



# Mal de Debarquement Support News

A Newsletter for the International Members of the MdDS Support Group and the Professionals Who Treat Them

Volume 32

February, 2009

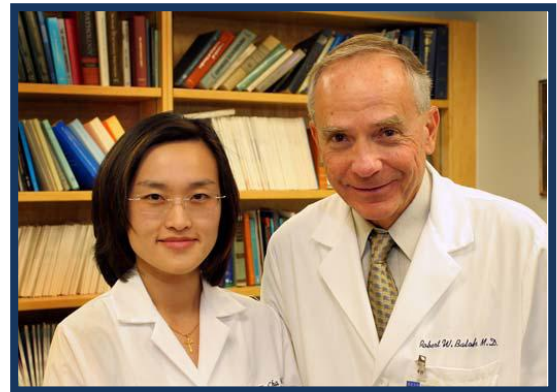
But, we don't want to!

## Significant Donation Makes it Possible for Dr. Yoon-Hee Cha To Investigate MdDS

Dr. Yoon-Hee Cha, recipient of the MdDS Balance Disorder Foundation's 2008 *Early Career Distinguished Investigator Award*, will move forward with her research into Mal de Debarquement Syndrome (MdDS) with further support provided by the Foundation. Trained in Neurotology, Dr. Cha is a researcher in the Department of Neurology at the University of California, Los Angeles (UCLA) where she provides clinical care and undertakes clinical and translational science investigations. In her 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 disease that manifests with sensations of rocking and swaying, false motion, imbalance and cognitive impairment. The wide spectrum of MdDS symptoms usually occurs after a cruise, plane flight, or other passive motion event and may persist for months to years. Presently, little is known regarding the basis for or treatment of this often-misdiagnosed syndrome.

The MdDS Balance Disorder Foundation is an international, all-volunteer non-profit organization dedicated to promoting MdDS awareness and research. The Foundation operates as a PA 501(c)(3) corporation with a mission to support biomedical studies designed to provide a better understanding of the dysfunction that underlies this motion and balance disorder. Support for MdDS research is based in part on a \$50,000 charitable contribution by an interested anonymous donor as well as donations received from numerous others.

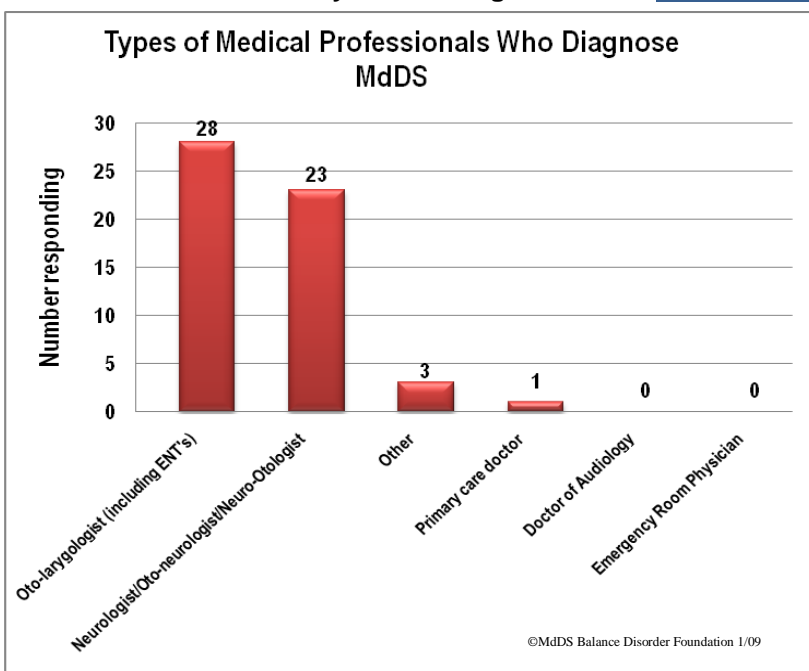


Yoon-Hee Cha, MD, and her mentor, Robert Baloh, MD from the Department of Neurology at UCLA. Dr. Cha received the 2008 *Early Career Distinguished Investigator Award* from the MdDS Balance Disorder Foundation. Photo by Reed Hutchinson.

For information, please access [www.mddsfoundation.org](http://www.mddsfoundation.org) or contact D. Russo at [mddsfoundation@yahoo.com](mailto:mddsfoundation@yahoo.com).

