



Mal de Debarquement Support News

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

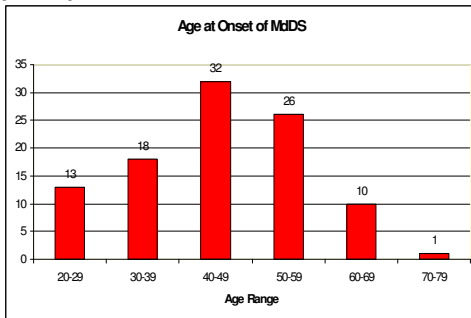
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Age of Onset of MdDS

As of June 1, 2007 we collected data from 107 participants who responded to a set of survey* questions that was developed with Dr. R. Tusa, a neurologist and member of our advisory council. Of the 107 surveys received, 100 qualified to be included in the data shown in the graph below. The participants all had symptoms of rocking, bobbing, or swaying that was significantly reduced by passive motion such as in a car. Also, the symptoms were persistent for 30 days or more.

Thirteen percent acquired the symptoms in their twenties, 18% in their thirties, 32% in their forties, 26% in their fifties, 10% in their sixties, and 1% in their seventies. Ten of the participants were male while 90 were female.



Of male participants, one acquired MdDS in his sixties, three in their fifties, three in their forties, one in his thirties, and two in their twenties.

Based on this data, average age of onset for males was 43.1 years, while the average age of onset in females was 45.1 years.

*Participation in these surveys is strictly voluntary. Information derived from the survey may be included in future presentations to medical or scientific audiences; in this case, you will never be identified in these reports. The MdDS Foundation does not provide personal information including email addresses to anyone.

“My MdDS started when I experienced an earthquake while on the thirtieth floor of a hotel in Hawaii.” DJF

Multiple Episodes of Mystery MdDS

I am a 40-year old woman who has three children, two stepchildren and seven grandchildren. I'm on my 12th episode with MdDS in eleven years. I have had remissions and pray for one now. My first five episodes were from riding in elevators, but it took me a whole five times to figure that out. I gave myself excuses for feeling the way I did, so I did not go to see the doctor about the feelings of rocking until the sixth episode. I had no way to explain what I was feeling so I used the word “dizzy” but kept trying to tell him that is not how I really felt. So he tried me on meclizine and scopolamine. These either did nothing for me or made me worse. So I gave up and just lived with it in silence.

The episode that made me go back to the doctor was the worst one, lasting for more then five months while the others only lasted two to three months. It was so bad I had to take off from work and have others drive me. Then one day, like the other times, the MdDS was gone. I had a few more episodes that weren't so bad. But, again I gave myself excuses that I was tired, or hungry, or stressed even when I was not. Then I started to think I was crazy. My current episode was brought on by a 260-mile round trip car ride with a week of camping in the middle. We did not do any boats or water activities, just hung out with friends. No stress. I sought help and was finally diagnosed in October 2006.

After reading the brochure from the Mal De Debarquement site I cried. It was like someone was telling my story. Then I joined the site I cried for days from reading the posts. I was reading my diary. My husband was relieved that I was not crazy, not that he ever thought I was, but I did. Now I'm so miserable. I have the worst time with fatigue and brain fog. My body hurts from walking funny. The symptoms have only increased in severity over the past 10 months which scares me. I have not worked since April of 2006. I miss my life I miss working; I never thought I would say that but I do. I was a hardworking woman who would take on extra hours and extra days. I would always help out. I loved paperwork and being social. Now I'm almost a hermit. I can't stand loud noise; I don't go out much at all. I don't watch TV much. I have the worst time reading or writing, and it takes me all day to cook a meal. If I have to go out to do anything I will be wiped out for a day and a half. I don't have my life as I knew it. My husband is trying to work to keep a roof over our heads and sinking fast. I have no money, no job, no insurance, no car, no life; I'm tired of trying to look, sound, walk, and feel normal. I'm embarrassed to go anywhere because I think people view me as drunk or crazy. I live with a hidden disability.

As for medications I have tried diazepam, amitriptyline, cyclobenzoprine and now on prepanil for migraines which have increased with MdDS. I have had more tests than I can count and it's costing me everything. My medical bills are so much that I will never get out of debt. So far, the only thing that the medications do is cost me lots of money. Nothing has helped; I would love to have one day of normality without the sensations of rocking and bobbing, or pain, or feeling wiped out. I have nights where I can't sleep then I have days I can't stay awake. Not knowing which type of day I'm going to have is difficult; it's hard to plan my life. I'm currently on my first appeal for disability. I don't know how to get them to understand how this has affected, and is still affecting my life. I would love for this to go away and let me get back to work. I was a very independent woman and I hate that I have to rely on anyone for help. My pride is gone. CS, female

SURVEY NEWS

We would like to continue to encourage people to complete two surveys at www.mddsfoundation.org.

One is aimed at identifying symptoms that were present at the time of diagnoses with MdDS. Also, we ask you to complete a second survey that identifies characteristics of MdDS.

Dr. Ronald Tusa, director of the Dizziness and Balance Center at Emory University, will be using slides from the data in upcoming presentations.

On the **Publicity Front**, one support group member used a unique method of educating people when cruising again. She didn't leave the ship for the entire cruise, prompting people to ask, “Why aren't you leaving the ship to participate in any excursions?” She handed each one a brochure and gave them an explanation of MdDS. Upon disembarking and waiting in line, she took the opportunity to hand out 60 more brochures sparking conversation among those waiting along with her.

Also, visit <http://groups.myspace.com/maldedebarquement> to see the Space that Cynthiya has developed. You do not need to have a Myspace account to view the site which supplements our publicity efforts and will help direct more people to our web and support sites.

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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Marla at mcmor@msn.com

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<http://mddsfoundation.org/>

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