Mal de Debarquement Support News

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

Volume 28 May 2008

MdDS Balance Disorder Foundation at the American Academy of Neurology (AAN) Annual Meeting

The American Academy of Neurology held it's 60th annual meeting in Chicago, IL from Saturday, April 12 through Saturday, April 19, 2008 at the McCormick Place West Convention Center - America's largest convention facility.

Approximately 12,000 neurologists from the United States and worldwide attended at some point throughout the week.

The Mal de Debarquement Syndrome Foundation was represented by ***Marla and Ken Cruise*** on Monday - Thursday, April 14 - 17. Also in attendance were ***Jacinda Tessman*** who assisted on Monday and Tuesday, ***Nancy Braun***, and ***Julie Lipp*** who assisted on Wednesday and Thursday.

Approximately 120 doctors stopped by our booth to learn more about MdDS. We prepared and distributed 80 compilations of our literature, which included a copy of our brochure, 3 survey reports, a business card, and a copy of the March and April 2008 Newsletters.

Many physicians had never heard of MdDS and were intrigued with our disorder. Some reported having seen a few patients with MdDS but were not aware that it had a name, others were well informed and grateful to discover that we had a support site. These doctors said they would share this information with their patients. Often, the neurologists asked us what the recommended treatments for MdDS are. These doctors said they would share this information with their patients.

Others who stopped by our booth shared their theories about MdDS with us.

One doctor shared his thoughts that there are two forms of MdDS, Primary MdDS and Secondary MdDS. Primary MdDS would have no predisposing factor. He believes that secondary MdDS is the result of a previous insult to the vestibular system such as a head or neck injury, labyrinthitis or vestibular nerve damage. He also feels that a history of migraines is a predisposing factor causing a person who suffers from migraine to be more susceptible to getting MdDS after prolonged motion exposure.

Another stated that people should not take any medication for MdDS because he feels it will prolong the course of MdDS. He also agrees with the migraine theory.

One doctor from El Salvador spoke with me for about 15 minutes and reported that he has approximately 20 patients and has published an article on MdDS. He did a fellowship with Dr. Hain, with whom he has published a number of other articles in both Spanish and English.

On Wednesday, Dr. Ronald Tusa presented a half-day course on Neuro-ophthalmology/Neuro-otology with a focus on the assessment and treatment of the patient with dizziness. He stopped by our booth on Thursday to meet us and said he was able to mention MdDS briefly during his lecture. Dr. Zee and Dr. Baloh were co-lecturers along with Dr. Tusa.

One neurologist mentioned that there was a Major League baseball pitching coach for the Orioles named Leo Mazzoni who complained of a rocking sensation. He suspects that this person might have MdDS. I believe we should investigate this further in order to determine if he does indeed have a diagnosis of MdDS. Maybe he will turn out to be our "celebrity" and help us with publicity.

I also met a woman named Estelle Benson who is on the Board of Directors for NORD. She was representing the GBS (Guilliene Barre Syndrome) group and provided me with some ideas on how to achieve some financial backing from the drug companies. This is an avenue that requires further consideration.

Overall, it was worthwhile to attend the conference, to talk to the many physicians, and to distribute our educational material.

Marla Cruise, Nancy Braun

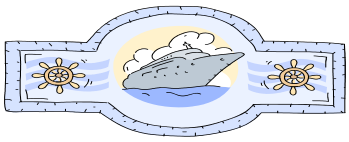
Be sure to visit the MdDS Balance Disorder Foundation page on YouTube to view our videos that detail living life with the symptoms of MdDS.

http://www.youtube.com/user/mddsfoundation

©2008 MdDS Balance Disorder Foundation DMR2008

We do not offer medical advice or diagnose medical conditions. We do share ideas about what has or has not worked for us. Always confer with your physician for a plan of action.

Over Seven Years Adrift at Sea



In October 2000, only days before my fifty-fifth birthday, my husband, Donald and I, boarded the Paradise Ship for a seven day/night cruise from Miami, Florida to the American Virgin Islands on what would prove to be both my physical and mental undoing. Before we boarded the ship, I tore the cartilage in my left knee on the shuttle bus. We did not do anything but rub Aspercreme on the knee for pain, which caused me to turn in early each night of the cruise except for one night of entertainment. On the second day out, we ran through rough waters due to the grade two hurricane named Michael. I was rocking, as were Donald and many other passengers who also experienced typical seasickness symptoms.

After flying home to Houston, Texas, both my husband and I were rocking for the first three days, after which he ceased, but I did not. Ergo, I began making appointments with my general practitioner, an ENT, and a neurologist. After many clinical tests as well as trials of Antivert at different dosages, I continued to rock and sway. The neurologist ordered an MRI and an MRA that were negative. In the meantime, I had arthroscopic surgery on my knee, which totally failed, and I continued to rock. Finally, the neurologist referred me to Dr. Newton J. Coker at Baylor University.

Dr. Coker ordered an ENG, X-Rays, an MRA of my head with and without contrast, an MRI, and many lab and balance tests. Then, taking into account negative test results and my recent motion event, he diagnosed me as having Mal de Debarquement Syndrome and handed me over to the therapist, Dr. Helen Cohen. She gave me two head movement exercises and placed a cane in my right hand. After a return visit to the first neurologist, I trialed Topamax to no avail.

During that first year, I was overcome with fatigue, and found it necessary to nap between 1 to 2 PM each day. In addition, I withdrew from actively helping formulate any house plans we had begun before the cruise. Upon moving into the house, I felt encouraged that I would endure, until the dizzy, rocking imbalance would subside. For a year or so, I faced each day wondering if "...this would be the one that I'd cease rocking?" I rocked on, except in my nightly dreams. My subconscious refused to accept the rocking state.

During the next seven years, I encountered a number of other health problems including the need for more knee surgery, and back problems. In addition, my marriage failed. In the beginning, I tried to remain active, but now I spent more time reading, watching television, and communicating with others either on line or through snail mail. Each day, I read the messages at the Yahoo support site and attempt to reach out to researchers. I have concluded that we still are in an elementary study stage of our imbalance condition. We have only begun coming to terms with this dastardly, life altering condition.

Jo Schneider

Support Site membership is quickly approaching

700

with many people receiving a diagnosis but still searching for a treatment.

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.
We are now able to accept contributions using Pay Pal and credit cards.
Visit www.MdDSfoundation.org or use the donate button below.

Donate

Or please send checks 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 about the Foundation or to learn more about MdDS, please visit our website at www.MdDSfoundation.org

Send comments, questions, or suggestions to the Newsletter Editor.

©2008 MdDS Balance Disorder Foundation DMR2008
We do not offer medical advice or diagnose medical conditions. We do share ideas about what has or has not worked for us. Always confer with your physician for a plan of action.