

MdDS Support News

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

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We are often asked how folks cope with the limitations of MdDS. The following is a suggestion from one of the Support Group Members

Exercise is important for both physical and emotional health. Although many people with MdDS report that they can still participate in their usual activities, others have issues with balance that limit what they can do. Enter the recumbent tricycle. I started riding a recumbent "tadpole" trike several months ago and it is wonderful. Like many with vestibular problems, I was finding my world getting smaller and smaller. The trike has allowed me to gain more independence and has provided an activity I can enjoy with my family. The one I ride is the Greenspeed GT3. Although these trikes are expensive, you can find used ones on the internet. The position of the trike is similar to a car where your back is stabilized and the trike itself is extremely stable which eliminates the risk of falling. The biggest problem you may have is getting your kids or grandkids off of it as they look at it as a fun go-cart.

Seven Years Later... Rocking Again!

I am experiencing MdDS for the second time. The first time was 7 years ago, when I was 45 years old, after riding a ferry boat from one island in Mexico to another. I was not sick and did not have any problem until after I got off the boat and then after the flight home things got much worse. After a couple of weeks of rocking and nausea and trying over-the-counter drugs for this problem I went to a local ENT. He tried the usual medications and patches for vertigo and motion sickness which none helped. He did a lot of testing including, an MRI of my brain, and found no problems. Then he sent me to an ENT/dizziness/motion disorder specialist. He did more testing, looked at my MRI and told me I had MdDS. My first reaction was "does this mean I have lost my mind" because this was how I was feeling. Of course he said no and explained to me that there is not a lot known about it, but they think the brain does not send messages to the body that you got off of whatever movement you were on. He started me on a low dose of Valium and I had to slowly increase to 15 mg. a day. I managed to work during this time, but not much of anything else. After 10 months I was off my meds and symptom free. He told me not to get on another boat which I have not nor have I flown since then.

I have had no problems until this past January 14, 2006 when I rode a small charter (36 passenger) bus for 8 hours to an Elvis Impersonator Competition. The last hour of the trip was on a curvy road and it was a windy day and the bus rocked quite a bit. I had no problems while on the bus. After standing in the check in line for about 10 minutes that rocking feeling hit me and there was no doubt what it was. You don't forget that feeling. Neither my doctor nor I have ever seen this caused by a bus. I waited about 2 weeks to contact my doctor and after my appointment with him he put me back on a low dose of Valium again. I have reacted very differently this time. I have not gotten better, but worse. So we are in the process of taking me off which he does very slowly and if I am not better then he will do some balance testing. I have had a much harder time dealing with the symptoms this time, maybe because I am 7 years older (52) and do not have the tolerance I had before. It has made a big change in my life because I was very socially active and it takes about all I have to just make it through the work week. At least I have a job where I sit most of the time. The only time I do not feel the rocking is in a car or when I am lying down flat.
(Female, 52)

* As our member numbers increase please help us collect information about the MdDS experiences of our Support site members. If you are a current support group member please be sure to visit the site to fill in the Geographic and Symptom Databases. Also, if you are a new member take a few moments to complete the Questionnaire that is posted periodically by Judy. *

Although your contributions count, we have to ask you to hold them until the transition to our new tax exempt status is complete.



Greetings of
Peace and Health
in the
New Year

As another year comes to an end we would like to thank all of those who worked so diligently to give credibility to MdDS as a syndrome. From the Board of the MdDS Balance Disorder Foundation, the doctors who have served as advisors and included MdDS in their conference materials, websites, and preliminary research, to those who contributed to all of the Foundation initiatives and finally, to those on the Support group who share coping skills and encouragement to those of us who live with MdDS on a daily basis; we wish you Peace and Health in 2007.

**If you are interested in volunteering to assist with our programs, please email: Roger at rjosselyn2@comcast.net or Marla at mcrnor@msn.com.

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

Great job, Linda L., in getting an article about MdDS published in the Scottish version of The Sun newspaper. We gain much each time MdDS is recognized in the media and we would love to report more success in this area.