



Mal de Debarquement Support News

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

Volume 24

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Many Thanks to Roger Josselyn, Founder of the MdDS Balance Disorder Foundation !!!

Asked to reflect on what's happened during my nine years of involvement with MdDS efforts, I've decided to favor substance over dates and data. The latter would clearly show that with a membership that grew from a few dozen to over 600 worldwide, we've made great proportional progress toward finding those souls who suffer from lack of knowledge about MdDS. And although we have made the medical profession more aware of this widely misdiagnosed disorder, we have a long way to go before someone can walk into her/his family doctor and be promptly diagnosed with MdDS, otherwise known as Mal de Debarquement Syndrome.



As a retired business manager, it was natural that I would pick up on the heels of Stanford PhD candidate Evan Torrie after my wife Marilyn contracted MdDS from our Russian waterways cruise. The nudge came when Evan's MdDS caused him to abandon his pioneering website dedicated to the disorder. Marilyn and I met with Sue Barnes and decided to pick up on

Evan's abandoned efforts. We shunned the complexities of forming our own non-profit in favor of gaining those benefits under the umbrella of the National Heritage Foundation. By January of 2007, after our first three years, we were able to wade through the complexities of becoming our own 501(c)(3), subject to the usual state and federal regulations.

Although our goal was to harness research toward effective treatments and a cure for MdDS, the lack of specific tests to diagnose it relegated us to soliciting volunteers willing and able to "spread the word". Those suffering from MdDS, and their families, needed to know what they suffered from, and the medical profession needed to stop guessing about it. One early boost was from a not to be named MIT professor who confirmed that this could indeed be a failure of a brain balance mode to restore to normal performance after a motion experience such as a cruise.

Once we found volunteers, our first publicity was through local newspapers and an occasional reference in professional articles. We distributed an informative brochure, and were greatly assisted through the efforts of VEDA and NORD, the latter having listed us through NIH. We are grateful for the support of our five member Advisory Council of physicians. We have managed to gain international attention through the efforts of our volunteers. We succeeded in being listed as an index item under **ICD-9-CM code 780.4, "Diagnosis, Dizziness & Giddiness Syndromes"**. Our members participated in tests with two forms of tactile brain retraining devices. We published a "severity scale" which helped quantify the extent to which members were impaired by the disorder. Our newsletter to a growing number of medical professionals has gained significant attention through the publication of survey findings from our 600+ members. And when we reached the national press and TV, large numbers of those suffering from misdiagnosis were able to identify their disorder and join our [Internet based support group](#). Their gratitude at "finding I'm not crazy" was overwhelming.

Still lacking the substance to target and obtain research, we turned more efforts toward the medical profession through attending the 2006 and 2007 Otolaryngology conventions. We were delighted to see many professionals who had diagnosed "a few" of their patients with MdDS, but their predominant query at our convention booth was **"how can I treat it?"**

I want to express my deep gratitude for those volunteers who have contributed large amounts of personal time and skill toward the above accomplishments (without compensation and often at their own expense). We are grateful to those who have made contributions from their own resources. And, my sincere thanks to attorney Sharon Renschler for her willingness to take over the helm. Her new Board that includes more key players than before offers great promise that we may finally take the first real steps toward research. My best wishes for success.

Roger Josselyn

Young Mother Disabled by MdDS

I was a healthy, active 38 yr old, wife, mother and daughter before I went on my first 5 day cruise to the Bahamas in April 2007. We experienced turbulent seas the last day of the cruise while returning to port. Immediately after, I began severe symptoms of imbalance, swaying, leaning to the right, constant dizziness, visual perception problems, intolerance to busy patterns, lights, and moving crowds. Thinking I had salt water in my ears from snorkeling, I went to an ENT. He found no water in my ears and wrote on a piece of paper the words "Mal de Debarquement Syndrome". He told me that a few people experience this after a cruise. It is a rare vestibular disorder and that time and rest was the ONLY answer for it. He advised me to look up the information on the Internet and prescribed Klonopin. After a week, my symptoms lessened some and I tried to return to work. To my dismay, I could barely walk without hugging the walls and furniture! My co-workers thought something bad was wrong with me and I agreed! I took a leave of absence from work and started my quest for answers. I visited my primary care physician and he had no clue what MdDS was. After some research, he prescribed Amitriptyline. Unfortunately, I had to discontinue it because it made my blood pressure drop when standing and it caused lightheadedness along with the dizziness. So my quest continued by seeing a Chiropractor. He was able to help with my balance some, but the dizziness became more pronounced and so I stopped treatment. I visited an acupuncturist a few times and that landed me in bed for 3 days! I went to 2 physical therapists. The first one had no clue what MdDS was and therefore, was afraid to treat me. The second therapist had expertise in vestibular/balance disorders but after 4 weeks of intense therapy I was worse than when we started. She discontinued therapy and advised an appointment with a neurologist. The neurologist sent me for an MRI that was negative and a BAER test (Brainstem Auditory Evoked Response) which I passed. She stated that there is little known about this syndrome and is planning to refer me to a specialty clinic possibly at Vanderbilt University in Nashville, TN. She prescribed Nortriptyline and it caused sleeplessness and lightheadedness, therefore I had to discontinue taking. I have not had much success on any drug therapy as of yet. It has been almost 7 months now and I can no longer work, be involved in the choir ministry at church, or take care of routine household chores. Simply going to the grocery store is a nightmare, however riding or driving in a car and sleep are the only two things that give me relief. My family is so concerned and I am becoming very discouraged. My life has completely changed from one who was extremely active and full to one of a disabled person. I have exhausted the internet searching everything I can find. I am praying for a breakthrough and for a doctor or clinic that can take a real interest and has knowledge about MdDS. Although my mother does not have diagnosis of MdDS she has suffered a similar balance problem for the past seven years.

