

Mal de Debarquement Support News

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

Volume 16

May, 2007

Initial Symptom Survey Update

Sixty people with a confirmed MdDS diagnosis completed a survey which is looking at commonalities in initial symptoms. Only surveys which identified the diagnosing doctor's name and contact information will be included in the results which will be tabulated in the coming weeks.

Website Revamp

As you know the MdDS Balance Disorder Foundation is no longer under the auspices of the National Heritage Foundation. Therefore, we encourage you to use the www.mddsfoundation.org website for your updates and to recommend to your patients. The website will be revamped in the near future to make it more user-friendly and easier to update. The National Heritage Foundation site is no longer being kept current.

“My first episode was from roller coasters, I've never been on a cruise. M.G.

Life on a Permanent Aircraft Carrier

Like all of the others I thought I was alone. I'm a 63 year old male and MdDS has been my constant companion for 40 years. The first symptom showed up while in the Navy serving on a very busy aircraft carrier. This mild symptom happened while sitting in close quarters and turning my head from front to the right and back, I would get the feeling of movement with out moving.

1977- 10 years later- Once again I experienced a full blast symptoms, holding on, rocking floors, can't walk in wide open white spaces, had to sit in chairs with arms; no symptoms in a car. Doctor prescribed antivert (did nothing) and a battery of tests including a CAT scan, EEG, hearing and balance, and a nerve test of the legs. I consulted with a neurologist and ENT but no cause was found. The best medical guess was that it was a virus. But, I coped and finally got used to having my companion.

1987-10 years later- Again I experience a full blast. Same tests, same result. Once again I coped and it finally calmed down after about a year.

1998-10 years later - Another full blast that this time included brain fog, I had the same tests only this time an MRI of head, neck and spine plus an MRA of the head. A full work up was done at the University of Pennsylvania in Philadelphia at the vestibular center. No cause was found and I was told to come back when the symptoms worsened. My physician put me on 20 mg Paxil and within 30 days full blown went down to a whimper. I have been taking 10 mg Paxil ever since then. My companion starts every morning in the shower. Therefore, I keep busy and active and walk for exercise. I believe that this is viral and has settled in my ear, eye or brain and rears up when something in life triggers it. I would like to know if any doctor has tried anti-viral medication. It seems that I get a full blown attack every ten years; that is coming up; we will see. Jim

Each day the Support Group grows with more bewildered people looking for answers. We continue to seek those answers as well as providing moral support. We continue to work diligently to find a researcher who is dedicated to working with those living with MdDS.

On the Publicity Front, one of the Support group members is pictured in the Massachusetts Eye and Ear Infirmary's Annual Report with a short caption that mentions Mal de Debarquement. The publication can be seen at the Mass. Eye and Ear Infirmary's website (<http://www.meei.harvard.edu/what/pdf/ar06.pdf>) and was mailed to their many supporters.

MdDS changes your window of the world.



Please send tax deductible contributions to:

**MdDS Balance Disorder Foundation
Marilyn or Roger Josselyn
255 Copper Beech Drive,
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ICD-9 780.4, Indexed

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

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