



# Mal de Debarquement Support News

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



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## MdDS, MAV, and MdDS-like Syndrome Distinguishable Disorders?

Robert Slater, MD

Mal de Debarquement syndrome (MdDS) and migraine associated vertigo (MAV) may have some symptoms and clinical presentation in common, but they are not the same. Diagnosis of both is occurring more frequently as doctors and patients become more familiar with the syndromes. Unfortunately, confusion between the two disorders has increased as the number of cases has increased. However, it is difficult to “set the record straight” when the record has not yet been written on MdDS and syndromes that resemble it. There is also a tendency to diagnose anything as MAV if we do not know how to characterize it. Nevertheless, there are distinguishing characteristics among these disorders.

With classic MdDS: Occurs more often in women than men (women:men, 9:1 ratio) and usually follows a travel (ship, boat, airplane, train, car) or movement event; symptoms begin immediately or within a few days of the motion event. Sensations include rocking, bobbing or swaying not unlike the motion of a boat and are continuous or nearly continuous. The sensation is usually discrete; sufferers can literally count the movements. The symptoms may be more troublesome when moving about, but the major symptom is not changed by movement and indeed usually decreases when moving in an automobile or back on a boat. This disorder is somewhat unique in that the same sensations of motion (rocking, bobbing or swaying) NORMALLY occur in most individuals after extended travel or movement; since these sensations only persist for a few hours or days in normal subjects, it seems likely that no damage is involved in the development of these symptoms.



Migraine associated vertigo (MAV) can take many different forms.



The most typical is discrete attacks of spinning vertigo that start intensely and decrease over hours or days. These may or may not be accompanied by classic migrainous symptoms such as headache, nausea and vomiting, and visual alterations (light flashes or blurred vision). In contrast, some with MAV may experience persistent or lingering symptoms of lightheadedness, instability, and vertigo that can be confused with MdDS; rarely are symptoms 100% identical to MdDS. For this latter group, the condition is not yet described in the medical literature, but doctors who provide care for large numbers of dizzy patients have recognized this clinical presentation. Although some refer to this as non-classical MdDS, I personally prefer the term MdDS-like syndrome. To be considered an MdDS-like syndrome, the disorder should have all the typical features of MdDS.

- Initiated abruptly (over hours or a few days at most)
- Virtually continuous sensation of movement
- Discrete movement sensations (not spinning, but rocking, bobbing or swaying)
- Improvement (or no change) when riding in a car

- Troublesome when walking and turning but far less than other vestibular disorders that increase dramatically with head motion.

Clinically, distinguishing MdDS and MAV is complicated by the fact that MdDS may occur more often in individuals with migraine or at least a tendency toward migraine. Indeed, the two disorders may also co-exist in a given patient since females are predisposed to both, and migraine is quite common in the general population.

Distinguishing MdDS from MAV is further aggravated by secondary symptoms that can occur in almost any vestibular disturbance. Anxiety, depression, panic attacks, tinnitus, and vague ear symptoms may be seen but do not distinguish MdDS and MAV. Frank hearing loss is not seen with either.

Comparative features of MdDS and MAV include:

- Vestibular testing is always normal in MdDS but may be abnormal in MAV
- Treatment for MdDS and MAV overlaps but not completely. Anti-migraine agents such as beta-blockers and calcium channel blockers will help only migrainous disorders
- Anti-depressant and anti-anxiety drugs may help both MdDS and MAV patients. These medications not only help the accompanying psychological symptoms but may also suppress vestibular circuits to decrease the sensations of movement even in the absence of anxiety or depression
- Anti-seizure medications, specifically valproate and topiramate (Depakote and Topamax) help migraine patients, and in light of their tendency to “stabilize brain circuitry”, they may occasionally help MdDS patients as well.
- Vestibular rehabilitation often benefits MAV patients but rarely helps those with MdDS.
- Cognitive and behavioral therapy may prevent recurrences of MAV and may help MdDS patients deal with symptoms and reduce disability.

I have had a few patients prevent recurrent MdDS with constant use of benzodiazepine drugs at maximal tolerated dose during travel and starting at least 2 hours before travel begins. However, no clinical research studies have addressed this important question: how to prevent the recurrence of MdDS?



Given the above, it should be clear that *all that rocks and sways is not MdDS and all rocking and swaying in migraine sufferers is not MdDS*. If your symptoms started after travel and fit the description above for MdDS, it is likely that you have MdDS regardless of whether you have migraine or not. If your symptoms began spontaneously, it is probably MAV but perhaps we need a special classification for MAV that is completely identical to MdDS. Non-classical MdDS or MdDS-like syndrome is offered as possible diagnostic terms for future consideration.

