



**MYOTONIC
DYSTROPHY**
FOUNDATION

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FOR IMMEDIATE RELEASE

River's Ride: San Diego Father and Son Cycle Across Iowa In Support of Families Affected by Myotonic Dystrophy

SAN FRANCISCO, CA (May 12, 2014)--Eric Jensen and his three-year-old son River will be cycling through the state of Iowa in the Des Moines Register's Annual Great Bicycle Ride Across Iowa (RAGBRAI), July 20-26. The Jensens have named their participation in RAGBRAI "River's Ride" and are dedicating their journey to families affected by myotonic dystrophy (DM). Their ride will raise funds for the Myotonic Dystrophy Foundation (MDF) while educating and informing the public about this complex disorder. Both River and his mother Taylor have myotonic dystrophy type 1, an inherited disorder that manifests differently in each affected person. Myotonic dystrophy can cause muscle weakness, atrophy and myotonia, as well as problems in the heart, brain, GI tract, endocrine, skeletal and respiratory systems. Currently there is no cure for DM.

"We want to inspire hope for a cure for all those affected by DM," says Eric. "Our family is so blessed that we're able to go on this adventure together. We know that many people living with DM are not as fortunate as we are, and so we ride in their honor." The Jensens will be documenting their bicycle ride [online](#) so that the DM community and others can be part of the adventure. With more than 10,000 RAGBRAI participants and thousands more volunteers and spectators, River's Ride intends to educate the public about myotonic dystrophy throughout Iowa and beyond.

Eric's wife, Taylor was diagnosed with DM1 shortly after River was born. After a wonderful pregnancy and delivery experience, Taylor suffered muscle weakness and went to see her doctor, who ultimately referred her to a neurologist. The neurologist was able to make a DM1 diagnosis. Because DM is a genetic disorder, River was tested and diagnosed shortly before his first birthday. "It brings you to your knees," says Eric. "Taylor's diagnosis was so difficult, especially for me, and then for River to be diagnosed with DM, it was devastating."

Shaken at first, the Jensens took some time to let the diagnosis sink in, but in a few short months they were learning everything they could about DM. That's when they came upon the Myotonic Dystrophy Foundation (MDF), finding much needed support and up-to-date information on myotonic dystrophy. The Jensens have since begun holding annual fundraisers for MDF saying, "It was important to us that MDF not only provided support and information for families but also focused on funding research." They were especially interested in the funding of scientific fellowships specifically dedicated to DM research." Eric Jensen is a veterinarian and explains, "As a scientist and clinician, I know the importance of funding research, especially young DM researchers. MDF's Fund-a-Fellow program provides up and coming scientists opportunities to work with experienced principal investigators, seeding the future of DM research and helping discover and advance new therapies.

Since finding the Myotonic Dystrophy Foundation in 2012, the Jensens have been 100 percent committed to helping find effective treatments for DM. "It is our coping mechanism," say the Jensens. Eric however admits

he still feels great anxiety for what the future may hold for his wife and son. DM is not like most diseases that have a clear progression. Its symptoms and severity vary from patient to patient. “The unknown is the most difficult thing for me, but my wife Taylor is the rock in this family and she always reminds me how incredibly fortunate we are—she keeps me going,” he says.

The Jensens live in San Diego, California, however Eric is a native of Iowa. “I was born and raised in Iowa. It is a wonderful place—I have many fond memories of growing up in Iowa and have always dreamed of sharing my home state with my son,” Eric says affectionately. “For years my friends have talked about RAGBRAI and I’ve always wanted to participate in the ride. This seemed like the perfect opportunity for us all,” he says. “The chance to experience Iowa on a bike is perfect! There’s no better way to smell the corn fields, feel the humidity and meet the incredibly kind and hospitable people of Iowa than on a bicycle riding across the state.”

Taylor, along with Eric’s family in Iowa, will support them on their ride. With Eric’s sister Becka and her family, Taylor will drive the route and camp out along the way. River will have mom, Aunt Becka and family to provide him with a nice respite from the 418 mile cycling event while giving him the chance to play with his cousins along the way and get off the bicycle when needed. Eric’s other family members in Iowa will support Eric and River throughout their route and help spread the word about DM and River’s Ride.

An avid bicyclist, Eric rides his bicycle to work each day as Managing Veterinarian for the US Navy Marine Mammal Program. In preparation for River’s Ride in Iowa, Eric and River ride about 30 miles each weekend. “Keeping River enthusiastic about getting on the bike has been a priority so we sing and talk along the way and we especially like taking in the wildlife and nature one can only see by bicycle.”

When asked what Eric wants for his son’s future, Eric says tenderly, “I want him to grow up and live a fulfilling life full of wonder. I want him to be able to pursue his every passion in life.” Eric says of his son, “River is a very physically active and animated little boy who loves the water and outdoors and I don’t want that to change. I want a cure for River and other children and families affected by DM.” The Jensens say encouragingly, “Researchers are close to promising clinical trials and possibly a successful treatment. We’re committed to helping play a role in making that happen.”

To follow River’s Ride go to www.myotonic.org/rivers-ride or to the Jensen’s Facebook page [Pinching-tails for a Cure](#).

About Myotonic Dystrophy: Described as the most variable of all diseases found in medicine, myotonic dystrophy is an inherited disorder that can appear at any age and manifests differently in each individual. The most common form of adult-onset muscular dystrophy, DM affects somewhere between 1:3000 and 1:8000 people worldwide, and can cause muscle weakness, atrophy and myotonia, as well as problems in the heart, brain, GI tract, endocrine, skeletal and respiratory systems. There is currently no treatment or cure for DM.

About the Myotonic Dystrophy Foundation: The Myotonic Dystrophy Foundation (MDF) is the world’s largest DM-only patient organization. Its mission is Care and a Cure: to enhance the lives of people living with myotonic dystrophy, and advance research efforts focused on finding treatments and a cure for this disorder through education, advocacy and outreach. For more information go to <http://www.myotonic.org>.

About RAGBRAI: The Register’s Annual Great Bicycle Ride Across Iowa is an annual seven-day bicycle ride across the state. Heading into its 42nd year, RAGBRAI is the oldest, largest and longest bicycle touring event in the world. For more information go to www.ragbrai.com.

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