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MDF Dispatch



MYOTONIC
DYSTROPHY
FOUNDATION



The DM Diagnostic Odyssey

Researchers from the University of Rochester recently published the findings of a study on the DM diagnostic odyssey. The study found that study participants with DM1 experienced an average diagnosis delay of 7 years, and participants with DM2 had an even more stunning delay of 14 years. You can [read a detailed summary](#) of this study, prepared by Dr. Katharine Hagerman, on our website.

Tips on How to Manage Dysphagia: Watch our Webinar

Dr. Michael Groher—who literally wrote the book on swallowing disorders—gave a powerful overview of dysphagia during our most recent webinar, held earlier this week. Dr. Groher, Chairman of the Truesdail Center for Communicative Disorders at the University of Redlands, offered tips on how to improve the swallowing experience. These include avoiding cold liquids and foods that cause a delay in the esophagus, maintaining closed lips while swallowing, and dietary changes. You can view the webinar at any time by accessing it in our Digital Academy: [Treatment for Dysphagia](#).



New Speakers Announced for Conference!

We are delighted to announce that Andrew Hardwick, Metropolitan Public Affairs Specialist with the Social Security Administration (SSA) office in Houston, and Steve Rhatigan, Principal with the Archer Consulting Group, which specializes in creating lifetime solutions for people with special needs and their families, will co-chair the 2013 MDF Annual Conference Breakout Session on Financial Resources and

Insurance.

Mr. Rhatigan has over 32 years of experience helping clients navigate the disability claims process, special needs trusts, estate planning and more, and is a regular speaker at disability conferences. Mr. Hardwick, also a noted speaker at disability conferences, has worked with the SSA office in Houston for 11 years and won a number of awards for his SSA work. Click [here](#) for more information on the conference program, and to register.

Last Chance: Enter Our Summer Registry Contest!

There's only one week and one day left in our summer Registry contest. You could win a \$100 Target gift card! The Myotonic Dystrophy Family Registry is an important tool in helping researchers develop treatments and identify participants for research and clinical trials. And for the first time, DM patients who are registered can see and explore the anonymous data.



The Myotonic Dystrophy
Family Registry

Here is how the contest works:

1. You recommend that individuals living with DM join our Myotonic Dystrophy Family