## Who Makes the MdDS Diagnosis? - Survey Results

As the Mal de Debarquement Balance Disorder Foundation plans its information to be used at the American College of Physicians-Internal Medicine Conference in Philadelphia, PA in April, 2009, a survey to determine which type of doctor is most likely to make the MdDS Diagnosis was undertaken between 12/13/2008- 01/07/2009. Access to this survey was through a link at [www.mddsfoundation.org](http://www.mddsfoundation.org). During this short, focused survey, 65



people responded, with 55 of them having a positive diagnosis of Mal de Debarquement Syndrome.

For those living with MdDS it takes an average of 3.7 different doctors to receive a diagnosis. The maximum number seen before diagnosis was 10, minimum was 1, with a standard deviation of 1.99. There were 54 female responders and 1 male, whose average age was 52 years, 7 months (when the survey was taken).

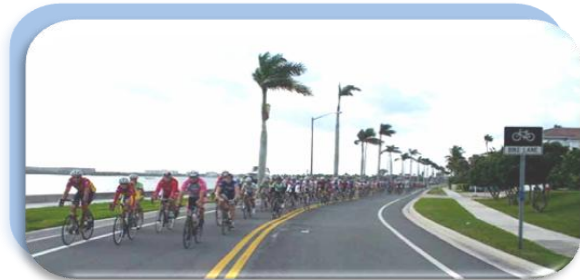
This information verifies what has been found in earlier surveys; it is not a diagnosis that is made by primary care or emergency room doctors.

***"I first saw an ENT who had no idea what I had, my primary doctor did not know either, a second ENT misdiagnosed me with MAV and finally the neurologist recognized my symptoms as MdDS, and he diagnosed my condition as such. I am followed by an ENT who is very educated about MdDS." Patient Statement***

## Cathy's Friends Ride for MdDS Awareness

On January 1, 2009, the MdDS Balance Disorder Foundation kicked off the year early with a breakfast for the 300+ cyclists who participated in the annual New Year's Day Lake Worth 60 mile Ride. MdDS stands for Mal de Debarquement Syndrome and is a rare balance disorder with no cure. The foundation is once again working hard to raise awareness of this rare disorder in hopes of identifying research opportunities, which will lead to a cure. This is the first of a number of awareness campaigns planned for 2009.

Cathy Helowicz, who could not participate in this ride due to her MdDS, single-handedly organized an MdDS Awareness Breakfast after the annual New Year's Day bike ride in Lake Worth, Florida. With the help of friends and the FatCats Bicycle Shop, Running Sports, and Cycle Science Bicycles-Jupiter, Cathy has made a difference and educated a new audience.



### Global Rare Disease Day Set for Feb. 28, 2009



Rare Disease Day

The Mal de Debarquement Balance Disorder Foundation will participate in a global Rare Disease Day on February 28th, 2009. As a Rare Disease Day Partner, we will join hundreds of other patient organizations, government agencies, medical societies, and companies in focusing attention on rare diseases on that day. This will be the Second Annual Rare Disease Day. The first was observed in Europe last year and was organized by EURORDIS, the European Rare Disease Organization, and the national alliances of rare disease patient organizations in each country. This year, EURORDIS invited NORD, the National Organization for Rare Disorders, to organize a similar observance in the United States. Activities are also being planned in some other countries. The ultimate goal is to have a global Rare Disease Day on the last day of February each year. The theme is that rare diseases are a public health issue, affecting millions of people around the world. The hope is that Rare Disease Day will increase awareness of rare diseases, the special challenges encountered by those affected, and the need for research to develop safe, effective treatments or cures. As a Rare Disease Day Partner, our organization has agreed to help publicize and promote Rare Disease Day.

**U.S. Rare Disease Day page on the NORD website:**  
[http://www.rarediseases.org/rare\\_disease\\_day/rare\\_disease\\_day\\_info](http://www.rarediseases.org/rare_disease_day/rare_disease_day_info)  
**Global Rare Disease Day website:**  
[www.rarediseaseday.org](http://www.rarediseaseday.org)

### Honor and Memorial Donations

- ❖ **Mr. and Mrs. J. Zawacki** contributed in honor of their daughter, **Deb Russo**. (A matching donation from the Mobil Corporation has been applied for.)
- ❖ A donation was made in honor of **Judy Messenheimer** by **Roger and Goldie Sample**.
- ❖ **Mike Russo**, contributed in honor of **Deb Russo** with wishes for a Merry Christmas.

Honor and Memorial Donations can be made in the following ways:

Use the PayPal Button at [www.mddsfoundation.org](http://www.mddsfoundation.org)

and indicate the honoree on the PayPal form.



