



***MdDS Balance Disorder Foundation***  
Dedicated to finding a cause and a cure for Mal de Debarquement  
Syndrome  
Volume 38, December, 2009

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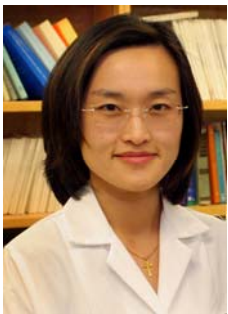
On behalf of the MdDS Balance Disorder Foundation, I would like to extend our thanks for a very productive year. The Foundation goals of educating the public and professionals progressed this year as witnessed by the increase in the number of people participating in the Yahoo support site, the Facebook sites, and by the frequency of hits on our public web site. Recently, we were in contact with doctors in Kuwait and India who have been able to diagnose patients based on the educational efforts of the Foundation and Dr. Ron Tusa, a member of the Advisory Board. And now, the goal of extending research efforts is taking shape as the NIH is funding research at the University of California at Los Angeles (UCLA). DZR

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***Clinical Study of Mal de Debarquement Syndrome (MdDS)***

***Will Be Supported by the National Institutes of Health***

Yoon-Hee Cha, MD, has been awarded a three year grant by the National Institutes of Health (NIH) to conduct clinical studies on Mal de Debarquement Syndrome. Beginning on January 1, 2010, Dr. Cha will receive funding from the National Institute on Deafness and Other Communication Disorders (NIDCD), a NIH institute that supports research on disorders of balance. The award to Dr. Cha (*Functional Neuroimaging and Transcranial Magnetic Stimulation in Mal de Debarquement*) represents the inaugural use of federal research dollars to research the cause and potential treatment of MdDS.



Dr. Cha is a physician-scientist in the Department of Neurology at the University of California at Los Angeles (UCLA) where she provides routine clinical care and undertakes clinical and translational science investigations. Based on her prior MdDS research efforts, Dr. Cha was a recipient of the *Early Career Distinguished Investigator Award* from the MdDS Balance Disorder Foundation in 2008. More recently, she was inducted into the *Researcher Hall of Fame* by the National Organization of Rare Diseases (NORD). In her impending NIH-funded research studies, Dr. Cha will collaborate with other specialists in brain function, neuroplasticity, vestibular rehabilitation, and neuroimaging to examine possible etiologies as well as improved diagnostic tests and treatments for MdDS.

MdDS is a rare, but often debilitating disorder that affects women more often than men and typically presents with imbalance, fatigue, cognitive impairment, and

sensations of rocking, swaying and bobbing. The wide spectrum of MdDS symptoms usually develops after a cruise, plane flight, or other passive motion event and may persist for months to years. Although sensations of movement or phantom motion perception imply an altered integration of sensory input in the brain, little is known regarding the basis for or treatment of this often-misdiagnosed syndrome. Dr. Cha's on-going research studies and her impending NIH grant to expand these efforts provide worldwide hope for those affected by this disorder.

The MdDS Balance Disorder Foundation is dedicated to promoting MdDS awareness and research and will continue to facilitate Dr. Cha's clinical research efforts. The Foundation is an international, all-volunteer non-profit organization that operates as a PA 501(c)(3) corporation in support of MdDS education and biomedical investigations.

### ***Macy's Shop for a Cause***



The MdDS Balance Disorder Foundation participated in Macy's *Shop for a Cause* on Saturday, October, 17th. We sold Macy's shopping passes that included exclusive savings for a \$5 donation. We had a table at Macy's Willowbrook Mall in Houston and sold passes to customers as they came in to shop. With our pre-sales and the in-store event, we sold over 300 shopping passes which netted over \$1,500 for our cause.

The success of this event would not have been possible without the help of friends, family, support group members, and board members. Thelma Triplett, a member of our support group who lives in Houston, volunteered with us at Macy's. Some "friends" of the Foundation also spent a few hours of their Saturday volunteering at Macy's. Thanks to Carolyn Roher, Rachel LeLeux, Sandra Hardy, Emily Bradley, and Mike Gibson.

Thanks to our Support Group Members Irene Hartman, Linda Hardy, Cori Williams, Kim Kepner, Thelma Triplett, Samantha Solomon, Judy Messenheimer, and board members, Deb Russo, Linda McManus, and Marilyn Josselyn who either purchased or secured donations for shopping passes.

With the success of this event, we anticipate including it as an annual fundraiser for the foundation. Hopefully, we can have more participation as we try to grow this to a national event.

Thanks again to those of you who supported the cause.

