



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

Volume 36, September 2009

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### **Educating Medical Professionals and Future Medical Professionals About Mal de Debarquement Syndrome (MdDS)**

\* On July 23, 2009 Dr. Robert Slater, MD spoke about Mal de Debarquement Syndrome at the Crozer Neurology Conference. The conference was held at the Crozer-Chester Medical Center in Upland, PA. Approximately eight area neurologists, ten physicians, five residents, and fifteen nursing personnel attended the lecture which was well received and generated significant interest in the syndrome. Dr. Slater, a member of the MdDS Balance Disorder Foundation Board of Directors, is a neurologist in Drexel Hill, PA.

\* Linda McManus, PhD, included a short introduction to Mal de Debarquement Syndrome in her 2009 presentations to second year medical and dental students during lectures at the University of Texas Health Science Center San Antonio. She described her situation with MdDS, and the limited clinical studies, diagnostic tests, and therapeutic options for the syndrome. Dr. McManus, a member of the MdDS Balance Disorder Foundation Board of Directors, is a Professor at the UT Health Science Center in San Antonio, TX.

\* We look forward to working with Dr. Ronald Tusa during his preparation for the lecture he will present at the University of Southampton in the United Kingdom, June 2010. Dr. Tusa, a member of the Advisory Council of the MdDS Balance Disorder Foundation, is a Professor at Emory University in Atlanta, GA.

\*The MdDS Balance Disorder Foundation has actively informed various health care specialists about MdDS through exhibits at annual meetings of the American Academy of Otolaryngology-Head and Neck Surgery, the American Academy of Neurologists, and the American College of Physicians. These educational efforts have been intended to extend awareness of MdDS to some components of the health care community that often diagnose or treat MdDS patients.

We would like to encourage those reading this newsletter to include MdDS in their educational endeavors with both current medical professionals and those who are in training. Our Support Site group includes doctors, physician's assistants, physical therapists, nurses, and dental personnel who all agree that their education did not include information about the syndrome that now affects them.

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Click [here](#) to read an article by Susan Murphy, the Houston Health Examiner, about MdDS that appeared online at [www.examiner.com](http://www.examiner.com) . The author quotes Dr. Hain's ten year old [survey study](#). At this point the Foundation has survey information from hundreds of people living with MdDS. We have been in touch with at three people from the Hain study who are still feeling the effects of MdDS ten years later. Although we appreciate any opportunity to inform the public about our syndrome we seek to update the information.

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## Art Rocks



The Art Rocks Benefit at the Lighthouse Center for the Arts in Jupiter, Florida has been rescheduled for April, 2010. The children at the summer camp were busy painting rocks to be included in the silent auction. If you are in the Jupiter area and would like to volunteer or donate to the event please let us know

[mddsfoundation@yahoo.com](mailto:mddsfoundation@yahoo.com)



What a **difference**  
a day makes!

Saturday, October 17, 2009

Since 2006, Macy's Shop for a Cause Event has partnered with non-profit organizations nationwide to raise more than \$28 million for their ongoing charitable efforts. This is your chance to be part of this monumental event on Saturday, October 17, 2009.

Shop for a Cause gives you the opportunity to help the MdDS Balance Disorder Foundation, a 501(c)(3) non-profit foundation. By donating \$5, you will receive a Shopping Pass \* for exclusive savings and special offers in every Macy's store on Saturday, October 17th. As a participating charity, we keep 100% of the proceeds from each pass. Plus, you can enter to win a \$500 Macy's Gift Card!

