March 2013 MDF News Update



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.

Congratulations to our first raffle winner!

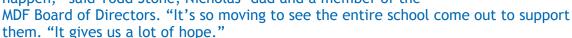


We're please to announce that Christopher Wilson of Saugus, California has won our first iPad giveaway raffle. Christopher's name was randomly selected from all those who joined the Myotonic Dystrophy Family Registry by 11:59 pm (PST) on Sunday, March 10. Don't worry: If you didn't win, you'll have another 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



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 <u>here</u> 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!*



Please post your suggestion on our <u>Facebook page</u> or email us by clicking <u>here</u>. Your entry must be posted or emailed to us by 11:59 P.M. Pacific time on <u>Sunday</u>, <u>March 31</u>, **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

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