# December 2013 Volume 1

# MDF Dispatch



# Jessica's Story - A Tale of Three Sisters

Jessica Flynn's mother and twin sisters all live with myotonic dystrophy; her mother has adult-onset DM, and her sisters have congenital DM. Although Jessica hasn't experienced any symptoms, she's also getting tested to determine if she's a carrier. She often hears the comment, "It must have been so hard growing up with family members affected by DM," but she didn't see it as a burden or a problem, it was just her normal life. Read about Jessica's story.



# Meet Conor, MDF's Newest Team Member

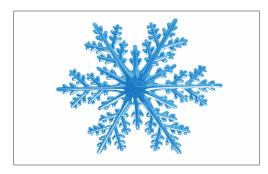
Please join us in welcoming Conor Lynch to the MDF team! Conor is our new Program Associate assisting with program support, fund development support, day-to-day operations and IT.

Conor, who is a New York native, attended the Hotchkiss School in Connecticut and has studied International Political Economy at the University of Puget Sound in Washington. In addition to his technical and professional skills, Conor brings a wealth of insight and personal commitment to MDF, given that he has multiple family members who are living with DM. <u>Click here to read more.</u>

### **Learning More About Caregiver Needs**

Last month we celebrated the many amazing caregivers in our community as part of National Family Caregivers Month. Earlier this fall, MDF conducted a survey of caregivers in the MDF community in order to help us create and deliver programs targeting their unique needs. Click here to find out what we learned about DM caregiver roles, their needs and challenges.





#### MDF Holiday Wish List

We've been blessed this year by the generosity of many. The MDF community has continued to provide support-financial and otherwise-to help us advocate for Care and a Cure. We're often asked, especially during the holiday season, if there's anything else we need for the MDF offices to help us work more productively and efficiently. In response, we've created this short "wish list" of office equipment and supplies. If you or someone you know has a desire to

help, please contact Haley Kennard at (866) 968-6642. Donations are tax-deductible and greatly appreciated!

- MacBook computer for video production
- Floor and desk lamps for the office
- USB flash drives for file transfer (large storage capacity 16 GB or better)
- 2 tall bookcases (66" x 33", 67" x 37")
- Small office tool set for general repairs
- 2 ergonomic desk chairs (Aeron or similar)

# **Webinar Provides Insights on Caregiver Needs**

In November's Caregiver webinar, "On Being a Fearless Caregiver," Gary Barg, Founder and Editor-in-Chief of *Today's Caregiver Magazine*, shared his personal caregiving story. It was Gary's own experience helping his mother care for his father that led to the launch of the magazine, a corresponding website and conferences that focus on supporting family caregivers.



Barg encouraged caregivers to identify as a "family caregiver" and view themselves as full members of

their loved one's care team. Citing research and MDF caregiving survey results (see above Dispatch story), Barg offered practical advice on how best to support loved ones while also taking care of yourself. You can view this webinar anytime in our Digital Academy.

The last webinar for 2013 - "Coping with Depression Associated with Having a Chronic Health Condition" - will be held on Monday, December 9, at 4 p.m. Pacific time (7 p.m. Eastern time). Please sign up in advance.

Join the community! Follow us on:



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

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

**Manage Your Subscription**