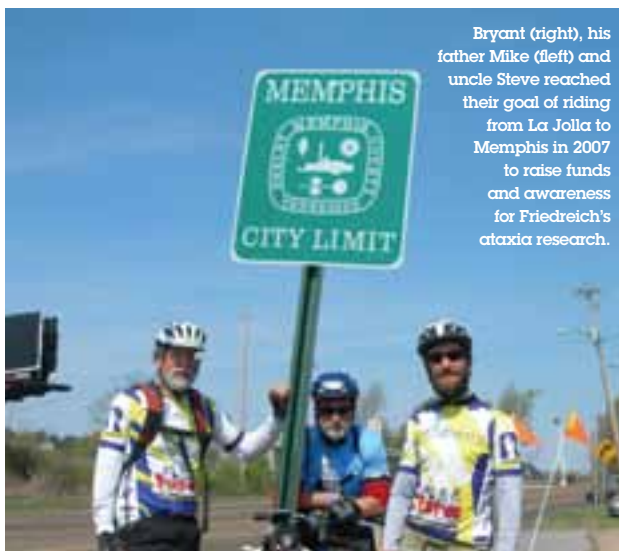
I had never heard of Friedreich's ataxia before. Nowadays when someone gets diagnosed, information is at his fingertips. This was 1997, 1998. The Internet was just starting to get big. So I don't remember that moment as being emotional because I don't think we had any idea what we were up against at that point.

I didn't know, for instance, that I could be looking at a life that is 30 years shorter than it would've been normally. [The average life expectancy for someone with Friedreich's ataxia is in the 40s.] Or that there was no treatment or cure.

Usually you receive a diagnosis and you go, "All right, so what can I do? What pill do I take?" In this case, the doctor said, "Well, there's nothing you can do."

I went into denial. I wasn't comfortable talking about [the diagnosis] for several years, even with my family. I just wanted it to go away so I ignored it. I think a lot of the silence was also due to feeling completely helpless. This disease had taken over my body and there was nothing I could do to make it all better.

Friedreich's ataxia, or FA, is a [degenerative neuromuscular disease] that affects every muscle in the body. It affects balance and coordination, hearing, sight and speech. It can cause diabetes and, in a large number of cases, also causes scoliosis and cardiomyopathy,



Bryant (right), his father Mike (left) and uncle Steve reached their goal of riding from La Jolla to Memphis in 2007 to raise funds and awareness for Friedreich's ataxia research.

"I'd never heard of Friedreich's ataxia before. I didn't know that I could be looking at a life that is 30 years shorter than it would've been normally. Or that there was no treatment or cure."

But even though a bike wasn't something I would need every day after I graduated, it was still a little alarming to know that I wasn't going to be getting back on it anymore. I rode a bike for four years straight almost every single day when I was at school—it was my main mode of transportation. And now it was something that was gone forever—that's what really hit me.

So I started searching online for different options. And I found this recumbent tricycle. My first thought was, "Well, that's kind of lame. That's just one more thing that's going to draw undue attention to myself. This is a disabled person's bike." But it was also perfect for me because even though my balance was suffering, I still had plenty of power in my legs. I was up against a roadblock, this situation that life had thrown my way, and this was my opportunity to choose my reaction.

I went for a test ride, and as I was rolling around in the parking lot, I fell in love. The freedom I felt on that trike was a freedom I hadn't felt in years. I didn't have to worry about falling over. I wasn't afraid of

which leads to heart failure.

In college—I went to UC Davis—FA started affecting my speech and balance more and more. If you saw me walking down the hall, you'd think I was drunk. It was hard. I felt like no one understood me. I remember one night my girlfriend and I were walking out of a party and this guy said to her, "You're going home with *that* guy? He can't even walk straight!" Or another night I left a party and there was a cop outside. He said, "Hey man, we need to get you a ride because you're way too drunk to walk home." And I wasn't. Stuff like that happened all the time and it wore on me.

Still, I didn't like to be seen as that "poor disabled kid," so since everyone [at UCD] rode bikes, I rode a bike to class every day, too. I definitely had some close calls—one time when I was getting ready to get off my bike, I fell into a stack of bikes and knocked it over. Things like that started happening more and more frequently. So when I graduated in 2005, I came to the realization that it probably wasn't safe enough for me to ride a bike anymore.

FACING FACTS

- FRIEDREICH'S ATAXIA (FA) AFFLICTS 1 IN 50,000 PEOPLE IN THE UNITED STATES.
- THE AVERAGE LIFE EXPECTANCY OF SOMEONE WITH FA IS 40-50 YEARS.
- CURRENTLY THERE IS NO EFFECTIVE TREATMENT OR CURE FOR THE DISEASE.

SOURCES: NATIONAL INSTITUTES OF HEALTH, UNIVERSITY HOSPITAL AACHEN

stepping off when I got to a stop sign and twisting my ankle. I thought I'd lost that part of my life completely, and here it was again—it was just the most amazing feeling.

So I bought the trike. It was \$3,000, one of the biggest purchases I'd ever made. But from then on, I started riding. And riding. My first ride was seven miles. I was so proud. I had no idea I had that in me. Then my next ride was 14 miles. Then 25, and then 50. And then, only four months after I had ridden my trike for the first time,

I signed up for a century ride.

