



### ***MdDS Balance Disorder Foundation***

Dedicated to finding a cause and a cure for Mal de Debarquement Syndrome  
Volume 40, May 2010

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

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## **UCLA Motion Perception Study**

Dr. Yoon-Hee Cha is currently recruiting individuals to participate in a motion perception study at the University of California at Los Angeles (UCLA). This research study will lead to a better understanding of MdDS.

[Click here for recruiting details](#)

In addition, the MdDS Balance Disorder Foundation is listed in *2010-2011 Resources Directory* published by the National Institute of Deafness and Other Communication Disorders (NIDCD). The NIDCD is the primary institute of the National Institutes of Health (NIH) (USA) that provides research grant opportunities for those who study balance disorders. This is the source of Dr. Cha's current NIH funding.

Mal de Debarquement Syndrome is listed in the current *NIDCD Fact Sheet of Balance Disorders*. This listing will assist those currently seeking recognition of their symptoms. (<http://www.nidcd.nih.gov/staticresources/health/balance/BalanceDisordersFactSheet.pdf>)

### ***June is Mal de Debarquement Syndrome***

#### ***(MdDS) Awareness Month***

The month of June is *Mal de Debarquement Syndrome Awareness Month*. The MdDS Balance Disorder Foundation is hosting fundraising and awareness events to bring information about MdDS to the forefront as we search for a cause and a cure for this rare disorder. Please let us know if you would like to sponsor an event or online fundraiser by going to [www.firstgiving.com/mddsfoundation](http://www.firstgiving.com/mddsfoundation) or by contacting us at [newsletter@mddsfoundtion.org](mailto:newsletter@mddsfoundtion.org).



- Hayley Wilkinson, a young lady from the United Kingdom, recently recorded a song entitled, "Rock the Boat" to help kick off MdDS Awareness Month. The song and video should be ready for release by the beginning of June, please watch for more information in the near future.

- On June 18th, *Dr. Ron Tusa*, of the MdDS Balance Disorder Foundation Advisory Board, along with *Jane Houghton*, of the MdDS Balance Disorder Foundation Board of Directors, will present at the "The Advanced Level Balance Course" organized by the *Institute of Sound and Vibration Research* from Southampton University in England. The three-day course is aimed at clinicians from all over the world who have a sound knowledge of vestibular assessment and management and wish to consolidate and advance their knowledge. The course incorporates group practical work and the examination of patients with specific disorders. Dr. Tusa will handle the diagnosis and treatment of MdDS while Jane will explain what it is like to live with MdDS to the sixty or so attendees from a patient's perspective. Recently analyzed patient survey information will be included in the presentation. There is always hope that one of those attending the conference just might be our future in cracking the mystery of MdDS!

- *~Catch the Chocolate Wave~* On June 18th, Terri and Mike Gibson will host an *Evening of MdDS Awareness at The Chocolate Lounge* in Old Town Spring, Texas. (<http://www.thechocolatelounge.net/Home.html>) The evening will feature dessert, chocolate, wine, live music, and a silent auction. Come have dessert and listen to the music of *Gary Floyd*. (<http://www.gary-floyd.com/>), participate in a silent auction, and enjoy the company of good friends while learning more about MdDS which Terri has been living with for over four years. For tickets, please go to: <http://mddswave.eventsbot.com/>
- For the June campaign, Terri Gibson created a new public service announcement explaining Mal de Debarquement Syndrome and the Foundation which can be seen at [www.firstgiving.com/mddsfoundation](http://www.firstgiving.com/mddsfoundation) or by clicking [here](#). It is also easy to make a donation while visiting the site. As always, you can find alternate ways to donate at the [MdDS Foundation](#) web site.
- *Putting a Face to MdDS*: We are currently looking for people to write recounts of their MdDS journey including their precipitating event, getting a diagnosis and coping skills for living with this life-altering syndrome. We would like to highlight these stories during Awareness Month and on the web site. (Please send information to [newsletter@mddsfoundation.org](mailto:newsletter@mddsfoundation.org))

