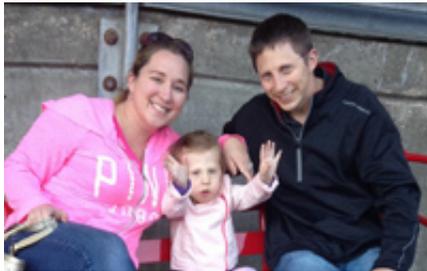


June 2014 Volume 1

MDF Dispatch



MYOTONIC
DYSTROPHY
FOUNDATION



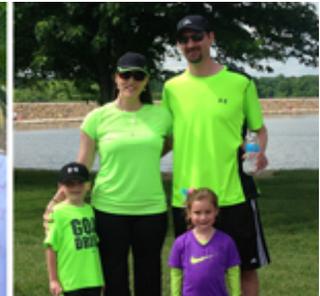
A Father's Story in Honor of Father's Day: Addison Our Little Rock Star

Craig Evans of Abington, Pennsylvania, talked to MDF about his family's journey with DM. As Father's Day approaches we are pleased to share this father's story.

"As corny as it sounds, my wife Lauren and I met ten years ago at my best friend's wedding. Upon first meeting her I realized she was one of the most personable and attractive people I had ever met. We'll be married seven years this fall." [Click here](#) to read more.

Fundraisers Exceed Expectations!

On Saturday, May 31st, MDF community members came out in force to support Care and a Cure! Near Kansas City, MO the Bormann family hosted the second-annual Muscles for Myotonic 5K Family Fun Walk, and in San Diego, California, the Jensens held their annual crawfish boil fundraiser, Pinching Tails for a Cure. Once again, both events were a spectacular success! [Click here](#) to read more.



Medical School Roadshow



Help Shorten the DM Diagnostic Odyssey- Volunteer with the Medical School Roadshow



As MDF community members know first-hand, myotonic dystrophy is significantly under-diagnosed, and the diagnostic odyssey for DM can average anywhere from seven to fourteen years in length. Because DM is so variable, it is often mistaken for other diseases entirely. A key MDF Care objective is to help shorten the path to diagnosis that our community members travel.

The Medical School Roadshow, a new TeamMDF volunteer initiative, will partner with medical schools to educate students about DM before they graduate and begin clinical work. [Click here](#) to learn how you can play an important role in this effort.

Update: Isis Phase 1 Clinical Trial

Isis Pharmaceuticals, Inc. announced this past Monday that it initiated a Phase 1 clinical trial to evaluate the safety of ISIS-DMPK Rx in healthy volunteers. This exciting news has generated a lot of community questions and discussion. We know our community members are eager for additional information and updates regarding the Phase 1 trial and what it means for them and their families.



Isis hopes to advance ISIS-DMPK Rx to a Phase 1/2a study to evaluate the safety and dose-range findings in patients with DM1 at the end of 2014. As Isis reported in the [fact sheet](#) MDF published on June 9, information on the Phase 1/2a study will not be available until the Phase 1 study has been completed and safety has been demonstrated. Details on the Phase 1/2a study will be made available through MDF and online at clinicaltrials.gov once the study has been designed, eligibility criteria have been established, and sites have been identified.

MDF will continue to share information about the Isis Phase 1 clinical trial as it becomes available. [Click here](#) for more information and to read the Isis announcement.

Events and Announcements:

[MDF's 2014 Annual Conference hotel block is filling fast. Book your room now!](#)

[Upcoming webinar July 17: "Everything You've Wanted to Know About CTG Repeats"](#)

[Participate in the 2nd Annual Grandparents Campaign!](#)

Join the community! Follow us on:



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