



MdDS Balance Disorder Foundation

Dedicated to finding a cause and a cure for Mal de Debarquement Syndrome
Volume 45, December 2011

Information for Those Living with MdDS and the Medical Professionals Who Support Them

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**On behalf of the Board of Directors of the MdDS Balance Disorder Foundation
All the best to you and yours in 2012!**

Research Updates

Dr. Yoon-Hee Cha, UCLA: Dr. Cha, Assistant Professor in the Department of Neurology, continues her functional neuroimaging studies of MdDS subjects at UCLA with research support provided in part by the MdDS Balance Disorder Foundation and the National Institutes of Health. She has completed fMRI and PET scans on 20 subjects with motion-induced MdDS in comparison to 20 age and gender-matched controls. Hypermetabolism was observed in several brain regions in MdDS subjects. These findings have been submitted for formal presentation next spring and a manuscript is in preparation. In addition, neuroimaging studies of subjects with spontaneous onset MdDS symptoms (in the absence of a motion-related event) are currently being evaluated; the results will be compared to those derived from patients with motion-related MdDS. Separately, Dr. Cha is examining the potential usefulness of repetitive transcranial magnetic stimulation for treatment of MdDS. In October Dr. Cha's work was featured during a news segment on the ABC affiliate in Los Angeles, CA. [Click here to see the segment](#), and to read her comments about MdDS and the research.



Professor Christine Dancey, University of East London: In November, Jane Houghton, a member of the Board of Directors of the MdDS Balance Disorder Foundation, was invited by Prof. Christine Dancey to provide a talk about the impact of living with MdDS to the second year students and staff at the School of Psychology, University of East London, England. The talk was part of the student's module "The Psychology of Physical Illness". Prof. Dancey and her "Chronic Illness Research Team" are currently studying the ways in which psychosocial factors influence quality of life and cognition in people with MdDS. Before the presentation, students watched a video by Dr. Cha in which she gave an academic perspective on MdDS, which included discussion of symptoms and mechanisms of MdDS. Both talks were well received and afterwards there was a question and answer session in which the students advanced some very good questions. Many signed up for the Foundation's quarterly newsletter as well. Prof. Dancey and her team no longer require further volunteers for their studies. At present, they are collating the information they have received. Please check out their [website](#) for future updates; their summary of MdDS research is unlikely to be included until Spring.

Dr. Brian Clark, Ohio University: Brian Clark, PhD, Associate Professor of Physiology in the Department of Biomedical Sciences, completed several MdDS studies during 2011. One of his manuscripts based on a survey study was accepted by the *Journal of Neurology* and entitled, "Social, Societal, and Economic Burden of Mal de Debarquement Syndrome"; this reports focuses on the quality of life and socioeconomic consequences associated with MdDS. Another manuscript is in review and provides findings related to the intracortical properties of patients with MdDS as compared to asymptomatic matched controls. This research study (Role of Intracortical Excitability in Mal de Debarquement Syndrome) was conducted with research support provided by the MdDS Balance Disorder Foundation. In addition to these manuscripts, several abstracts have also been presented. Dr. Clark is developing further research ideas and plans to apply for funding to support his continued MdDS research at the [Ohio Musculoskeletal and Neurological Institute](#) (OMNI) based at Ohio University in Athens, Ohio.

MdDS Research Applications 2012: The MdDS Balance Disorder Foundation is currently accepting applications for funding of pilot studies to define the cause and treatment of MdDS. Please send inquiries to mddfoundation@yahoo.com. A Research Subcommittee to the Board of Directors will evaluate proposed studies.



The MdDS Balance Disorder Foundation has joined the [American Brain Coalition \(ABC\)](#), an umbrella advocacy federation of over 50 professional and patient organizations that seek to advance an understanding of the brain and to reduce the burden of brain disorders.



