



Mal de Debarquement Support News

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

Volume 30

September, 2008

After a Lifetime of Sailing, One Race Leads to MdDS

If there was a magazine called Active Woman – I think I would be in it. I am a 48-year “young” woman, (currently living in Jupiter, Florida) who has been fortunate to lead a wonderful life. I grew up on the Chesapeake Bay and enjoyed everything that had to offer. I am an Author/Publisher/Teacher. I water ski, snow ski, cycle regularly (I did a 10-day cycling trip through the South of France in July 2006). I have raced sailboats competitively since 2000 (even tried out for the Women’s Rolex Race in September 2001). I am a volunteer instructor for a Therapeutic Riding Center that helps the physically challenged ride horseback and am an avid equestrian. I snorkel, swim, hike, love to dance and have traveled the world – that is until September 24, 2007 when my world came to a halt, a rocking halt. I did a two-day sailing race the weekend of September 15, 2007, a race not unlike any of the hundreds I had done before.



My story is not unlike many others, except that I was sailing. It took 6 months, 11 Doctors (three of whom said it was not possible that I had MdDS because I was not on a cruise and because it came on a week later) and 13 medications to finally get to a specialist who recognized what I had and confirmed the MdDS. I had endured six months of anxiety and stress. As I approach my one-year mark, I look back on all I have been through and others as well. I am currently on .75mg Klonopin which helps with the rocking, I have Acupuncture treatments (one of my saving graces) done on a weekly basis and I try to stay active and exercise, but keeping up an exercise schedule is a chore. I have tried Cranial Sacral work, Chiropractic, Massage Therapy, Vestibular and Otolith Therapy.

However, nothing gets rid of the rocking and nothing gets rid of the frustration of having this disorder and not being able to live life, as I knew it. I have not traveled at all since the rocking began. I fight constant fatigue and chronic neck and head pain. Working on the computer or reading is taxing, but it is my livelihood, so I have to do it. One of the hardest parts of this whole disorder though is not being able to do the things I love so much, especially sailing. While I feel fine on the boat, the increased rocking afterwards for days, even weeks, just does not make it quite worth it right now. I know in the big scheme of things, it could be worse, but I do not believe we were put on this earth “just to get by” and that is how I feel life is right now. I am actively attempting to educate the sailing community about MdDS and organize fund raising events to raise money for much needed research.

Cathy H. - Sep 07



Rock-N-Ride for MdDS

A Rock-N-Ride Bike-A-thon is tentatively scheduled for Thursday, January 1, 2009 in Jupiter, Florida. More details will follow.

Please watch **Discovery Health:**

Mystery Diagnosis on
December 8, 2008.

(Check your local
listings for the time.)

The segment features
a documentary about



life with MdDS. Ro, who has
lived with MdDS for over nine
years, and her son and
daughter explain what it has
done to their family dynamics
and daily life.

