

September 2013

# MDF Dispatch



MYOTONIC  
DYSTROPHY  
FOUNDATION

## Highlights of Current DM Research

Researchers have published several recent studies on advances in DM research. Dr. Katherine Hagerman, Ph.D., Research Assistant at Stanford University, has provided MDF with summaries of some of newly-published DM research, including:

- Research from the Scripps Research Institute in Florida into increasing the potency of RNA-targeting drugs
- Investigation of the muscle defects of individuals with DM1 by scientists at Baylor College of Medicine
- A summary of complications that occur during pregnancy in women with DM and other neuromuscular disorders, published by health care workers at The University of Tennessee



To read her summaries, and for links to more detailed information about these studies, click [here](#).

## Myotonic Dystrophy Family Registry--Explore the Data!



The Myotonic Dystrophy  
**Family Registry**

The Myotonic Dystrophy Family Registry has now enrolled almost 1,000 registrants. Researchers are using the Registry data to conduct new myotonic dystrophy research, and to find participants for upcoming studies. And for the first time in a DM registry, those registered can explore the anonymous data to learn more about this disease and the community of people living with it. If you are a member of the Registry, be sure to log into the [Registry website](#) and click on the Registry Data tab to learn more. If you haven't yet registered, visit the [Registry website](#) to sign up. For questions, contact the Registry Coordinator at 602-435-7496 or via email at [coordinator@myotonicregistry.org](mailto:coordinator@myotonicregistry.org).

## Upcoming Webinars: "Disclosing Your DM" and "Treatment Options for Pain"

The next two webinars in our Living With DM Webinar Series will take place in the next few weeks. These webinars were designed based on direct feedback from the DM community. Here's what's coming up:



1. On **Wednesday, September 25**, licensed psychologist Barry Cohen, Ph.D. will talk about "Disclosing and Talking About DM." He'll discuss the sensitivities surrounding disclosure and strategies for thinking about and communicating your DM status to friends, family, and intimate partners. The webinar will kick off at 5 PM Pacific Time (8 PM Eastern Time). Click [here](#) to learn more and sign up now.
2. One week later, on **Thursday, October 3**, Dr. Tetsuo Ashizawa of the University of

Florida's McKnight Brain Institute and the MDF Scientific Advisory Committee will discuss various pharmacological and non-pharmacological treatments for the muscle pain often experienced by persons with DM1 or DM2. This webinar will be held at 2:30 PM Pacific Time (5:30 PM Eastern Time). Click [here](#) to learn more and sign up in advance.

## An Update on our Grandparents Campaign



Earlier this month, on Grandparent's Day, we kicked off our latest fundraising campaign led by a group of grandparents whose families are affected by DM. To date, the campaign has raised over \$32,000 and is going strong! If you haven't read about these inspiring grandparents and their beloved grandchildren, please visit our [Grandparents Webpage](#) to learn more and make a donation.

## Attention Gmail Users!

Due to a recent google update, your Inbox settings have changed! To avoid missing an email from MDF: drag this email to your "Primary" tab and click "yes" to ensure that future emails go to your Primary Inbox.



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