## Making History by Fighting to Receive Total Permanent Disability

In April of 2004, I took a short, routine flight for my job. As soon as the plane stopped at the gate, I noticed something was wrong. I felt like the plane was still taxiing. Once deplaning I had difficulty walking and found the nearest chair to sit down. I was traveling with a R.N. from work and she re-assured me the strange feelings would pass. The feelings did not pass and I told her to catch the next plane without me. This presented a huge problem since I was there to train other staff on a program I created to educate medical professionals about rules and regulations on Medicare mental health benefits. Immediately, we called company headquarters to report the situation. This was the first report of my injury to my employer. Their worker's compensation insurer spent the next six months "investigating" my claim. At six months, they accepted liability. In the meantime, I was under the care of an ENT who put me through tests, had me trial drugs for Migraine Associated Vertigo (MAV) which made me worse and in the end said he could not help me. My primary physician referred me to a neurologist who ordered more extensive testing in March 2005. In late March, worker's compensation notified me by mail that they were denying my benefits. I also received a call from my employer ordering me back to work the following Monday. I asked why I was denied and they told me it was based on a response letter they received from the ENT that stated he felt I had MAV which that meant my condition was not caused by the flight. I exercised all my appeal rights to no avail and was ultimately terminated by my employer who also denied my Long Term Disability (LTD) benefits. In April 2005, the neurologist diagnosed me with MdDS after interpreting all my tests. I met with an attorney in June and he advised me to contact a WC attorney as well as to pursue legal action to receive LTD benefits. I hired a WC attorney and we filed for **Total Temporary Disability**. There is about a 10-month waiting period

in Wisconsin to receive a WC Hearing date. The next two years ('05 – '07) I reached a settlement with the WC Insurer for lost wages prior to the Hearing dates. In June '07, my attorney and I filed a claim for **Total Permanent Disability**. I was notified of a hearing date for Feb '08. Although my case was to be heard at 1:00PM, I reached a settlement agreement for **Total Permanent Disability** at 9:30 AM on that date. The incredible doctors I have, their documentation, and advocacy on my behalf helped make this possible. The sum I received is for lost future wages and a separate medical account to cover future unpaid expenses until I am 82, which is my life expectancy. I believe I have made history by being the first person with MdDS to win a WC disability case.

This process took an emotional toll on me. After my employment was terminated, and I was denied disability benefits, I lived with the constant fear and stress of becoming homeless and bankrupt. I took for granted I could always support myself, after all I was an educated professional with a great career. Over the course of three years, I cashed out all my investments so I could maintain housing and basic living needs. My symptoms were very high and I struggled to get through each day. Many days I did not want to get out of bed, I had nothing to get up for except feeling motion that was nonexistent and a world that did not understand my condition. However, I fought on. I persevered against all odds. That is what all people with MdDS must do. Just because this awful syndrome is not well researched, written about, or well known, we cannot allow the giant legal entities to defeat us. I have been up against my legal opponents who say I cannot have this syndrome because I did not have a long, turbulent flight because there is no literature available to indicate otherwise. Regardless, I won my case on merits and supportive physicians and expect to win my pending LTD lawsuit too.  
Female, age 41

### 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.

We are now able to accept contributions using Pay Pal and credit cards. Visit [www.MdDSfoundation.org](http://www.MdDSfoundation.org) or use the donate button below.



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](mailto:lodilawyer@yahoo.com)

For further information about the Foundation or to learn more about MdDS, please visit our website at [www.MdDSfoundation.org](http://www.MdDSfoundation.org)

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

# **Attention to those who live in the Los Angeles Area: Patient Recruitment for MdDS Study**

Please see the details in the box below to find out if you are eligible for inclusion in Dr. Cha's on-going clinical research studies. If you are interested and want to find out how to be included, contact Dr. Cha for additional information.

## **UCLA Research Study** Visual Motion Sensitivity

A UCLA research study on visual motion sensitivity is currently recruiting subjects between the ages of 25 and 80, who are either severely sensitive to visual motion or have high tolerance to visual motion. Participation will require a brief screening interview over the telephone. The study entails one hour and involves some questionnaires and several computer generated visual motion tasks.

A subset of qualified subjects will be invited to undergo a functional MRI scan of the brain. Payment for parking and compensation for participation offered.

For more information, please contact Dr. Yoon-Hee Cha at [yhcha@mednet.ucla.edu](mailto:yhcha@mednet.ucla.edu) or call 310-825-5759.

Date of Preparation: January 2008

UCLA IRB#: 07-04-055

Expiration Date: 9-18-08