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*On the evening of April 25th, Jane and Neil Houghton hosted an awareness and fund raising event at the **Toft Cricket Club** in Knutsford, Cheshire, United Kingdom. Attendees enjoyed music by "Roped In" and participated in a Silent Auction that benefitted the Foundation. Educational brochures about MdDS were distributed in order to increase international awareness of the syndrome.*



## ***MdDS in the News:***

*During the months of February and March, awareness of MdDS was increased by media coverage.*

### ***Washington Post***

*On March 16, 2010 the following article appeared in the Washington Post. The article contains input by Dr. Zee and Dr. Cha, as well as from support group members.*

*It is reprinted with the author's permission.*

### ***Rare disorder makes people feel off balance for weeks or months***

*By Diane Daniel  
Special to The Washington Post  
Tuesday, March 16, 2010*

*When Claudette Broyles tries to describe to friends how she feels, she likens herself to a balloon on a string, tied to a post.*

*"I'm constantly rocking and swaying, but the level changes," said Broyles, 60, of Woodstock, Va. "If I'm having an average day, then it's like I'm a balloon in a mild breeze. If I'm having a bad day, it's like it's really windy."*

*I hadn't heard the balloon analogy before, but I could relate.*

*Broyles and I suffer from mal de débarquement syndrome (MdDS), an uncommon balance disorder that one researcher describes as "motion hallucination." For weeks, months or even years at a time, we feel that we are rocking, bobbing, swaying, even though diagnostic tests for balance, hearing and vision show up normal. The name for the illness is French for "disembarkation sickness," so called because it most frequently occurs after being on a boat.*

[Read more](#)

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### ***Palm Beach Post***

*On March 19, 2010, The Palm Beach Post carried an article entitled, "Jupiter Woman Reaching Out to Bring Awareness to Rare Disorder," about life with MdDS based on an interview with Cathy Helowicz. It can be read [here](#).*

### ***~Valentine's Day Challenge and Race to Rare Disease Day~***

***Both the Valentine's Day Challenge and the Race to Rare Disease Awareness campaign and fundraisers were very successful. We had many new donors and made contact with established members of the Support site who we had not heard from in some time.***

[\(click here to see the donor list\)](#)

**\*Thank you to all of the support group members, their families, and friends who supported these initiatives. A special thanks to Carmen, Susan and Emily Russo who did a phenomenal job of raising awareness and funds in the New England area.\***

*There were also two successful but smaller fundraisers. During the month of April we wished the co-founder and current president of the MdDS Balance Disorder Foundation, Marilyn Josselyn, a "Happy Birthday" with well wishes and contributions through [www.firstgiving.com/mddsfoundation](http://www.firstgiving.com/mddsfoundation).*

*A Mother's Day Fundraiser was held through [www.firstgiving.com.mddsmomsday](http://www.firstgiving.com.mddsmomsday) in honor of mothers living and coping with MdDS.*

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## Summer Planning:

- **Dr. Linda McManus and Terri Gibson, members of the MdDS Balance Disorder Foundation Board of Directors, will exhibit at the 61st Annual Session and Scientific Assembly of the Texas Academy of Family Physicians (TAFP) to be held in San Antonio on July 23-24. They will be available to provide brochures, survey results, and first person accounts of life with MdDS.**
- **Look for results of our recent Initial Survey and Water Related Onset Survey in our next issue.**

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### Volunteers:

As always volunteers are needed to help with the ever growing commitments we are taking on. And, of course, your ideas and suggestions are always welcomed!

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**To donate to the MdDS Balance Disorder Foundation please go to [www.firstgiving.com/mddsfoundation](http://www.firstgiving.com/mddsfoundation) or <http://www.mddsfoundation.org> for alternate ways to donate.**

Remember to join us on [Facebook](#) and [Facebook Causes](#).

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