Clinical information about MdDS is now readily available to health care providers who have access to the internet service provided by [UpToDate](#). This is evidenced-based, peer-reviewed information resource, is provided to those with a subscription. Given the challenges to patients whose health care providers are unfamiliar with MdDS, this resource may improve awareness. MdDS is included in the section entitled, *Pathophysiology, etiology, and differential diagnosis of vertigo*.

[Rare Disease Day 2012](#)

Rare Disease Day: A curriculum supplement on rare diseases for high school biology classes has been developed by a genetic counseling master's degree student in collaboration with The National Organization for Rare Disorders (NORD). This curriculum contains background information for teachers and creative, flexible classroom activities to promote active learning. The activities focus on advancing scientific understanding of rare disorders; promoting compassion, empathy and respect for people with different abilities; developing critical thinking skills; and preparing students to make informed decisions as citizens.

The video posted on YouTube about MdDS has been listed as a resource in the curriculum. The curriculum will be available to download from the Rare Disease Day USA website (<http://rarediseaseday.us/>) in the coming weeks and is intended for biology teachers to use on Rare Disease Day 2012 (Feb 29) and on the days leading up to Rare Disease Day.

Year in Review:

2011 was a busy year for the MdDS Balance Disorder Foundation and its supporters:

January and February – The foundation instituted a **"Race to Rare Disease Day"** which culminated with world-wide Rare Disease Day on February 28 which is sponsored by NORD and EUORODIS. The Foundation and its supporters raised awareness about MdDS by receiving declarations from many state governors.

June – J.A.M.- June Awareness Month for MdDS: This initiative entailed fundraisers and awareness events including the Gibson's Wine Tasting Event and Silent Auction in Texas, ArtRocks and Rock Out for MdDS in Florida, and donations from the sales of Homemade Gourmet, WineShop at Home products, and Cookie Lee Jewelry. Also, the Foundation reprinted and updated the professional brochure that is available for patients and professionals. (Send a request to mddfoundation@yahoo.com)

August – Macy's Shop for a Cause once again spread information and raised much need contributions. This effort was spearheaded by the Gibson's. Also, during August, the Foundation received a **\$2 for \$1 Matching Donation Challenge**, from an anonymous donor, up to \$50,000. This set off a series of events aimed at **"Making the Match."**

September – In order to **"Meet the Match"** a pledge system was implemented at Click & Pledge, which donated licenses of Salesforce for Social Good to manage donor information for the Foundation

October – October was an extremely busy month that started with the **Gibson Girls Open House** which was followed by the **Denver Rock-n-Stroll and Friendraiser**. This event brought together sufferers and supporters as we worked for a common goal. The initiative was started by Karen, Holly, and Wendy in Denver and spread world-wide. Hayley ran a half-marathon in the United Kingdom as the kick-off event before teams walked and raised funds in Texas, Florida, New England, Washington, New Mexico, California, and the UK. This event set off a series of articles in newspapers across the country which can be accessed under the news tab on the main website by clicking [here](#) or by visiting the Foundation's Facebook [page](#). Click [here](#) to see more pictures of the Walk activities and [here](#) to read Karen's wrap-up.



Throughout the year almost 1,500 professional brochures were sent out.

And, as of January 1, 2012, Holly Balog will join the Board of the Directors. Welcome Holly.

The MdDS Balance Disorder Foundation is happy to announce that we

"Made the Match"

and received a very generous donation from anonymous donors.

This would not have been possible without the support of donations from contributors all over the world. The Foundation received many donations from first time supporters. We would like to thank the anonymous donors for their very generous matching gift for MdDS research.

Links to fundraiser pages are below.

