



MYOTONIC
DYSTROPHY
FOUNDATION



SAN DIEGO
HARLEY-DAVIDSON

Care and a Cure

Dear Friends and Sponsors,

On June 11, 2016, we will be hosting our 5th Annual Crawfish Boil Fundraiser (“Pinching Tails for a Cure”) to benefit The **Myotonic Dystrophy Foundation (MDF)**. We are especially excited to have **San Diego Harley Davidson** host this year’s event – it is going to be very special.

Our goals are two-fold: to raise awareness of the most common form of muscular dystrophy known as myotonic dystrophy (DM); and to raise funds to continue the research that will enable treatments and an eventual cure.

Thanks to last year’s sponsors and donors, the Jensen Crawfish Boil was overwhelmingly successful – raising over \$25,000 - bringing us to a total of \$80,000 over the last four years! We are deeply grateful for so much generous support.

In 2012, my 5-year old son, River, and I were diagnosed with myotonic dystrophy. We have learned first-hand how complex this disease is and how it impacts an entire family. In 2014, we learned that my father, brother, and aunt all have this disease as well. Myotonic dystrophy is a multisystem, inherited disease. This means a variety of tissues and organs may be affected: the heart, lungs and eyes, as well as any other muscles in the body. Deterioration of bodily functions can continue for decades - how slowly or swiftly it occurs varies from person to person.

We have exciting news to share from the foundation: for the first time ever, we can say it - people living with myotonic dystrophy are receiving a potential therapy. The first DM clinical trial began this year, evaluating a medication that targets not just disease symptoms but the genetic mutation that causes the disease.

MDF donors and friends like you brought us to the truly hopeful moment we celebrate today. But there is a continued need to grow the science and investigate more promising treatments for this disease.

This is where you can help us! We are seeking monetary donations and/or gift certificates for our fundraiser’s silent auction and raffle. Your support enables the MDF to pursue its mission to mobilize resources toward effective management, treatment, and eventually a cure for Myotonic Dystrophy through education, advocacy, research, and hope.

Like any parents, what we hope for is a treatment and ultimately a cure, so that our son River will never, ever, experience the severe symptoms of this disease.

Please help us help River. We thank you for your consideration and support!

Sincerely,

Eric, Taylor and River Jensen
4430 Santa Cruz Avenue
San Diego, CA 92107
619.884.6507
Taylor24@me.com



The Myotonic Dystrophy Foundation is a 501(c)3 non profit public charity. All monetary donations made out to the MDF are tax-deductible to the full extent allowed by law. The MDF IRS tax EIN number is: **20-5014628**. For more information about our event, please visit <http://www.myotonic.org/crawfishboil>.