

July 2013

MDF Dispatch



MYOTONIC
DYSTROPHY
FOUNDATION



Cecilia's Family

Cecilia Stearns first learned about DM when her daughter and twin grandsons were diagnosed shortly after the boys were born. Although she and her husband relinquished their golden years to care for them, Cecilia says "We get so much love in return and I can't imagine my life without them."

Her story is about the transition from survival mode to proactive mode and finding support in the DM community. Click [here](#) to read how this strong and positive grandmother is caring for her daughter and twin grandsons.

Grandparents Day: A Letter from Sharon & Mollie

Hello to all our fellow MDF community members. We would like to introduce ourselves and invite you to join us in a special project for MDF grandparents.

Our names are Sharon Allison and Mollie McKool. We both have grandchildren affected by myotonic dystrophy, and we want to help MDF raise funds to find treatments and a cure for this devastating disorder. The love a grandparent has for his or her grandchild is incomparable, and creates a special urge to get involved and create change.

We'll be launching the first-ever Grandparents Campaign on Grandparents Day, September 8th, 2013. We'll send specially-designed cards to our friends, complete with photos of our grandchildren and notes from us, to help raise funds for DM research. All funds raised through the Grandparents Campaign will help advance research - and the opportunity and the need for this funding is now more critical than ever.

Please join us - if you are the grandparent of a child with myotonic dystrophy and would like to send a custom card to your family and friends to raise research funds, please click [here](#) for more information, or call Aly Galloway, MDF Community Engagement Manager at 415-800-7640, to get involved.

We look forward to working with you to create a brighter future for our grandchildren.

Sincerely,
Sharon Allison and Mollie McKool



You asked, MDF Answers: Tune In for the First Ever MDF Webinar

The Living with DM Webinar Series will begin on Monday, July 22nd at 5PM Pacific Time with an interesting and informative talk on Dealing with the Decline of Executive Functions of the Central Nervous System (CNS) with Dr. John Day, MD, PhD, Director of Stanford University Neuromuscular Program.

Dr. Day will provide an overview of this DM symptom and share

treatment and management strategies as well as a CNS research update. This topic was chosen by you, the DM community, from our webinar survey. For more information on how to attend the online webinar, click [here](#).

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