

March 2014 Volume 1

MDF Dispatch



MYOTONIC
DYSTROPHY
FOUNDATION

Casting a Light on DM2

As our community members know, there are two well-characterized types of myotonic dystrophy: DM1 and DM2. They are caused by mutations in different genes, but have many overlapping symptoms. This month, we have a spotlight on DM2.

Later in March we'll be talking with Dr. Matt Disney of the Scripps Research Institute about the DM2 research he's conducting in his lab. We are starting off our focus on DM2 by sharing a conversation we recently had with Waltraud (Val) Reeber—who is living with DM2—and her husband and caregiver, Bob. [Read our interview.](#)



Save the Date

Join us for the 2014 MDF Annual Conference in Washington DC!

Friday September 12 and Saturday, September 13.

Early Bird registration starts April 15.

This year's Conference features three session tracks, congressional office visits and more. [For more information click here.](#)

MDF Goes to Washington! Care and a Cure

At MDF, our mission of "care and a cure" means that we are dedicated to advancing efforts to improving quality of life for people living with DM, and treating and curing this devastating disorder. Members of the MDF team went to Washington, DC to raise awareness and meet with elected officials and federal agencies about myotonic dystrophy and the needs of those affected by DM. This is critical to improving research funding, treatment development, services and care. [To read more click here.](#)



Webinar: Living with DM2

A DM2 research update with presenters Matthew Disney, PhD and John W. Day, MD, PhD

Date: Monday March 24

Time: 5 PM PST, 6 PM MST, 7 PM CST, 8 PM EST

Engage our experts as a participant! [Click here for more information and to register.](#)

Previous webinars are available online through the MDF [Digital Academy](#), including last week's webinar, [Tips for Parents Caring for Children with Congenital DM](#).

Join our Virtual Caregiver Support Groups

Looking for support? [Click here to find a support group](#) in your area. We have just added two new groups in Seattle and Phoenix. [Check the MDF calendar for support group meeting times.](#)

Start a group

We've identified several urban areas with a large concentration of MDF families: New York City, Boston, Philadelphia, Washington, DC, Miami/Fort Lauderdale, Chicago, and Ann Arbor, Michigan. If you live in one of these areas and want to launch a support group please contact Leslie Krongold at leslie.krongold@myotonic.org.



Thank You Volunteers!

We all appreciate our wonderful volunteer support group facilitators. They took the first step by calling or emailing us about a desire to engage their local DM community. Once you take that initial step, MDF will train and support you along the way. You'll receive a Support Group Facilitator Handbook, quarterly webinar training, access to an online group to communicate with other facilitators, and guidance by Leslie Krongold, EdD - our Outreach Director with over 14 years of support group facilitation experience.

Join the community! Follow us on:



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