Honor Donations since September 2011:

Chris Carr Make the Match - in honor of Lynne Kanne	Gary & Connie Orr In honor of Diane Bruning
Alice B. Beal School We walk for Deb!	Virginia and Julian Zawacki Make the Match for our daughter, Deb
Chuck Gass In honor of Suzie Gass	Eric and Merideth Sidewater To Aunt Marilyn, It is great what you and Roger have done to raise awareness for this disorder. I hope a cure is found soon. Love always, Eric & Meredith
American Box and Recycling Corp. Stuart Parmet Make the Match for Aunt Marilyn	Larry Parmet For Aunt Marilyn
B. Thompson Helping to find a cure for my mother, Nancy Braun.	Scott Epstein/Motorola Mobility Foundation Make the Match - In honor of Marilyn Josselyn
Marilyn Josselyn In honor of Roger Josselyn, whose efforts led to establishing our Foundation, and contacting our Medical Advisors, which led us to Dr. Cha!	Craig Becker/ Collette Riesbeck Sylvie Becker from her mother Colette Riesbeck. God Bless
Nelle & Harvey Jenkins Make the Match in honor of Terri G.	Paul Devlin Make the Match for Sylive Becker
Ann & O.C. Adcock For our daughter Sue Gass	Sue Majka Make the Match for MdDS Research and my friend Deb
The Katalina Group - Kathy Teter Make the Match - In honor of Holly Balog	Scott & Tina Epstein Seeking a cure for mom, Marilyn J.
Robert N. Sidewater Seeking a cure for my sister, Marilyn J	Chuck Gass In honor of my wife, Sue Gass.
Anonymous For all of us	Lois and Gerald Goldberg Stop the Rock - Make the Match - For Karen
Wendy Shiao Good luck, Karen!	Katrina & Matt Katsarelis We love Cori Williams!
Noah, Zac and Lila Galinkin Good luck Mom!	Stephanie, James, Jolie & Perri Supporting the Galinkin Family!
Michael and Peggy Pitt Make the Match - For Karen	P. Eng Good Luck Holly!
Margaret Filliman Go, Wendy!	Larry & Phyllis Galinkin for Karen's Denver Walk
Drew, Kara, & Bailey Berube for Karen's...all our love Drew, Kara, and Bailey	Carmen & Matt Chalek good luck Karen!
The Jacobson Family What a great event, Karen. You are a super star!	Mary Kay Hayman You, go, Wendy!
Judy & Quintin Best of luck Holly!	Colleen & John Dunn Good luck Holly!
Joel and Carol Yesley In honor of Karen G	Martin & Davia Leach Plantation, Florida "Rock & Stroll" in honor of Karen Galinkin and her first annual walk for MdDS
Donald & Linda Kosh Plantation, Florida "Rock & Stroll" in honor of Karen Galinkin and her first annual walk for MdDS	Barry & Jean Salner Salner Plantation, Florida "Rock & Stroll" in honor of Karen Galinkin and her first annual walk for MdDS
Clayton & Judith Sattler Sattler Plantation, Florida "Rock & Stroll" in honor of Karen Galinkin and her first annual walk for MdDS	Lito Valderrama in honor of Wendy
Paula Moran Celebrating my beautiful friend Deb!	Irene & Tim Hartman In honor of our 30th anniversary. :)
Jim & Gina Whipple Walking for our friend Debi.	Sue Majka, her family and friends To Deb, the bravest women I know
carol noske Go Deb! Melanie and I will be walking for you!	Darren Bondy - Fundraiser in honor of his mom
Cori Williams For Rudy, in honor of my beloved Molly.	Tom and Rhonda Pierce Best wishes Cathy for reaching your goal!
Maria Happy Birthday Cathy!	Terri Gibson Happy Birthday, Cathy!
Roy & Jackie Troppman Best of Luck Cathy!	RICK SCHOLL GO CATHY! Best regards, Rick
Egoscue Palm Beach Gardens Keep Up All Your Hard Work Cathy!!	Katie Deits Great job Cathy! See you on Sunday
James Morris My daughter, Kimmie, has been fighting this for years.	Gail Duvall For my daughter Kimberly. (MdDS for 8 years)
Jack Hope to find cure for Leslie. :-)	Hayley's Half Marathon in honor of Jane Houghton
Brett Nelson - in honor of Mike Nelson	

