

September 2013

MDF Dispatch



MYOTONIC
DYSTROPHY
FOUNDATION



Grandmother Travels the World to Help Her Grandchild

"There's nothing more special than grandbabies," says Mollie McKool, grandmother to a young child with DM and one of the co-chairs of the **Grandparents Campaign, which kicks off Sunday**. "As grandparents, we feel helpless and there's a real pressure to unlock doors and get answers," she says.

[Read more](#) about Mollie and her tireless advocacy on behalf of her grandson and others living with DM.

Recruiting for Congenital DM Study

The **Myotonic Dystrophy Family Registry** has been asked to assist the University of Utah in recruiting children with congenital myotonic dystrophy between birth and 13 years old for a natural history study. The study seeks to identify the most critical symptoms affecting congenital DM patients and how those symptoms change over time. For more information, click [here](#) to visit the **Myotonic Dystrophy Family Registry** website.



The Myotonic Dystrophy
Family Registry



Tell us About Your Caregiver!

November is National Family Caregivers Month and to recognize this, we're planning a number of activities that focus on DM caregivers, **an incredibly important part of the DM community**. Please help us by doing the following:

1. Take our Caregivers Survey by Sept. 22

If you are a friend or relative helping someone diagnosed with DM manage their daily living activities, MDF wants to understand more about what you do and how we can help you. Please [take our anonymous survey](#) by Sept. 22.

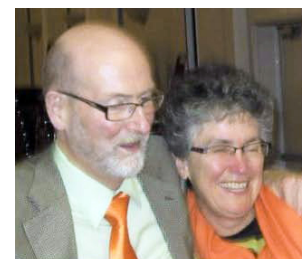
2. Help us give a Shout Out to Your Caregiver

Throughout National Family Caregivers Month, we'll be featuring caregivers on our website, in the MDF Dispatch and on our Facebook and Twitter pages. If you'd like to honor your caregiver or a DM caregiver that you know, please see our [Caregivers Month webpage](#) to nominate your caregiver and give them a public pat on the back.

Doug Mowat Wins the Family Registry Referral Contest!

Congratulations to Canadian Doug Mowat who is the lucky winner of The Myotonic Dystrophy Family Registry referral contest and a \$100 Target gift card!

Even though the contest is closed, we hope everyone who hasn't yet joined the Registry will do so, and continue encouraging others to



join as well. Remember, this is the only DM Registry that allows those who've joined to access and review the anonymous data. The more people that join, the more accurate and useful the Registry will be. Visit the [Registry webpage](#) for more information.



Reminders:

The MDF website includes a wealth of information to help those living with DM and the caregivers who are helping them. One area that may be particularly helpful is our [Resources page](#), which includes:

- A [Financial Resources Guide](#)
- The [Medical Professionals Referral List](#) that provides the names and contact information of doctors and medical professionals who have experience working with DM patients
- The [MDF Toolkit](#) with valuable information for affected individuals and their families, including a medical alert card, a medical history sheet, and resources for medical professionals
- [Anesthesia guidelines](#)
- Information about [MDF Warmline](#) phone support
- A list of relevant articles and organizations

Why not take advantage of the [resources](#) available to you?

Attention Gmail Users!

Due to a recent update, your Inbox settings have changed! To avoid missing an email from MDF; drag this email to your "Primary" tab and click "yes" to ensure that future emails go to your Primary Inbox.



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