



Mal de Debarquement Support News

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

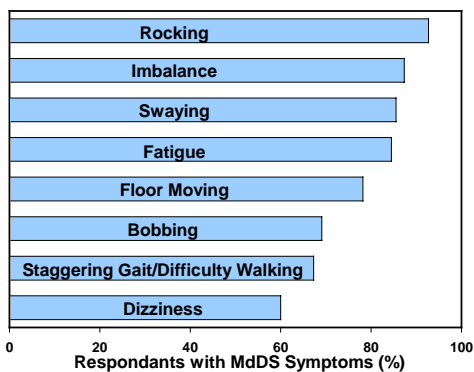


Volume 19

August, 2007

2007 MdDS Symptom Survey

A survey of 110 members of the MdDS Support Group was recently concluded. A confirmed diagnosis of MdDS was a prerequisite for participating in this survey. Responses were in regards to symptoms at time of diagnosis. This represents the world's largest database of clinical findings about MdDS and reveals the relative frequency of symptoms related to abnormal sensations of movement.



Clearly, symptoms are not identical in all persons with MdDS. However, almost all (92.7%) report a rocking sensation. Imbalance (87.3%) and difficulty walking (67.3%) were reported to be worse in the dark; this likely reflects the fact that visual cues are enhanced as an adjustment to the inappropriate sensation of movement. Thus, in the absence of visual input, perceptions of movement are exacerbated. These observations are consistent with the theories described by Christian Chabbert, PhD (Director of the Research Group on Vestibular Disorders at the Institute of Neuroscience in Montpellier, France) provided elsewhere in this edition (page 2).

In addition to the above, this 2007 MdDS survey also provided information regarding a variety of symptoms related to cognitive impairment. These will be described in future editions of this Newsletter. The complete results from this survey are available online (<http://www.mddsfoundation.org>). The MdDS Foundation encourages clinical research studies to better understand the cause of this disorder and the identification of improved methods for MdDS diagnosis and treatment.

A Long Time Floating

The only indications I had that I would someday slip into a seemingly permanent state of floating was that for an hour after riding an elevator, I would have an odd dizziness. I also became sensitive to the movement of the floor in large department stores on the top floors of malls and would feel dizzy. Upon returning to the bottom floor, I would feel normal.

In the spring of 1995, I began to feel a floating or bobbing during the afternoons. Possibly, car trips after a stressful day could have triggered this. I was also going through a period of intense migraines. Suffering a migraine had always made me mildly dizzy. This particular spring was a very stressful one for me at work and within my family. By the summer, the strange symptoms had increased and had become 24/7. I had a strong floating sensation and felt that the floor was moving. At the same time gravity seemed to have increased. During this time I had also been trying to cut back on the use of Dalmane at night for sleep as I had been taking it for many years.

My husband and I had a trip planned to Costa Rica. I believed that my strange symptoms might have something to do with the Dalmane, so I increased the amount I was taking to see if it would improve my symptoms during the trip. The symptoms improved somewhat but did not go away completely. When I got back from the trip, I developed just about every MdDS symptom listed. I began to visit doctors and also sought answers on my own. I did come across some information about MdDS and although the symptoms were the same including the fact that I felt normal in a moving car; I thought from what I was reading that this was only something you got from a cruise experience. So I thought that the similarity in symptoms was just a coincidence. After getting no answers from local doctors, I became aware in 1998 of a balance expert at the University of Pittsburg medical Center, Dr. Joseph Furman. He seemed to think it could be linked to migraine, anxiety, and an imbalance of neurotransmitters and gave me a diagnosis of a vestibular system ailment akin to MdDS. He also gave me a prescription for 1 mipramine which did not help me. I continued to work as a teacher until 1999 when I decided to take a break to see if absolute rest would help. I did not work for five years and tapered slowly off the Dalmane.

The symptoms of MdDS muted somewhat over all this time to a level of 4/5 most of the time with good days being 2/3 and occasionally 1/2. I decided to try to work again but exhaustion, brain fog, and vision problems took their toll.

After a year back at work, I went to the Mayo Clinic in Minnesota. I had developed a new symptom over the last three years or so that worried me. The bobbing feeling seemed to be going along with my heartbeat. At Mayo they did MRI's to rule out vascular malformations and a CT scan of the temporal bone to see if it had thinned too much in proximity to blood vessels. I also had all of the other vestibular tests that I had in the past. Dr. Eggers, the neurologist I saw at Mayo gave me a diagnosis of chronic disequilibrium suggesting Mal de Debarquement syndrome and migraine without aura. I finally had to come around to accepting the MdDS diagnosis even if I have never been on a cruise. I try to be very good to myself and enjoy my life. Luckily my husband is very supportive.

*Please read the article on page 2 entitled "Peripheral Origin for Mal de Debarquement" by Christian Chabbert

Cured?

We encourage practitioners to share information on those they have cured of MdDS.

Click on www.mddsfoundation.org for our most recent media entries.

Membership has grown to 578 people living with MdDS.

