

Mal de Debarquement Support News

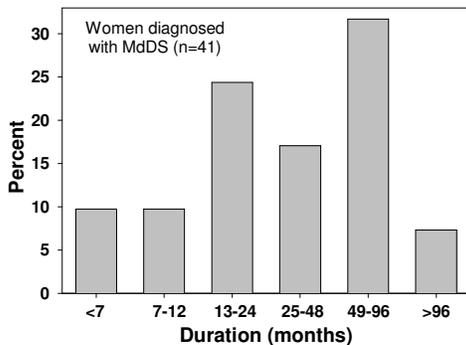
A Newsletter for the International Members of the MdDS Support Group and the Professionals Who Treat Them

Volume 13

February, 2007

MdDS Symptoms & Duration

The [online databases](#) supported by the MdDS Foundation continue to produce new and interesting information of those affected with MdDS. Fifty-three entries regarding symptoms were collected in four months; 50 were from women. Of those 41 women diagnosed with MdDS, the duration of symptoms ranged from 7-360 months; 44% had symptoms for 3 years or more.



The average age of women diagnosed with MdDS was 51.8 ± 1.8 years (\pm sem). Initially, the average [intensity of symptoms](#) was 7.7 ± 0.4 . Interestingly, with time, the intensity of symptoms was reduced in 88% of these women. Among all diagnosed women (including those whose symptoms increased), the average symptom level was 5.3 ± 0.4 at the time of participation in this survey. At this time, the average duration of symptoms was 52.5 ± 10.3 months.

Much additional information has been accumulated regarding those things that reduce MdDS symptoms as well as those which increase them. These will be summarized in the near future. Of course, the value of our observations will be enhanced by increased numbers of entries. For this reason, everyone is encouraged to participate. It is hoped that the continued collection of anonymous information about those with MdDS will be valuable to our understanding and treatment of this uncommon, devastating balance disorder. (Symptom severity scale can be found at http://www.mddsfoundation.org/mdds_scale.html)

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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

Attempting to Get a Diagnosis

Upon landing after a routine flight, it felt as if the plane was still in motion. As I attempted to walk into the airport, the world spun and I dropped to the floor. My traveling companion, a registered nurse got me into a hotel room where I lay for three days. The spinning stopped, the rocking sensation began. I flew home three days later and my odyssey of seeking a diagnosis began.

A balance disorder "expert" at a university hospital initially diagnosed me with MAV (migraine associated vertigo). He is so highly regarded by his peers in the area ENT community that I was referred to him out of my insurance network by my health plan. He told me that one of three meds cures the symptoms of MAV in 80% of cases. Of course, this gave me great hope! Over the course of 4-5 months I trialed all three (I had to wait to get one drug out of my system before starting another) and was horribly DIZZY. I felt much more disabled than by the MdDS alone. I felt like I was going to faint or lose consciousness, which is very different from typical MdDS symptoms I experience. Two of the drugs are traditionally used to treat high blood pressure, Atenolol and Verapamil. I think the third was the anti-depressant Nortriptyline. Has anyone else tried any of these meds? For those of you with a diagnosis of MAV, it might be worth inquiring to your doctor re: these meds.

Next, I consulted with a Neurologist who ordered brain scans, EEG, ECG, carotid ultrasound, and 19 blood tests, which were mostly normal. The scans did show an "anomaly" in the artery leading into the right side of my brain and the neuro-radiologists cannot conclusively say that this is not causing my symptoms; but they do not think so. The Neurologist concluded that I had MdDS given the onset of symptoms immediately following air travel. He stated that MAV is episodic and not 24/7, and I have no history of migraine so he did not agree with the MAV diagnosis. Therefore, it seems to me that docs are also in major disagreement regarding MAV! Makes me go "hmmmmmm"!

Female Age 39, MdDS 4/04

2000 MdDS Brochures have been distributed since December, 2005

Wanted: Researcher to investigate the cause of and cure for Mal de Debarquement Syndrome. This is one of the main goals of the MdDS Balance Disorder Foundation.

Nonprofit Status

As a result of the Pension Protection Act of 2006, changes had to be made to our Foundation. We are now certified as a Pennsylvania nonprofit corporation and we have obtained an official TIN (Tax Identification Number) from the IRS. A checking account has been established in the name of "MdDS Balance Disorder Foundation".

Please send contributions to:
Marilyn or Roger Josselyn
255 Copper Beech Drive,
Blue Bell, PA 19422.

During the month of January, 86 new people joined the online Support Group bringing our membership to 445.

On January 24, 2007, two members of the Support Group participated in a segment of ABC Primetime's Medical Mysteries. Kimberly and Deb met with John Quinones at Massachusetts Eye and Ear Infirmary to discuss the repercussions of living with MdDS. Dr. Richard Lewis explained the theory of the brain's adaptation to motion and lack of re-adaptation after a motion event. Drs. Wall and Oddsson explained their current experiments with a balance vest and balance socks aimed at helping those who suffer from balance disorders. As a result of the national show, Julie, Wendy, Rosanne and Linda filmed segments with their local ABC affiliates which were aired either before or after the show. As a result many people contacted the Support group and Massachusetts Eye and Ear Infirmary. These were important steps in increasing awareness of this invisible syndrome. (More information at <http://www.mddsfoundation.org>)

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

Roger at rjosselyn2@comcast.net or

Marla at mcrnor@msn.com

ICD-9 780.4, Indexed

<http://mddsfoundation.org/>

mddsfoundation@yahoo.com

<http://www.nhffoundations.net/mdds>

Send comments, questions, or suggestions to the Newsletter Editor (editor@mddsfoundation.org)

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