

February 2014 Volume 2

MDF Dispatch



MYOTONIC
DYSTROPHY
FOUNDATION

Meet DM Pioneer Dr. Richard Moxley

Dr. Richard Moxley of the University of Rochester Medical Center is a global leader in myotonic dystrophy clinical care and research. We recently talked with “Mox,” as he’s known to his colleagues, about his long and exceptionally distinguished career in neurology. [Read more about Mox](#) and why he’s one of the most respected and loved clinicians in the DM community.



Rare Disease Day; Help Us Advocate for DM

Each year the global rare disease community celebrates Rare Disease Day on the last day of February. MDF is proud to be a Rare Disease Day partner, and we have launched a grassroots advocacy program to raise DM visibility as part of this year’s celebration.

Representatives from MDF will be going to Capitol Hill next week to advocate for DM and you can help us from home! Consider writing a letter to your member of Congress or stopping by their local district office to drop off an informational packet about DM and the MDF. You can learn more about how you can help with local advocacy [on our](#)

[website](#).

We’ve also created a training video to help explain grassroots advocacy and how your voice and actions make a difference in Washington and around the country. [Click here](#) to access the video via our MDF Digital Academy.

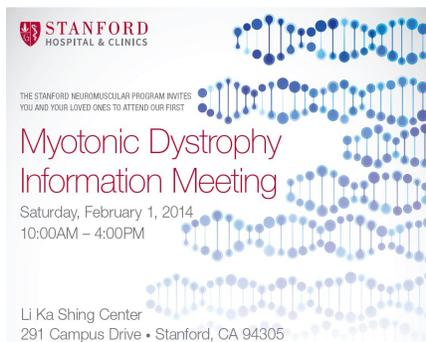
February Webinar: Tips for Parents Caring for Children with Congenital DM

Our first webinar for the 2014 [Living with DM Webinar Series](#) begins next week! On Wednesday, February 26 at 6 PM Pacific (9 PM Eastern), Erica Kelly and Sarah Francheteau-Berman will facilitate a session on “Tips for Parents Caring for Children with Congenital DM.”



These mothers will share their knowledge and experience in a one-hour session, discussing topics that will include managing gastrointestinal challenges via diet and natural supplements, and advocating for your child's Individualized Education Program (IEP).

Participating in the live webinar will be the only opportunity you will have to ask questions, however the webinar will be recorded and available via the [MDF Digital Academy](#). To sign up for the live webinar, [click here](#).



First Annual Stanford DM Information Meeting a Big Success

Dr. John Day welcomed more than 100 people to the first annual Myotonic Dystrophy Information Meeting on February 1, 2014, which was held at Stanford School of Medicine. [Read more about the meeting.](#)

Join our Caregiver Virtual Support Group

Last fall MDF conducted a survey to learn more about our population of caregivers. Nearly 44% of respondents felt they didn't have the necessary emotional resources to handle caregiving, while many specifically said they wanted to connect with others in a similar situation and/or attend a support group.



We've taken this feedback to heart and are happy to announce our new **Caregiver Virtual Support Group!**

We've set up a secret, closed group on Facebook (no one will see posts or comments unless they are approved group members) that will allow caregivers to interact, share challenges, offer advice, and connect with other caregivers in the MDF community.

As part of this Virtual Support Group, we will also offer quarterly support via facilitated calls for up to 12 participants. These calls will be conducted on a rotating basis by one of three generous DM caregivers: Cecilia Stearns, Marty Benner, or Regina Thompson. More information on how to participate will be posted on the Caregiver Virtual Support Group Facebook page.

If you're interested in joining this group, please email Leslie Krongold at leslie.krongold@myotonic.org.

Join the community! Follow us on:



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