



# MdDS Support News

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

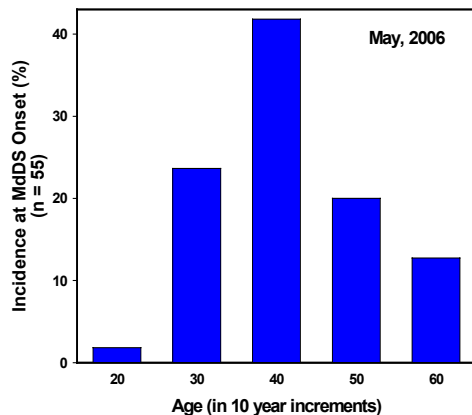
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## Foundation's Database of MdDS: World's Largest Provides New Findings Regarding Age of MdDS Onset

The MdDS Foundation has been soliciting information from members of the [MdDS Support Group](#) since Nov 2005. Eighty-nine entries were received from around the world: Australia (1), Canada (4), Lebanon (1), New Zealand (1), UK (14), and USA (68). Seventy-eight (88%) females and 11 males (12%) were included. *Over 70% had been diagnosed with MdDS.*

The distribution of age at onset in those diagnosed with MdDS was different than that expected based on the few published studies. In brief, as illustrated below, approximately 40% were in their 40's at the time of MdDS onset, however, over 20% were in their 30's and about 20% in their 50's. In an [important study](#) in 1999 of 27 subjects with MdDS, greater than 50% were in their 40's at the time of onset and only 10% presented in their 30's or 50's.



These details will be helpful to physicians and researchers interested in the possible causes (and potential diagnostic testing or cures/treatments) for MdDS. In the meantime, we need to continue to obtain information from those with MdDS to provide a better "picture" of this disorder. Watch for announcement of the Foundation's bigger survey and for more results from this database in the near future.

## One Member's Personal Story

My permanent journey began almost three years ago after a relaxing week on the island of Aruba. Flying into Puerto Rico and arriving right on time, we immediately boarded our plane bound for Aruba. Little did we know that we would leave San Juan and return three times in the next three hours. It took us eight take offs and landings to finally reach our destination. Once there, we stayed in a beautiful room on the top floor of the hotel: up and down the elevator we went many times each day. After awhile I noticed that I tripped when leaving the elevator but only at the top. The week was a restful getaway for two and I am so glad that I sat and read for hours. I can recall the feeling of just sitting still and enjoying it. With one-day left, we decided to take a two-hour snorkeling trip. While floating and watching the fish, one of the guides placed a large starfish on my goggles which caused me to snap my neck back and I was unable to snorkel at our next stop but did hang onto a rope attached to the boat while it bobbed above me. We walked miles on our trip and I felt refreshed and reconnected as we flew home. I was going home to a new job that I had been waiting months to begin. We landed on a Saturday evening; I slept well that night and felt great in the morning until I decide to go for my run. As I started out the road, I felt as if it was coming to meet my face and the rocking began. Within a week, I was in vestibular therapy that helped with the walking but not the rocking, swaying sensation. Many trial medications and exercise routines later, I am still rocking. There was a period when I rocked every other day. I was perfectly normal on those off days but they vanished. Will I ever know if it was the flights, the snorkeling, or the elevator that set off the motion? At this point, all aspects of my life are affected. One of the few positives was finding [the Support site](#). I am one who still wants to believe that if we work hard enough and make enough contacts we will find a way to conquer this syndrome. DMR



## MdDS Support Group-May 2006

Members: 371

May Online Posts: 503



Recently, we added members from South Africa, and Qatar. Other international members have stepped up their efforts to publicize the need for research into the cause of and treatment for MdDS by agreeing to work in Canada, and Australia/New Zealand. The efforts in the USA and UK are ongoing.

### WHAT WILL YOU DO TO HELP?

Please complete the [Questionnaire and Geographic Survey](#). Simply sign in and go to the Files or Database for questionnaire or survey, respectively. Gathered information is available for your use and for our educational and research efforts. Please contact [Judy](#) or [Linda](#) if questions.

### Your Contributions Count!

Donations to the MdDS Foundation in support of educational and advocacy programs should be made to **MdDS Balance Disorder Foundation** and sent to the address below (for logging/acknowledgement) or 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 email: Roger at [rosselyn2@comcast.net](mailto:rosselyn2@comcast.net) or Susan at [sadiesailor8@yahoo.com](mailto:sadiesailor8@yahoo.com)

### MdDS Balance Disorder Foundation

A National Heritage Foundation

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<http://www.nhffoundations.net/mdds>

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