

March 2013

MDF News Update



MYOTONIC
DYSTROPHY
FOUNDATION

MDF launches the new Myotonic Dystrophy Family Registry

As most of you already know, on February 28 – Rare Disease Day 2013 – we launched the brand new Myotonic Dystrophy Family Registry. The Registry is designed to help researchers, doctors and the community better understand myotonic dystrophy and help identify possible participants for clinical trials and research studies. The more people who participate, the better the Registry will work for everyone. Over 500 people registered in the first two weeks, but we hope to reach a milestone of 1,000 by May 1st. Won't you join us in this cause? [Read more about the Registry](#) and join today.



The Myotonic Dystrophy
Family Registry

Congratulations to our first raffle winner!



We're please to announce that Christopher Wilson of Saugus, California has won our first iPad giveaway raffle. Christopher's name was randomly selected from all those who joined the Myotonic Dystrophy Family Registry by 11:59 pm (PST) on Sunday, March 10. Don't worry: If you didn't win, you'll have another chance. We'll be having additional raffles in the near future and anyone who has joined the Registry at the time of the drawing will be eligible.

High School Basketball Team Champions Inclusiveness Through Athletics

Nicholas Stone loves playing basketball and is a valuable member of the team at Deep Run High School in Virginia. Although Nicholas has DM, his diagnosis doesn't prevent him from participating. In fact, every team member is a student living with developmental or physical challenges.



“Nicholas and the other kids work so hard to make this happen,” said Todd Stone, Nicholas' dad and a member of the MDF Board of Directors. “It's so moving to see the entire school come out to support them. “It gives us a lot of hope.”

Click [here](#) to watch the story featured on local CBS affiliate WTVR.

Dr. John Day discusses Stanford's new Center for DM Care and Research



We recently chatted with Dr. John Day about the development of Stanford's new Center for DM Care and Research. Click [here](#) to read the interview and learn more about this new DM Center of Excellence.

Help MDF Name the eNewsletter

MDF needs your creative thinking skills! Each month we send you this eNewsletter with the most recent and relevant news about DM and the MDF community. However, we think the name “News and Updates” could use an update. Tell us your idea for a new newsletter name and you could win two complimentary registrations to the MDF Annual Conference in November!*



NEW! Financial Resources for Families Living with DM
Now Available on MDF Website
MDF is pleased to announce the addition of a new section to the Resources page of the MDF Patients & Families section of myotonic.org. Dr. Leslie Krongold, a member of the extended staff team, a San Francisco Bay area DM support group leader and a DM community member, has created a comprehensive listing of federal and national financial resources available to people and families living with myotonic dystrophy. You'll find information on the difference between SSI and SSDI, who is eligible for each program and how to apply, information and resources on Medicare and Medicaid, rental and housing financial assistance, support for low-income women and families, information on employment assistance and much, much more.

Please post your suggestion on our [Facebook page](#) or email us by clicking [here](#). Your entry must be posted or emailed to us by 11:59 P.M. Pacific time on **Sunday, March 31, 2013**. Once a new name has been chosen, the winner will be notified by email and announced on Facebook. Good luck!

*Registration fees to the MDF Annual Conference will be waived. Prize does not include travel or other expenses.

Save the Date for the 2013 MDF Annual Conference

- November 8 and 9, Hilton Houston North in Houston, TX
- Registration will open mid-May via the MDF website

“Like” us on Facebook!

Address: 1259 El Camino Real, #150 Menlo Park, CA 94025

Phone: 866-968-6642 or 650-267-5562 Email: info@myotonic.org

<http://www.myotonic.org/>

This message was sent to email@example.com from:

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

Email Marketing by



Manage Your Subscription