Terri Gibson  
Treasurer  
MdDS Balance Disorder Foundation

## [Facebook Cause Page](#)

Thank you to all who have visited the Mal de Debarquement Foundation Cause Page on *Facebook*. Over \$2,000 in donations were made through this page including those from supporters who participated in Parade Magazine's *America's Giving Challenge* and those who supported Cathy in her birthday challenge.

### **Honor Donations**

We would like to acknowledge those who made honor donations:

#### For *Cathy Helowicz' birthday*:

Terri Gibson, Marilyn Josselyn, Heidi Vandor, Steve Hill, Debbie Kammerer, Don Dillion, Terri Hall, Dominic Molyneax, Ruth Staiman, Amanda Finnis, and Mary Lou Dorio

#### For *Deb Russo's birthday*:

Mike Russo, Terri Gibson, and Marilyn Josselyn

*\*In lieu of a holiday gift, please consider making an honor donation for someone you love.*

*Many thanks!!*

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## ***World-wide Rare Disease Day will take place on February 28, 2010***

In the United States, Rare Disease Day is sponsored by [NORD](#), the National Organization for Rare Diseases.

If anyone in the United Kingdom, who is formally diagnosed with MdDS, is willing to share their story with the media to help raise awareness of this condition please contact Jane: [jane@mdds.org.uk](mailto:jane@mdds.org.uk)

Stay tuned to find out how you can get involved in both Europe and the United States. [Top](#)

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### **[Patient Perspective](#)** **[Difficulty Getting a Diagnosis in the UK](#)**

Although my symptoms started on 17<sup>th</sup> October 2004, whilst on our first wonderful three week cruise, I was finally confirmed as having MdDS on May 9<sup>th</sup> 2008, by Dr. Tim Mitchell MA, FRCS (ORL-HNS) at Spire Southampton Hospital.

It became noticeable on land at Lisbon, our last port of call before disembarkation. I visited our excellent GP, here in Worthing, on November 8<sup>th</sup> 2004. Yes, I thought I was still very much at sea. Pushing a friend in a wheelchair somehow defied an intelligent description, but was extremely peculiar; I thought there was something wrong with the wheelchair but, of course, I later realised that it was me!

By the end of November, I had had to give up my two exercise classes a week; I also had to give up my long service as a Samaritan volunteer, after 35 years. All domestic activities became an ordeal, even walking upstairs was an unpleasant experience.

In early December I saw an excellent ENT consultant at Goring Hall Hospital in Worthing. He found nothing to suggest that the problem was to do with my ears, and referred me to a neurologist who was a colleague at Goring Hall, whom I saw just before Christmas 2004. I had an MRI scan on 30<sup>th</sup> December, which proved that my brain was normal!! He tried me on propranolol for six months, all to no effect.

In April 2005, a neurologist referred me to a famous vestibular professor whom I saw in London on 6<sup>th</sup> May, and she diagnosed the condition as being a vestibular disorder. She was dismissive, when I brought up the suggestion of MdDS, and assured me that my condition ".....had nothing whatever to do with having been on a cruise; it was pure coincidence"! She also arranged for me to have a series of tests carried out at the Royal Neurological Hospital in Queen's Square, London; too numerous to list for someone who types with two fingers!! Again, these showed that everything was normal, other than a very slight vestibular disorder.

She then arranged for me to have intensive vestibular rehabilitation with a physiotherapist, in Harley Street. I did everything she asked me to do, diligently, twice a day for ten months. When I found that there was absolutely no improvement whatsoever that changed my persistent rocking, swaying and bobbing, I stopped doing the exercises.

Of course, all the above information is a mere snapshot of my whole situation. My youngest nursing, as in medical, daughter was the one who put her finger on the problem, within the first few weeks, back in November 2004, so I have had the comfort of learning all I could way back, by finding much information on the internet. In fact, she herself has experienced 4 or 5 episodes, following various forms of travel, though her symptoms have not been severe or disruptive, and have not lasted longer than about 4 months. She is 43 and I am 65.

My other two daughters, aged 44 and 45, have also had one or two periods of rocking, not spinning, following plane and/or sea travel, so it seems to be a familial problem.

My husband's extreme kindness and Jane Houghton's support are hugely important to my ability to bear this dreadful condition. SC

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**Please consider making a tax deductible year-end contribution to the  
MdDS Balance Disorder Foundation:**

Use the PayPal Button at [www.mddsfoundation.org](http://www.mddsfoundation.org) and indicate the honoree on the PayPal form.

Send Cash and Checks:  
MdDS Balance Disorder Foundation  
c/o Marilyn Josselyn, President  
But we don't want to ...  
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