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KYLE BRYANT RECEIVES FIRST-EVER PUBLIC RECOGNITION AWARD

"If you can't fly then run, if you can't run then walk, if you can't walk then crawl, but whatever you do you have to keep moving forward." – Dr. Martin Luther King Jr.

The 2014 Public Recognition Award is presented to Kyle Bryant by the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) for his tireless efforts to raise awareness and research dollars for Friedreich's ataxia (FA). This award is given to an individual whose extraordinary efforts increase public awareness of the diagnosis and treatment of muscle and nerve disorders.

"I accept this award on behalf of all advocates for rare disease. Thousands of people pour their lives into raising awareness and research funds for the rare disease that affects them or their loved ones. I am honored to be a representative for all of these people," said Bryant. "Thanks to the AANEM for recognizing the incredibly important role of the patient in the research and clinical process."

From early childhood, Bryant was a multi-talented athlete. By the time he reached middle school, he was accomplished in golf, baseball, basketball, and football. At 17 years of age, his life changed when he was diagnosed with FA. As the disease progressed, he had to give up the sports so interwoven in his life growing up in Northern California.

However, instead of giving up on athletics all together, Bryant pushed through his limitations and focused on recumbent bicycling. It was the beginning of a new journey, best summarized in his words, "Little did I know this was just the beginning and that this disease would lead me to things beyond my imagination." Bryant started small, with an initial ride of seven miles. However, within four months, he had accomplished 100 miles in one day.

In 2007 Bryant started Ride Ataxia, planning and completing a 2500-mile, 59-day ride from San Diego, CA to Memphis, TN, to raise awareness and much needed research funds for FA. Since then he has completed rides from Sacramento to Las Vegas, Portland to Seattle, and the 3000 mile Race Across America (RAAM), in which his four-man team finished in 8 days, 8 hours, and 14 minutes.

“Diagnosis of a rare disease or any perceived disability should not limit the height of one's ambition; it should only change the approach to challenging situations and the way we deal with them. Getting from point A to point B may require wheels now, but it does not change where I plan to end up,” said Bryant.

In 2009 Bryant became the spokesperson for the Friedreich's Ataxia Research Alliance (FARA). With Bryant as its program director, Ride Ataxia has become a landmark fundraising event. Not only has he been an inspiration and help to those with FA, but he also has been a tremendously successful fundraiser, bringing in more than \$2.5 million for FA research and logging more than 20,000 miles including training and events.

“Starting Ride Ataxia was a way that we could take action, moving my family and me out of a place where we felt alone, helpless, and threatened,” said Bryant. “Cycling allows me to take back control and feel empowered. I want to share that feeling with others.”

Bryant's journey has raised significant awareness for FA and serves as inspiration to researchers, doctors, patients, and advocates continuing to fight for patients with all varieties of NM diseases.

Bryant noted that collaboration is the key to improving the lives of people living with FA and other rare NM diseases. He said, “We all have our roles. I am not a scientist, I cannot do lab work. However, I can raise the money that will keep scientists moving forward, and I can make sure they know that their work means the world to the patients and families who do not think about anything else.

“We all have an important role to play,” he continued. “Working together collaboratively, we will assemble this puzzle of treatments and cures for rare disease.”

About AANEM

Founded in 1953, the AANEM is a nonprofit membership association dedicated to the advancement of neuromuscular, musculoskeletal, and electrodiagnostic medicine. Nearly 5000 physician members—primarily neurologists and physiatrists—are now joined by allied health professionals and PhD researchers working to improve the quality of medical care provided to patients with muscle and nerve disorders. AANEM programs are guided by its five pillars: education, professional standards, advocacy, communications, and research. Its administrative office is located in Rochester, MN.

More information about AANEM Achievement Awards and Mr. Bryant is available at www.aanem.org/awards.

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