



*MdDS Balance Disorder Foundation ~ June 2009*

**Information for the International Members of the MdDS Support Group and the Professionals Who Support Them**  
***Mal de Debarquement Syndrome***

[Researcher Hall of Fame](#) [Medical Conference](#) [Personal Perspective](#) [Fund Raising and Events](#) [Information](#)

**Dr. Yoon-Hee Cha**  
**nominated to the**  
**NORD Rare Disease Day Researcher Hall of Fame**

[http://www.rarediseases.org/rare\\_disease\\_day/Hall\\_of\\_Fame](http://www.rarediseases.org/rare_disease_day/Hall_of_Fame)

Dr. Yoon-Hee Cha was recognized, along with eleven other outstanding researchers, who are working to find cures for rare diseases that affect both young and old. We extend our appreciation to both NORD and Dr. Cha for their determination in addressing the needs of those who live with rare diseases and their families.



**Dr. Yoon-Hee Cha**  
***MdDS Balance Disorder Foundation Represented***  
**at**  
***The American College of Physicians Internal Medicine***  
***2009 Meeting***

The meeting was held at the Pennsylvania Convention Center in Philadelphia from April 21 to April 25, 2009.

For the first time the *MdDS Balance Disorder Foundation* was represented at a meeting for primary care, internal



medicine personnel. Roger and Marilyn Josselyn, Irene and Tim Hartman, and Elaine Sola manned a booth for four days of the conference. They were able to speak with the many doctors who stopped by our booth. First the medical professionals would look at our posters and the banner and then approach ready to ask questions. They were intrigued by the name *Mal de Debarquement* and what it meant. The MdDS representatives explained that it literally meant “illness of disembarking.” There were only a few who had heard of MdDS before and only a very small percentage of those doctors had patients with MdDS. Since there were three people who have lived with MdDS for varying lengths of time, they were able to talk from experience about onset and medications

Over 110 brochures were handed out to doctors, fellows and nurses. While some simply took our brochure (and some candy) and moved on, over seventy percent of those stopping by spent from five minutes to fifteen minutes discussing MdDS with us, showing a real interest in its onset and possible treatment. Many were interested in learning more through the e-newsletter, brochures, and research.

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✦ The *MdDS Balance Disorder Foundation* Support Site on [Yahoo](#) continues to grow.

People of all ages and walks of life are living with MdDS and many have been searching for a name for their symptoms for years. Now we are all searching for a reliable, consistent treatment for the debilitating symptoms. Below is one woman's perspective on life with MdDS. Many people would find this impossible to do as their balance is impaired and the rocking sensation is increased with physical exertion.

### ***A Personal Perspective of MdDS***

***by Robin***



My name is Robin, and I have suffered from MdDS since July 2004. I was 44 at the onset, and very active and healthy. During the month before MdDS came on I traveled by plane to Florida to help my sister thru a difficult surgery, and was her private duty nurse for three days without much sleep. After landing home, exhausted, I felt the rocking motion for about 48 hours and then, it went away.

A month later, we drove to the beach eight hours away. At the beach there is a shopping area with a floating bridge going over a waterway; I felt the sensation hit while walking on it and it hasn't gone away .

I had a year of going to different doctors, trying several medications without help. Nasonex is the only medication that seems to help the symptoms a little. I felt sorry for myself that year and became a couch potato. I did continue to work, but found myself growing more tired earlier in the day and by the end of the work day, I just plopped on the couch and prayed for things to stop moving.

After a long time of feeling sorry for myself, I decided it wasn't going away with being a couch potato, so I got out and walked several miles a day. After a few days, I noticed the symptoms improved some. I kept going, and soon started running. The symptoms were a little better

each day - tolerable levels.

My life has changed in many ways, and I have to be careful what I do as things still trigger the symptoms. Malls and stores increase my symptoms as do jobs that require my eyes to move up and down frequently. Shuffling cards, washing potatoes or fruit sets it off, but like many people - short car rides make it go away temporarily.

Now I've run six half marathons with respectable finishes, and will be training soon for my first Marathon in January 2010.

***If you see Robin running in her MdDS t-shirt give her a wave!***

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**🚩Upcoming Events and Fundraising:**

**"Art Rocks"**

**Wednesday, September 2, 2009**

**Lighthouse Center of the Arts**

**Gallery Square North**

**373 Tequesta Drive**

**Tequesta, FL 33469**

**(561) 746-3101**

**Children from the summer camp will be painting rocks for the MdDS fundraiser (approximately 60 rocks - paperweight size). In addition, we hope to get some celebrity "signature or doodle" rocks (much larger garden size). We anticipate that the parents and children will attend the fundraiser. The silent auction items will be "rock themed" such as hot rock massages, rock speakers, wine with names that include the word rock in them, handcrafted rock(stone) jewelry, etc. Light appetizers and wine will be served. Ticket prices- \$10.00.**

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**During the month of April a \$300.00 Matching Donation challenge was met, and exceeded through the generosity of the MdDS support site members, their families, and friends. *Thank you.***

**The *MdDS Balance Disorder Foundation* received a matching corporate donation from the Mobil Corporation. Original donation made by Mr. and Mrs. J. Zawacki.**

**Elizabeth Hefferon donated on behalf of Joan Dreux.**

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***Find us on [Facebook!](#) The MdDS Balance Disorder Foundation can be found in the Causes section.***

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 The MdDS Balance Disorder Foundation is an all-volunteer PA 501(c)(3) nonprofit foundation dedicated to promoting awareness of Mal de Debarquement Syndrome and seeking treatments and a cure for people suffering from this disorder.

In order to make a donation 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  
22406 Shannondell Drive  
Audubon, PA 19403



But we don't want too..

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