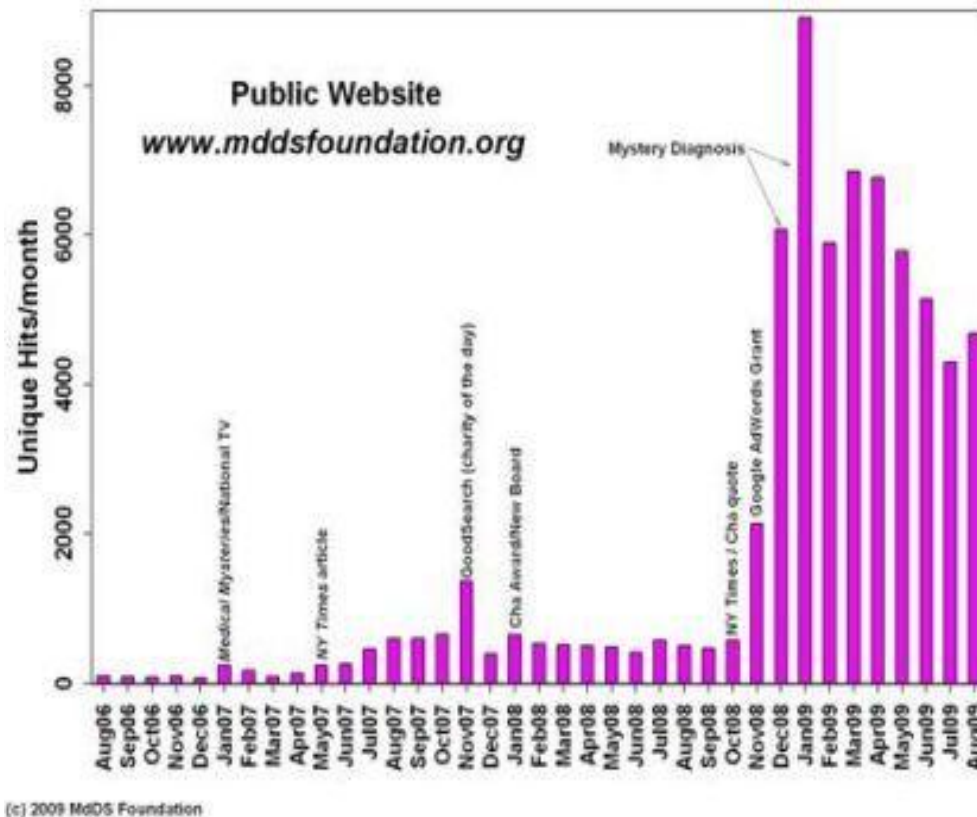
Come together with Macy's and the MdDS Balance Disorder Foundation, and while you're out enjoying a day of shopping and great savings, you'll be helping our cause at the same time.

To receive shopping passes, please make your donation using the Pay Pal button on the [www.mddsfoundation.org](http://www.mddsfoundation.org) web site. Or, send your request and check to:

MdDS Balance Disorder Foundation  
c/o Marilyn Josselyn, President  
22406 Shannondell Drive  
Audubon, PA 19403

Be sure to include your mailing information with your request for shopping passes.

## Our Public Website Continues to Thrive!



The [public website](http://www.mddsfoundation.org) of the MdDS Balance Disorder Foundation remains a vital resource for new patients with MdDS as well as for the health care professionals who treat them; this is often the place where many initially learn about the syndrome. Created three years ago, annual usage of the site continues to increase. Here, you'll find a repository of all previous Newsletters, clinical research supported by the Foundation, new patient surveys and results of previous survey efforts, details of fund-raising.

### **Patient perspectives: How does MdDS affect employment??**

As we know MdDS can be a long term, debilitating illness. Many people continue to work to the best of their abilities often with modifications to workspaces and schedules. Others find it impossible to work or lost their jobs because employers do not understand the true nature of the disorder. The following are quotes from people who have a confirmed diagnosis of MdDS by a medical professional.

- I have lost my full time status and health benefits at work, and haven't been able to earn a real paycheck in six months. It has severely blocked my ability to work at a computer-based job. My other work as a singer has also been completely impossible for six months, as the unpredictable dizziness and nausea make me unreliable (and therefore un-hirable) as a performer. The inability to travel makes being a traveling opera singer very challenging. (Female, mid-30's)

- I work for my family's business, so fortunately they understood that I could not work. I was out for several months straight. Now I work 1-2 hours per day at the office and then do work each afternoon from home lying on the floor. Side-work, like volunteerism, was halted for the first year, and now I am slowly getting back into it. I do not drive. (Female, late 20's)

- Huge effect since I am a Firefighter/paramedic and climbing ladders is very difficult. My employment is in jeopardy. (Male, mid-30's)

-I had to quit my job about 18 months ago (newspaper ad sales) . I could not function, couldn't remember what to say when I answered the phone.

- Had to give up work. I had been with the same company over 10 years and in the field over 30. I was completely unable to function at work.

- I had to retire from my dental assisting career of 34 years for fear of hurting my patients. (Female, early 50's)

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Thank you to Marla Cruise for making Mal de Debarquement Syndrome bracelets and for donating a portion of her sales to the Foundation. If you would like to order a bracelet, please contact Marla through [mddsfoundation@yahoo.com](mailto:mddsfoundation@yahoo.com).



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:  
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Audubon, PA 19403



But we don't want too..

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