Lisa

Message from the New Chairman of the Board

In this new year, we look forward to many exciting possibilities for the MdDS Balance Disorder Foundation, and look back at the milestones. We look back to Roger and Marilyn Josselyn who cared enough to start the MdDS Balance Disorder Foundation, and ultimately, the non-profit corporation that now exists for us to build upon.

We look to the future with exciting possibilities for research, education and publicity of this little known disabling syndrome; – research which will bring us closer to one day finding the cause, education of the general public and those suffering with this syndrome, to know how better to cope, how to understand what this is, and publicity to further our goals, to bring more professionals into an understanding of treatment and cause, to raise interest in professionals in helping to discover the cause, and to bring those who suffer together to discuss various ideas that are common and different in all of us.

Specifically my goals for the coming year are to:

- 1) Increase the members communicating on our web site;
- 2) Expand television publicity about MdDS as we did, thanks to Deb Russo, with the [ABC Primetime television](#) presentation on MdDS in 2007.
- 3) Encourage print publications about MdDS as we accomplished in 2007 with publications in the [New York Times and the Curry Coastal Pilot](#).
- 4) Expand our work with researchers in 2008.
- 5) Encourage and endorse the submission of grant proposals to support further research on MdDS.
- 6) Support an active and informative [Internet based support group](#) where MdDS sufferers worldwide can come to exchange ideas and talk to those who have had this for a longer period of time, thanks to Marla Cruise and others.
- 7) Utilize our expanded international Board provided by the addition of Jane Houghton of England to facilitate additional help, ideas, and expansion throughout the world;
- 8) Increase our information and manner in which to approach governmental entities where it become necessary to file for benefits, thanks to Marla Cruise;
- 9) Marilyn Josselyn is continuing her good work to spread the word that contributions are needed in order to fund convention presentations, research expenses, publications, and Foundation operations.
- 10) Gain a greater understanding of MdDS patients as a whole and of the medical communities' awareness of MdDS thanks to Robert Slater, MD, Linda McManus, PhD, Deb Russo and Marla Cruise, RN.

We will be looking for help from our MdDS population in the coming months. If you have a particular area of expertise that you feel could further the above projects, or know of a publication that may be receptive to publishing, an organization that may be receptive to contributing funds, a professional that would volunteer time or their expertise in discovery of a cause, PLEASE [e-mail](#) me in order that we can work together to further the cause. Communication will be our key to success.

Finally, it is the goal of the Board to keep everyone informed of news in these areas through our [website and newsletter](#). Stand by!

Sharon Renschler, Esq.

lodilawyer@yahoo.com

Chairman, MdDS Balance Disorder Foundation

Request from an MdDS sufferer- PLEASE, PLEASE: FORGET the idea that the symptoms have to persist for 30 days for them to be MdDS. Every plane, boat trip that I have undertaken for 35 YEARS has resulted in strong, classic MdDS symptoms that lasted for around two weeks each time. These were absolutely debilitating and have prevented me from enjoying holidays or functioning normally and properly on business trips. Several years ago the symptoms finally became continuous. I received a diagnosis only 2 years ago. It's been hell.

Your Contributions Count!

Operating as a 501(c)(3) nonprofit organization, your tax exempt donations to the MdDS Balance Disorder Foundation in support of research and educational and advocacy programs are encouraged. Please send them to:

**MdDS Balance Disorder
Foundation,
Marilyn Josselyn, Treasurer
255 Copper Beech Drive
Blue Bell, PA 19422**

**If you are interested in
volunteering to assist with our
programs, please email:**

Sharon: lodilawyer@yahoo.com

For further information,
please visit our website at
www.mddsfoundation.org

To all associated with the
MdDS Balance Disorder
Foundation, the **623**
members of the Support
Group and their families,
we wish for you only the
best in 2008!

Send comments, questions, or
suggestions to the [Newsletter Editor](#).