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MDF Dispatch



MYOTONIC
DYSTROPHY
FOUNDATION



A Mother and Grandmother's Quest

When Marty Benner's granddaughter, Sophia, was born in November 2006, the doctors didn't know what was wrong and, after many weeks, suggested she be taken off life support. But, as a grandmother, mother and nurse, Marty insisted they not give up. After Sophia was diagnosed with DM1, Marty's daughter and husband also tested positive for the disease. Since then, the family has been on a quest to learn all they can about DM and be their own best advocates. Click [here](#) to read more about

Marty and her family.

It's Here! The Medical Professionals Referral List!

Many MDF community members contact us to get referrals for doctors, therapists and other medical professionals who have experience with myotonic dystrophy patients and are knowledgeable about the disease. In order to assist community members in accessing high-quality DM care, MDF has started the **Medical Professionals Referral List 1.0** and a list of **DM Centers of Excellence in Clinical Care**. Both lists are now available on the MDF website with an interactive map to help you locate medical professionals in your area. Click [here](#) to check it out!



The **Medical Professionals Referral List** is created by you, our community members, and we need your help to improve and expand it. Do you have a great doctor? A knowledgeable therapist? A helpful pediatrician? Click [here](#) to fill out a Medical Professional Referral Form and help others in the DM community find the best care possible.



Grandparents Take Charge

In just less than a month, our Grandparents Campaign will kick off on Grandparents Day: September 8th! If you have grandchild, why not honor that relationship by sharing your story and helping raise funds for DM research? We have a number of grandparents already signed up, including Jamie Brewster, grandmother to two young grandsons diagnosed with DM.

"I experience many emotions, fears, anxiety and times of prayer, not only for Jackson and James, but for my two daughters with DM, Anna and Allison," Jamie says. "But wringing my hands, letting my fears ruminate, and asking 'why my family?' will not change anything. What does have potential for change is getting involved with MDF to lobby for more research, tapping into resources to improve quality of life, and educating the medical community on diagnosis and treatment of DM. As grandparents, we can make a profound difference for our family members with DM."

If you'd like to participate, MDF staff can help you put all the pieces together. Visit the MDF [Grandparents Day page](#) or email MDF Community Engagement Manager Aly Galloway at alyssa.galloway@myotonic.org for more information.

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Phone: 866-968-6642 or 415-800-7777 Email: info@myotonic.org
www.myotonic.org

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Myotonic Dystrophy Foundation | info@myotonic.org | Myotonic Dystrophy Foundation | P.O. Box 29543 | San Francisco, CA 94129



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