[MdDS Balance Disorder Foundation](#) (main fundraising site)

[First Annual Walk-a-Thon and Friendraiser for MdDS](#)

[New England Walks for MdDS](#)

[Team Jupiter](#)

[Team Texas](#)

[Darren Bondy's Fundraising Page](#)

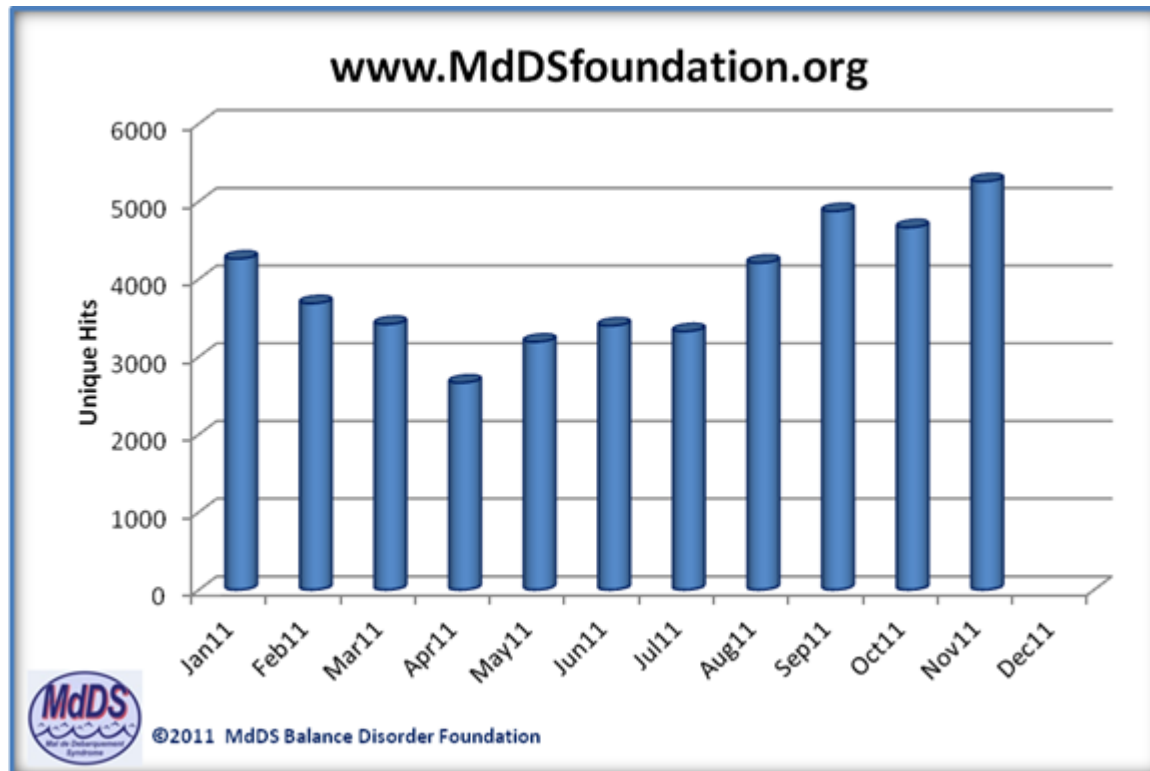
[Team Leslie](#)

[Hayley's English Half Marathon](#)

[Pam Kelly](#)

[Maria Lavelly](#)

Public Web Site Use through November, 2011:



The public website of the MdDS Balance Disorder Foundation (www.mddsfoundation.org) continues to serve as a much-needed resource for those who seek information about MdDS. This site also facilitates fund raising and MdDS research awareness. There have been 270,000 hits on the MdDS Balance Disorder Foundation website since its inception.

Contact the MdDS Balance Disorder Foundation - newsletter@mddsfoundation.org

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