Please send tax deductible contributions to:
MdDS Balance Disorder Foundation
Marilyn or Roger Josselyn
255 Copper Beech Drive,
Blue Bell, PA 19422

- ICD-9 780.4, Indexed
- If you are interested in volunteering with our programs, please email:
Roger at rjosselyn2@comcast.net or
Marla at mcrnor@msn.com
mddsfoundation@yahoo.com

- Send comments, questions, or suggestions to the Newsletter Editor:
editor@mddsfoundation.org
<http://www.mddsfoundation.org/>

Kroger Share Cards: If you live in Texas or Louisiana, please contact Terri (terrig@entouch.net) to obtain a Kroger Share Card. Each time you present the card after shopping at Kroger, the MdDS Balance Disorder Foundation will receive a donation. Small things add up to big when done on a regular basis.

My symptoms started after a short car trip of one hour and were diagnosed as "spontaneous onset". CH



A Peripheral Origin for Mal de Debarquement Syndrome?

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http://www.inmfrance.com/us/1_team2_chabbert.php

Although a growing number of otolaryngologists over the world are beginning to become familiar with MdDS (thanks to the dynamism of the MdDS Newsletter editor!), its physiological causes remain to be elucidated. Comparative studies with other types of vertigos may provide interesting clues for scientists that are trying to elucidate the mechanisms by which MdDS occurs. One of them, Space Motion Sickness (SMS), which presents several analogies to MdDS, is the subject of investigations that may bring such insights towards a better understanding of the molecular events that contribute to MdDS.

SMS is a vertigo experienced by astronauts during orbital flights. As with MdDS, SMS occurs following changes in environmental conditions. Episodes of dizziness, nausea and a persistent feeling of movement occur during the switch from earth gravity to microgravity, as well as when astronauts come back to earth gravity after a long stay in weightlessness. In the latter, it is called re-adaptation syndrome (RAS). SMS and RAS symptoms normally appear during the first hours in orbit or upon return to earth gravity and may last several hours to several days. As with MdDS, the likelihood of SMS is difficult to predict and seems to indiscriminately affect males and females, trained or not, with or without a history of motion sickness. Furthermore, like MdDS, SMS is resistant to most pharmacological treatments and the effectiveness of promethazine or scopolamine remains under debate.

One of the proposed causes of SMS is the thesis of a sensory conflict. Basically, the idea is that human orientation on earth combines sensory inputs from several receptors (vestibulus, eyes, and muscles). When the environment is altered in a way that information from the different receptors (sensors) are not well-matched, motion sickness may occur. The sudden alteration of gravity is obviously sufficient to trigger SMS. The challenge in a weightless environment is to adapt to conditions that do not exist during normal growth and development.

Studies performed on rats that flew on space missions (Space Life Sciences, Neurolab) indicated that vestibular end organs might be directly affected by sustained environmental changes (in the absence of gravity). During flights of several days, **changes were identified at contacts (called synapses) between vestibular sensory cells and their corresponding**

nerve fibers. Vestibular sensory cells are special cells in the inner ear that detect and transduce the information of movement into bio-electrical signals that are then transmitted from the inner ear to the brain stem *via* nerve fibers (once this information has been analyzed by the brain, a motor or movement response develops). Such synaptic changes or *rewiring* could be part of the adaptation process in response to sustained differences in the new environmental condition (*i.e.*, no gravity). It is thought that these biological adjustments are transient since recovery of the initial wiring generally occurs during the days following a return to earth's gravity. However, we don't yet know whether the recovery is complete or partial. Also, details of the relationship between the observed synaptic changes and the impairment of vestibular function remain to be established.

If we extend the observations about space flights to the conditions that lead to MdDS, it is conceivable that a similar adaptation process occurs in people that have taken a long cruise. Once the body has become accustomed to constant motion, the vestibular system, which controls balance, may set up a new wiring pattern in adaptation to the new motion environment. Rearrangement of the synaptic contacts between vestibular hair cells and vestibular primary neurons may enable this adaptation process. Unfortunately, the paucity of available observations and the lack of scientific studies on MdDS preclude conclusions at present.

Our investigations on rodents raised in or transiently submitted to altered gravity provide interesting insights into the biological adaptations that occur during changes in the gravitational environment. We also recently documented that when rats are raised under *enhanced* gravity during gestation, branching of the vestibule to the brain, which normally occurs around birth, is delayed a few days; in parallel, the function of vestibular sensory cells is also altered. We are currently investigating to what extent these changes are transient or permanent and whether these changes can be modified by altered vestibular function. Since it is now clear that changes in gravity may also induce alterations in the adult mammal vestibule, we are presently initiating investigations in collaboration with the French and European Space Agencies with the aim of *identifying the molecular mechanisms that control adaptation processes in response to modified environmental conditions*. Such identification is a prerequisite for the future development of pharmacological and/or medical strategies to control related vestibular dysfunctions in humans.

* Research supported by the French National Institute for Health and Medical Research (INSERM - U583)

The MdDS Foundation encourages basic biomedical research into the basis of balance in order to help define the cause and provide treatment and/or prevention of MdDS.