

March 2014 Volume 2
MDF Dispatch



MYOTONIC
DYSTROPHY
FOUNDATION



Dr. Matt Disney Talks About DM2 Research

This month we are focusing on myotonic dystrophy type 2 (DM2). Country-based studies in western Europe indicate that DM2 prevalence may be on par with DM1, which is assumed to be somewhere between 1:3000 and 1:8000. Because the genetic mutation that causes DM2 was discovered more than 10 years after the mutation for DM1, DM2 translational research has lagged behind DM1. Researchers like Dr. Matt Disney are helping change that. [Click here to read more.](#)

Genetic Testing for Myotonic Dystrophy:

Insights from Genetic Counselor Carly Siskind, MS, LCGC

MDF community members often contact the Foundation with questions about genetic testing. Their questions range from how to find facilities that conduct genetic testing for myotonic dystrophy (DM) types 1 and 2, to whether or not they should be tested and how to assess the benefits and risks of having a genetic test. [Click here to read more.](#)



The Myotonic Dystrophy
Family Registry

Pregnancy Study Seeks Participants!

MDF has partnered with Dr. Nick Johnson, assistant professor of neurology at the University of Utah and MDF Fund-a-fellow grant recipient, to collect data on how the lives of women with DM are affected during and after pregnancy. This is an online survey and takes between 5-15 minutes to complete. [Click here for more information.](#)

Orphan Drug Designation Given to a DM Drug Under Development at Valentia Biopharma

The European Medical Agency (EMA), the European version of the United States FDA, has granted orphan drug designation to the Valentia Biopharma drug VLT015, which Valentia is developing as a potential treatment for DM1 and DM2. While VLT015 is still in the early stages of development, the designation is encouraging. Valentia Biopharma is based in Peterna, Spain and focuses on the development of drugs to treat rare genetic disorders. [Click here to read more.](#)



Muscles for Myotonic 2014: Sign Up Now!

For the second year in a row, the Bormann Family will raise awareness and money for myotonic dystrophy in honor of their daughter Anna by hosting the Muscles for Myotonic 5K Family Fun Walk.

Last year's walk had over 250 participants! Learn how you can participate, support the Bormanns and their walkers, or host an event in your community. [Click here to read more.](#)

You like us. You really, really like us!

We are delighted to announce that our Facebook page has reached over 2,000 followers. If you haven't already done so, be sure to like us on [Facebook](#) for more news, updates, and photos from both MDF and our community!



Check out these important events and announcements!

[2014 MDF Annual Conference: SAVE THE DATE](#)

[Register for our upcoming webinars](#)

[Caregiver Virtual Support Group](#)

[Join the Repeat Club and become a monthly donor!](#)

Join the community! Follow us on:



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