



MdDS Support News

A Newsletter for Members of the Mal de Debarquement Syndrome (MdDS) Support Group and the Professionals Who Treat Them

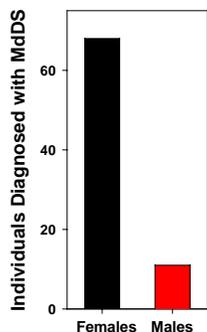
Volume 8

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MdDS Database Provides New Information on Gender and MdDS

The on-going collection of data from those affected with MdDS by the MdDS Foundation continues to expand and constitutes the world's largest single set of data regarding MdDS. With over 100 entries from individuals throughout the world, 79 have been diagnosed with MdDS. This MdDS Database is a valuable resource for understanding the incidence and characteristics of this very rare syndrome that leads to imbalance.

Previously described as a balance disorder primarily affecting women, it is



now clear from the MdDS Database that almost 14% of those diagnosed with MdDS are men. Based on these findings, it seems unlikely that hormonal effects on the brain or vestibular system cause MdDS.

Other interesting gender-based differences appear from the MdDS Database. For instance, the average age of onset in women is ~46 years whereas in men, it is ~39. In fact, over 1/2 of men with MdDS were diagnosed before 35 years of age while over 1/2 of women with MdDS were diagnosed by 46 years of age. About 75% of women developed MdDS following a cruise/boating activity while less than 50% of men reported cruise/boat-related MdDS. Indeed, ~40% of men appear to spontaneously develop MdDS (less than 3% of women describe spontaneous MdDS). These and other differences may be useful in research efforts to identify the cause(s) of MdDS.

The MdDS Balance Disorder Foundation is dedicated to improving our understanding of this disabling syndrome. Hopefully these efforts will contribute to better approaches to the treatment and prevention of MdDS.

Werner Schraemli, Male, 63 Years Old, MdDS Sufferer

In June 2000, my wife and I spent a weekend in Venice, Italy and then went on a one-week-cruise from Venice to some Greek islands. In Venice, we took the boats on the Grand Canal to travel around the magnificent city. That is when my troubles began; the ground seemed to move after we left the boat. After the cruise to the islands, my troubles would not stop for 8 months. Then, I had the flu with 40° C fever, took paracetamol for a week, and after that, I was perfectly well again.

In October 2002, we took a one-hour's-boat-trip with a fast catamaran on a Swiss lake in very windy weather. It started all over again and lasted 9 months this time. I am not sure what stopped it, possibly when I took something to get rid of a strong headache.

Now, I am in my third episode: In September 2005, we went to the Swiss mountains by rail. Rail usually did not bother me and I liked it, especially in the "Gison" mountains. The train is very comfortable, the scenery beautiful with great food and wine in the dining cars. However, this time, I felt my old troubles when we entered the hotel room in St. Moritz. The trigger was not the waves on the water, but apparently the curvy ride on that beautiful mountain-train.

The third episode is ongoing, the symptoms being worse than in the first weeks. The troubles are bad when I am standing or walking. It is like being on a boat or a trampoline. I often have to get hold of something stable (a wall or the furniture). Sitting is a bit better, usually even good. When it gets worse, the headache starts and I feel like my brain is not getting enough blood. Then, I often have to lie down, which makes it better instantly. Fortunately, I sleep well since lying down is the only position where my troubles never occur.

My wife and I are fond of ballroom dancing, standard and Latin, we have been practicing it for 25 years now. When on the dance floor and in motion, I generally feel better. Unfortunately, I often take insecure, inappropriate steps. Luckily, I have not fallen to this point.

We like to take walks in nature, especially in mountain places that are just an hour's car drive away. Since my first MdDS episode, I can only take short and slow steps, as if I was about 99 years old or so.

Prof. Straumann of the Zurich University Hospital diagnosed MdDS and prescribed Sibelium. This medication is used in Europe to treat inner-ear-vertigo and migraine. It contains Flunarizin that ameliorates blood supply in texture. Unfortunately, there are no positive effects yet.

Since our July newsletter, we have welcomed 18 new members. One gentleman has been dealing with undiagnosed MdDS symptoms for 32 years, since his Air Force days. His symptoms were present most often following air travel but a train trip three years ago sent his symptoms soaring. He recently received a diagnosis and was dismayed to find that there is no cure available. Let's hope that with further awareness and education no one will have to wait twenty-nine years for a diagnosis and someday, a cure.

Questionnaire and Geographic Survey

Please complete the [Questionnaire and Geographic Survey](#). Information is available for your use and for our educational and research efforts. Please contact [Judy](#) if questions.

Your Contributions Count!

Donations to the MdDS Foundation in support of educational and advocacy programs should be made using the preferred method for logging and acknowledgment by sending them to the

MdDS Balance Disorder Foundation
A National Heritage Foundation
255 Copper Beech Drive
Blue Bell, PA 19422

Or, send them directly to
The National Heritage Foundation
6201 Leesburg Pike, Suite 405
Falls Church, VA 22044

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

Roger at rjosselyn2@comcast.net or
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