



# 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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### Conference Attendance Key In Educating Physicians

"One of the best ways to educate doctors and promote understanding of MDDS is for support site and Foundation members to maintain a presence at professional conferences like the OTO EXPO," said a U.S. doctor who attended the September conference in Washington, D.C.

That was one of the most encouraging sentiments I heard from a doctor the day I attended the conference with Roger and Marilyn Josselyn and Pat DeRoche. Dr. Daniel Morrison of Dartmouth, Hitchcock Medical Center, who treats MDDS patients, said our attendance is paramount in helping get the word out. Morrison visited our booth last year at the OTO-EXPO Canada.

Looking at the symptom survey results that Roger shared with attendees, Morrison said most of his vertigo patients answered similarly and those in the cervical vertigo category share many of the same symptoms as MDDS patients.

**"We have to define what it (MDDS) is in terms of symptomatology," he said. "It is a constellation of symptoms in "X" percent of the population. It's such a nebulous thing. How do you know what it is? How do you identify it?"**

Vestibular rehabilitation was key in a MDDS treatment plan among many doctors who visited our booth, including a number from Europe. Dr. Mans Magnusson, of Sweden, said his patients' MDDS resolved within two weeks and that he treats it quickly according to a three-pronged treatment plan.

First, he prescribes diazepam (Valium) for only three days, and then begins a course of vestibular therapy, particularly the type with head movements. Next he adds an SSRI. If this initial treatment was not helpful, he suggested beginning cognitive behavioral therapy.

Since balance is comprised of all of our senses, if our brain and/or vestibular system are compromised, he said, how we perceive the world becomes filtered through that "damaged" system. Because the brain continues to misinterpret the signals, it becomes trapped in a "chronic feedback loop."

To illustrate his point, he used Marilyn to demonstrate a form of vestibular rehab he uses to break that feedback loop. He had Marilyn to stand with eyes open and then with eyes closed. While she swayed a little with eyes open, she swayed markedly back and forth with eyes closed. Then Magnusson asked her to hold a cell phone and concentrate on feeling the phone she was holding. With either eyes open or shut, it was amazing to see the difference in Marilyn's swaying. She barely swayed when she concentrated on feeling the phone in her hand! Magnusson has his patients do this exercise at least twice a day, recommending a glass full of water or wine.

An American doctor, Dr. Dennis Poe, editor of *Consumer's Handbook on Dizziness and Vertigo*, whose book mentions MDDS, also advocated vestibular rehabilitation. Poe strongly recommends tai chi, as it is a form of balance training with complex movements that also involves moving the head without causing too much nausea. Tai chi, he said, involves a multitude of systems and stress the vestibular system slowly – which helps patients tolerate it. Kung fu also is a good option, he said, calling it an accelerated form of tai chi. Success, Poe stressed, largely depends on if the patient *sticks with it*.

I enjoyed talking to the doctors about MDDS. Many seemed as eager to learn from us as we were from them. They often seemed hopeful that we had something to share about this mysterious syndrome that they did not know, as were we. For the first time, I felt more of a collaborator than as a patient they could not help.

Karen Miller  
MDDS canoe, car 2003

### Could a Medication from Japan Help?

My first experience with Mal de Debarquement happened in February 2003. I had done two overnight ferry trips, about 3 days apart. I was living in Japan at the time, and after a month, I went to an otolaryngologist. He did a couple of tests of my ears and hearing, found nothing wrong, and prescribed an anti-dizziness medicine, which did not help. A second doctor found a problem with my left ear, and diagnosed me with Meniere's. I was given 2 new anti-vertigo medicines, neither of which helped. Later, I went to a third doctor at a major hospital in Sendai. There I underwent a battery of tests on my ears, hearing, and Vestibular system. All tests came back normal, and I was diagnosed with "stress-related vertigo". I was given Meilax (ethyl loflazepate), which I was told was a tranquilizer. I was to take 1 mg daily. My symptoms ended completely within a day or two of my first pill. It was such an incredible relief to finally be over this monster, after 3 months! Even better, I felt almost no side effects. When I ended the pills 2-3 weeks later, the symptoms did not return. Unfortunately, I ended up in surgery two months later, and after half a week of bed rest and limited exercise, I began to feel the symptoms again. When I was released from the hospital, I was given another prescription for ethyl loflazepate. As before, my symptoms went away entirely and did not return for over 4 years.

At this time, I have another episode of MDDS (now diagnosed), induced by working on floating platforms. I have tried lorazepam and diazepam, and have not felt the same results as I did with ethyl loflazepate. Lorazepam and diazepam reduced my rocking symptoms, but only slightly and never eliminated them. Both of these drugs had strong side effects, particularly sedative, and I gave up all prescription drugs after two weeks of treatment (at that time, my symptoms were mild enough that the side effects were not worth the weak benefits). Although I feel incredibly lucky that my symptoms have weakened significantly, I am frustrated that I cannot get ethyl loflazepate in the US. Instead of getting relief in a day or two, I expect it will be several more weeks of exercise and patience before my symptoms go away, if at all. I hope that this information will be useful to those in other countries who can get ethyl loflazepate, or to doctors and researchers who can find a similar drug more widely available.

LN, Age 32, Female