I was the last person on the road that day. All the other cyclists had finished their ride, packed up their bikes and were driving home by the time I crossed the finish line. But I had done it—100 miles in one day. I could hardly walk down the street, but I'd just ridden 100 miles. It was a huge accomplishment. That was my “aha” moment. I was more proud of my ability and less ashamed of my disability. And that was a feeling I wanted to bottle

up and recapture forever. I just wanted more and more of it.

So I had this crazy idea. After I finished the 100-mile race that day, I read about this guy with MS who'd circumnavigated the country on his trike. I thought, “You know what? Maybe I could do something like that. If I can do 100 miles in a day, I can do anything.” I had the idea that I wanted to ride my trike to the annual National Ataxia Foundation meeting. And that year [2007], the meeting was in Memphis, Tenn.

In the beginning, I just wanted to prove to myself and everyone else what I could do. But then I had the idea of wanting to start raising funds. At the annual ataxia meetings, I would hear about all these people having fundraisers and contributing first hand to the cause that we're all ultimately fighting for. I wanted to contribute also. That became one of the primary reasons of my ride: to do events, wave my arms and draw attention to Friedreich's ataxia.

I live in Sacramento, but I started in La Jolla because that's where the Scripps Research Institute, which is developing treatments for FA, is [based]. The ride was an amazing adventure, one that I still think about every day. My dad rode every bit of the way with me. My uncle met us in San Antonio and rode about 1,000 miles with us. And my mom, who when I told her about this idea said, “My only stipulation is that I'm going with you,” would drive ahead and set up camp at our next spot and have lunch or snacks or whatever ready for us. We also tried to hook up with different research centers across the U.S. and do little receptions and draw attention that way.

We started on Jan. 22, 2007 and got to Memphis on March 20. The [conference] was on March 22. When we rode up to our hotel in Memphis, we celebrated like crazy. The first thing I did was hug my mom and my dad. My brother Collin and his fiancée at the time [now wife] and some friends flew out and brought balloons and a banner. They also brought champagne and they shook up the champagne and sprayed it all over us. It was just an absolutely triumphant experience.

My goal was to raise \$30,000. We raised \$40,000, and then the National Ataxia Foundation and the Friedreich's Ataxia Research Alliance decided to each put in \$30,000. So the ride raised a total of \$100,000 for research. I couldn't believe it.

I was so incredibly happy and excited. I gave a talk [at the conference] with some pictures from our adventure and got a

standing ovation, which just meant so much to me. I totally lost it and was crying in front of everyone, but I didn't care.

The next year, the national meeting was in Vegas and we did it again, this time kicking off from the State Capitol. On that trip, we raised \$140,000. Then in 2009, we did a ride from Portland to Seattle that raised \$250,000. The momentum was building. My life was leading me toward a career in fundraising and raising awareness for Friedrich's ataxia. I wanted to do this for the rest of my life. So in October, 2009, I became the spokesperson for Friedrich's Ataxia Research Alliance [FARA]. I'm grateful every day because the things I was doing in my spare time, I now get to do full time.

On June 12, as part of a team representing FARA, I'm going to do Race Across America. It's an absolutely insane adventure. It's known as the toughest bike race in the world because it's longer than the Tour de France and also, unlike that race where they rest every night and race in stages, the clock never stops at Race Across America. It starts in Oceanside [California] and ends in Annapolis [Maryland] and goes 24 hours a day. We'll be a team of four [which includes Sean Baumstark from Elk Grove, who also has FA] and we're required to finish in less than nine days. We're splitting up into sub-teams of two and each sub-team will ride for four hours. We'll have to modify our sleep patterns very quickly!

The goal is to finish and to raise awareness, not so much fundraising. We want to make a scene for this cause and draw a lot of attention. FA is a lonely disease. You know, when I was diagnosed, my family and I were scared. We didn't know what the future was going to hold. And now through these rides, we have a huge base of support and it's absolutely amazing to see who comes out and just kind of shares the burden with us and truly makes it almost enjoyable. I mean, I hesitate to compare myself to Lance Armstrong, but someone with cancer sees Lance and goes, "Wow, it's possible. I can do [anything]." And I think that with me, I'm just a regular guy. And hopefully people will see me and go, "If he can do it, I can do it." Hopefully this inspires people to reach their potential. I am so excited. I can't wait to cross that finish line.

There is no stopping this disease right now. I've had a wheelchair for a little over a year. When I first started using it,

it was for traveling long distances, like if I were going out to Second Saturday or the State Fair. Now I've even started having to use it just to get around the house. And I will likely be confined to a wheelchair within the next two years. But I don't like to dwell on the future. I just push myself to the limit each day and try not to worry about what might come.

The advances in research in the last two or three years have been absolutely amazing and have given everybody hope for a cure. We have the most brilliant minds

in the world working on this thing. Within my lifetime I think we will find a cure.

That's why I go full force every day. It really is ironic that this terrible disease brought me purpose in my life. But the fact is, it did, and I'm grateful for that. I guess you could say that I'm riding like my life depended on it—because it does. 🌀

For more info or to donate or participate in one of Kyle Bryant's rides, please visit rideataxia.com. The next ride will take place in Philadelphia in October.