

February 2013

# MDF News Update



MYOTONIC  
DYSTROPHY  
FOUNDATION



## The Myotonic Dystrophy **Family Registry**

### New DM Family Registry Coming Soon!

On Rare Disease Day 2013 - February 28th - you'll be able to take a more active role in the fight against myotonic dystrophy (DM) by joining the new **Myotonic Dystrophy Family Registry (MDFR)**.

The MDFR will be unique in that it will not only help researchers find new, effective treatments and identify possible participants for upcoming clinical trials and research studies, but will also allow anyone who is registered to have access to the collected data, from academic and pharmaceutical researchers to individuals or families living with DM. And, the MDFR is a patient-driven, web-based registry. YOU register and complete the data survey online.

The MDFR – which will be completely anonymous – is different from other registries because it will include significantly more participants and will focus on statistically relevant demographic information, quality of life and other patient-reported information to support the development of clinical trials, research studies and advocacy efforts.

You'll receive an email from us on February 28 inviting you to join the MDFR. In the meantime, for more information about how the MDFR will work, click [here](#) to visit [myotonic.org](http://myotonic.org).

Questions? Click [here](#) to email the Registry Coordinator.

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New Address: 1259 El Camino Real, #150 Menlo Park, CA 94025  
Phone: 866-968-6642 or 650-267-5562 Email: [info@myotonic.org](mailto:info@myotonic.org)

[www.myotonic.org](http://www.myotonic.org)

This message was sent to [email@example.com](mailto:email@example.com) from:

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