

January 2013

# MDF News Update



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## Launching Next Month - the Myotonic Dystrophy Family Registry



### The Myotonic Dystrophy **Family Registry**

Help the research community better understand myotonic dystrophy and improve the lives of people and families living with DM by joining the Myotonic Dystrophy Family Registry (MDFR), launching in February

2013. When you join and create a profile, you'll aid researchers seeking to develop new, effective treatments for DM and identify participants for research studies and clinical trials. You'll also help agencies involved in the drug development process understand how this disease affects the quality of life of people and families living with DM, provide MDF with information we can use to advocate on behalf of the community with decision makers in Washington, D.C. and elsewhere, and much more. Your information will be completely anonymous and critically important. [Click here](#) for more information.

## Ritalin Could Curb Excessive Daytime Sleepiness in DM1 Patients

Methylphenidate, a psycho-stimulant drug also known by its 1948 trademarked name of **Ritalin**, could be useful in the treatment of excessive daytime sleepiness (EDS) for DM1 patients, according to a recent study conducted by The Department of Human Genetics at the Centre Hospitalier Universitaire de Quebec in Quebec City, Canada. [Click here](#) for more information.



## MDF Awards \$200,000 for Research into Treatments for Myotonic Dystrophy

MDF recently awarded two \$100,000 grants to postdoctoral Fellows working in universities and research facilities to encourage basic research in the management, treatment and cure of myotonic dystrophy (DM), for a total commitment of \$200,000. This award cycle brings the total research funding awarded by MDF to over \$1.5M since its founding in 2006, and builds on the Foundation's commitment to increasing the number of investigators focused on myotonic dystrophy research. [Click here](#) to learn more.



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## 2013 Annual Conference Planning - We Need Your Input!



Preparations are well underway for MDF's 2013 Annual Conference on November 8-9, 2013 in Houston, TX. Details and registration will be available in late spring. So that we can continue to deliver a best in class conference, we would like your input on the topics you wish to see addressed. Please [click here](#) to participate in a quick survey and help us make the most of your conference experience.

## "Dine Out for DM" and Honor Global Rare Disease Day February 28th

Global Rare Disease Day, scheduled for February 28th, 2013, has been established as a grassroots advocacy day and MDF is getting involved by launching the Myotonic Dystrophy Family Registry

(learn more above) and by partnering with the MDF community to hold “Dine Out For DM” events at local restaurants during the month of February. Invite your friends, family and community leaders to join you for a fun, easy fundraiser to benefit MDF and raise awareness of myotonic dystrophy in your community. [Click here](#) to learn more.



## We Met Our Match!

In December, MDF shared the exciting news that an anonymous family had challenged the DM community to match its \$150,000 gift to MDF during our annual fundraising season. Thanks to MDF community support, we are thrilled to report that we met our goal! Your contributions during our critical end-of-year fundraising period will allow us to continue to support people living with DM, and to embark on a year of unprecedented collaboration with the research community. From all of us at the Foundation, thank you for your very generous support!



## Save the Date!

2013 MDF Annual Conference - November 8-9, 2013 in Houston, TX

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