Honor and Memorial Donation

Forms

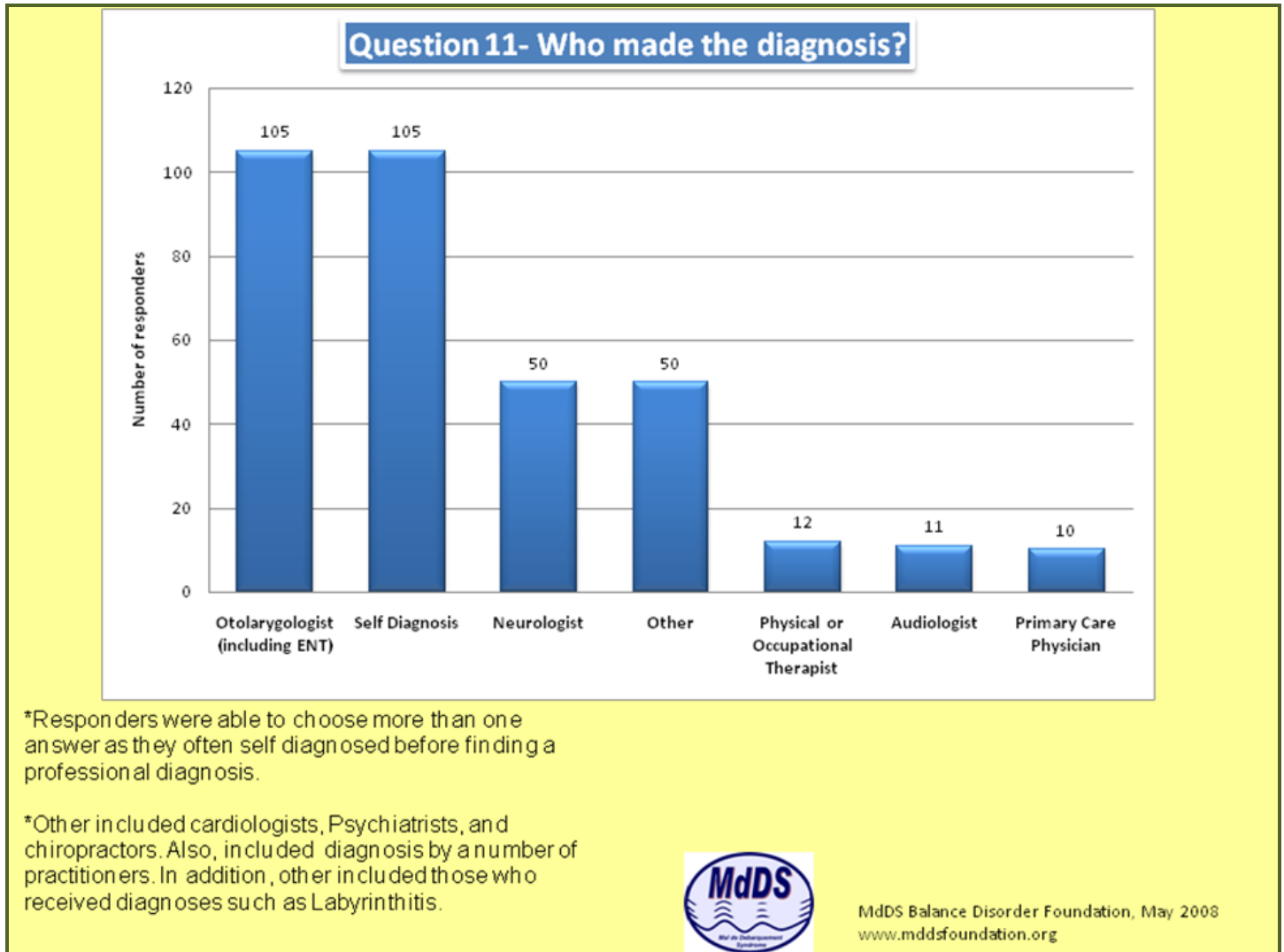
If you, your friends, or family
wish to donate to the MdDS
Balance Disorder Foundation in
memory of, or honoring
someone, we now have a form
available. The online form can
be accessed on the Foundation
website at

[http://www.mddsfoundation.org/
mdds_donation.html](http://www.mddsfoundation.org/mdds_donation.html).

Either include the completed
form with your check or indicate
the information on the PayPal
transmission.

Acknowledgements are placed
in the Foundation newsletter; no
amounts will be listed unless
indicated. The person being
honored, or memorialized will be
listed along with the donor's
name. Please let your friends
and family know that this is now
an option. See page three for
this edition's
acknowledgements.

In response to an online survey, 277 people who exhibit symptoms of MdDS, answered the question, "Who made the MdDS diagnosis?" As indicated by the survey, there is a need to educate primary care medical providers to the symptoms and ramifications of Mal de Debarquement Syndrome. Please help us peruse this endeavor through your professional and personal contacts. Please use this link to send us ideas. ([DMR](#))



Please take note of the address change for the MdDS Balance Disorder Foundation and donations that are directed there.

Operating as a 501(c)(3) nonprofit organization, your tax exempt donations to the MdDS Balance Disorder Foundation in support of research and educational programs are encouraged. Donations are accepted through Pay Pal by clicking on the button.



Or you can send cash or checks to:

MdDS Balance Disorder Foundation

Marilyn Josselyn, Treasurer

22406 Shannondell Drive

Audubon, PA 19403





Labor Day Challenge

Results

Our Labor Day Challenge collected \$1,633.56 which is a bit short of our \$2,000.00 goal.

Thank you to all who donated to this effort !

Honor and Memorial Donations

We would like to thank those who made an Honor Donation:

For Marla Cruise's recovery from surgery:

- ✚ Mandy Small
- ✚ Martha Ennes
- ✚ Terri Gibson
- ✚ Marilyn Josselyn
- ✚ Robert Slater, MD

In honor of our 31st Anniversary- for Deb from Mike Russo



The MdDS Balance Disorder Foundation would like to acknowledge that *Sharon Renschler* has stepped down from her duties as Chairman of the Board in order to devote more time to her law practice. Sharon, thank you for all of your contributions.

For more information about MdDS and the MdDS Balance Disorder Foundation visit www.mddsfoundation.org