**Send Cash and Checks:**

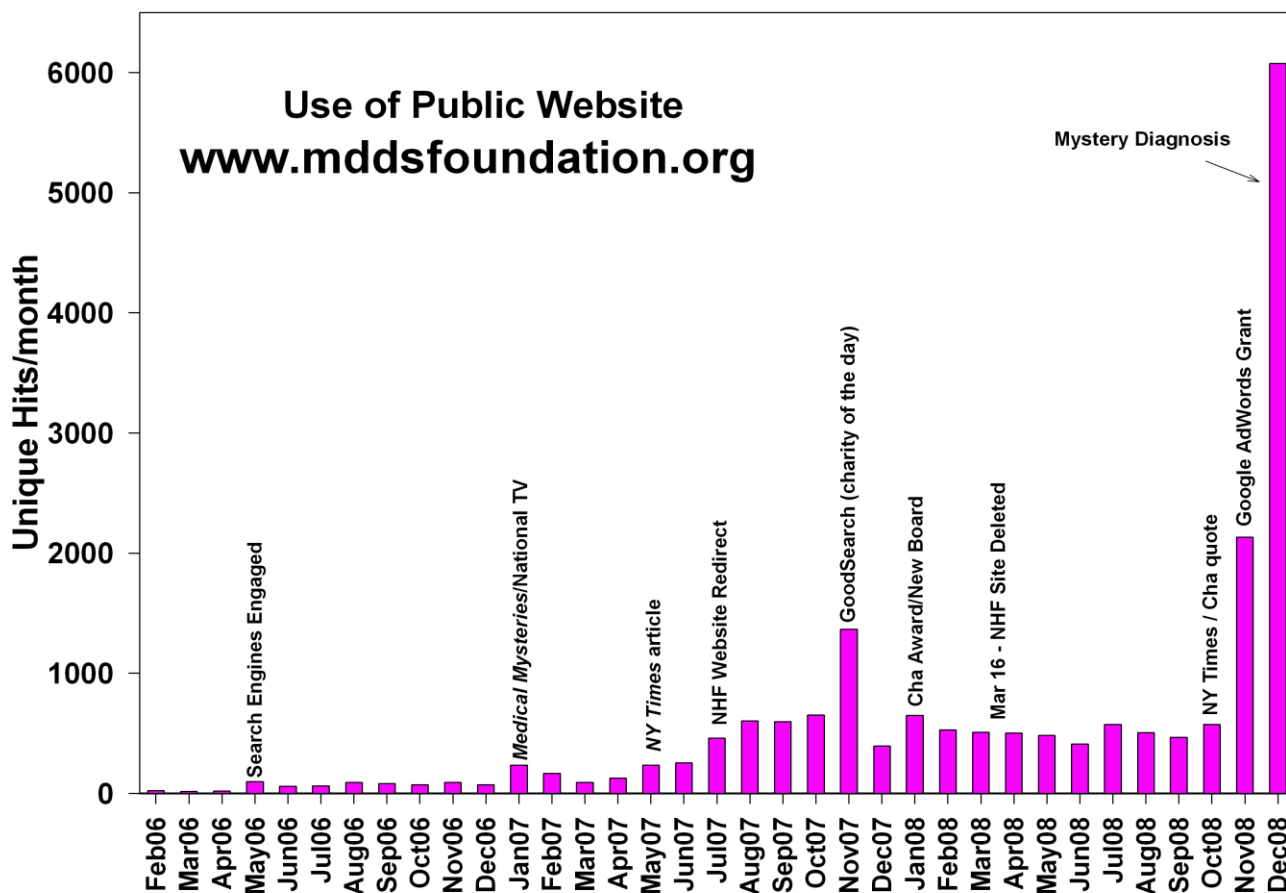
**MdDS Balance Disorder Foundation**

**c/o Marilyn Josselyn, President**

**22406 Shannondell Drive**

**Audubon, PA 19403**

In our last newsletter we reported that the Discovery Health Channel, *Mystery Diagnosis* would be airing a segment on MdDS, "The Woman Who Couldn't Stop Rocking," and that the Foundation received a grant from Google Ads. The show, which is still being shown on the Discovery Health Channel, features Rosanne Jensen and her family. The response to the show was, and continues to be phenomenal. The number of requests for Support Group membership and unique hits on our webpage have reached an all time high. (see graph). In case you have not seen our Google Ads, use the search engine to look up Mal de Debarquement, and at the top of the page or in the column on the right to see ads that link to our website.



(c) 2009 MdDS Foundation

**You can watch the Discovery Channel, *Mystery Diagnosis* Episode,**

***"The Woman Who Couldn't Stop Rocking"* on:**

**January 26, 2009 @ 10:00 PM**

**January 27, 2009 @ 2:00 AM**

**January 31, 2009 @ 5:00 PM**