



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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As Another Year Draws to Close...

As 2007 draws to a close, we have made positive progress toward reaching our Foundation goals of educating both medical professionals and the general public of the existence and extent of Mal de Debarquement Syndrome. In January 2007, two of our support site members appeared on ABC's Primetime [Medical Mysteries](#) and our membership grew quickly as a result of the exposure. More recently, that show aired in Australia, and again more people sought support and understanding for this frustrating condition. Our membership number hovers around 600. As the year progressed, MdDS was featured in print media both in the United States and the United Kingdom including a feature article in the Tuesday Health section of the New York Times. This article highlighted the plight of Marilyn Josselyn, one of the MdDS Balance Disorder Foundation's founders. Written by Elizabeth Svoboda, the article offered opinions about the origins and treatment of MdDS by Dr. Timothy Hain, along with Drs. Charles Oman and Robert Baloh, and other international neurologists. This article traveled around the world in its [online version](#). After that a number of members were featured in local articles, two by a boating magazine in California.

Other efforts that showed progress this year include the writing and analysis of data [surveys](#) that are conducted through a secure online data collection tool. The surveys are based on questions that arise from the medical community and members also suggest topics to be addressed. As always, one question leads to another but we hope to better define MdDS through the use of these tools. When Roger and Marilyn Josselyn, Karen Miller, Pat DeRoche, and Becky Test, a friend of the Josselyn's who does not suffer from MdDS, attended the OTO-EXPO in Washington, DC this fall, they were able to hand out a summary of the surveys to many interested doctors. We hope to interest a researcher to conduct a comprehensive, peer reviewable survey in the near future.

Use of the www.mddsfoundation.org website continues to increase; this site is updated on a regular basis. The number of unique hits averages 50-60/day, with a daily high of over 900 on the day that the MdDS Balance Disorder Foundation was listed as the "Charity of the Day" at the GoodSearch website. [See graph on page 2.](#)

Fifteen Years Later, Still Seeking Support

It is amazing to me that there is actually a support group now for people suffering from Mal de Debarquement Syndrome. My symptoms began on August 12, 1992. I remember the date clearly because my entire life changed at that time. After a long flight followed by a winding drive along the California coastline, my rocking began, and with only two short remissions, has continued ever since. It was terribly difficult to find a doctor then who had ever heard of the syndrome, much less diagnosed or treated people with MdDS. I was fortunate enough to be referred to Dr. Ron Steenerson and his physical therapist Gaye Cronin in Atlanta who were able to convince me I had a real, treatable illness that even had a name! The vestibular therapy I received from them enabled me to regain a relatively normal life although as you all know, there is no known cure. When we moved to Maryland, I decided to see if any new treatments were available at Johns Hopkins. I worked my way through the various levels of ENT doctors until I was sent to Dr. David Zee, the chief of neurology, who I believe saved my life. I was really depressed by then (almost 4 years from onset), and I finally got some relief from the Prozac and Klonopin he prescribed. Sometimes I think just having been diagnosed by two world class doctors did as much good as the medication.

I know you all have been through a time of wondering if you were crazy. I won't say it was easy to come to an acceptance of my condition, but it was the only way to have a life. In fact, I encouraged my husband to accept a transfer to China and a few years later to Japan. You won't believe what trans-Pacific flights can do to someone with MdDS! As a result, I didn't fly back from China for over two years. It was then that I had my two 6-week remissions. Airplane flights are definitely a factor for me! I tried seeing a Hong Kong physician who probably still wonders whatever happened to that crazy foreigner. I tried seeing a practitioner of traditional Chinese medicine who had no help to offer. When we returned to the States, I saw a renowned doctor who refused to give me the diagnosis of MdDS since he couldn't believe my condition had lasted so long although he did agree I had had some of the best medical care available in the USA. After that, I resorted to just checking medical literature for research and stayed in contact with Dr. Timothy Hain for whom I had participated in a study. So, that's my story. I realize some of you will be horrified to hear that the condition can last so long, but so am I! I am always looking for sources of help-- that's why I joined your group.

Sometimes, I think it's easier to live with the symptoms than to be disappointed by the lack of progress in treating the problem. I will do anything to help the medical world understand how prevalent this problem is!

Barbara

Looking Forward to a New Year....

As you will soon see, the New Year will bring changes to the Board of Directors of the MdDS Balance Disorder Foundation. Sharon Renschler, Esq. will take over the leadership position for the Board and a number of new members will be added including Dr. Linda McManus, Jane Houghton and Deb Russo. Marilyn Josselyn, Marla Cruise, RN, and Dr. Robert Slater will remain on the Board as it moves forward with the goal of finding a cause and a cure for MdDS, along with its educational goals.

Preliminary Survey Results

A survey aimed at determining the length of time it takes to get a MdDS diagnosis revealed the following. Of the 105 participants in the survey, 89 had been diagnosed with MdDS. Otolaryngologist/ENT's diagnosed 48, neurologists (including otoneurologists) diagnosed 26, but only 1 was diagnosed by a general practitioner. Therein lies the need for educating medical school students and residents in general practice and internal medicine. The others were told they had MdDS by chiropractors, audiologists, physical and vestibular therapists, and a psychiatrist. More data from this survey will be available in an upcoming newsletter.

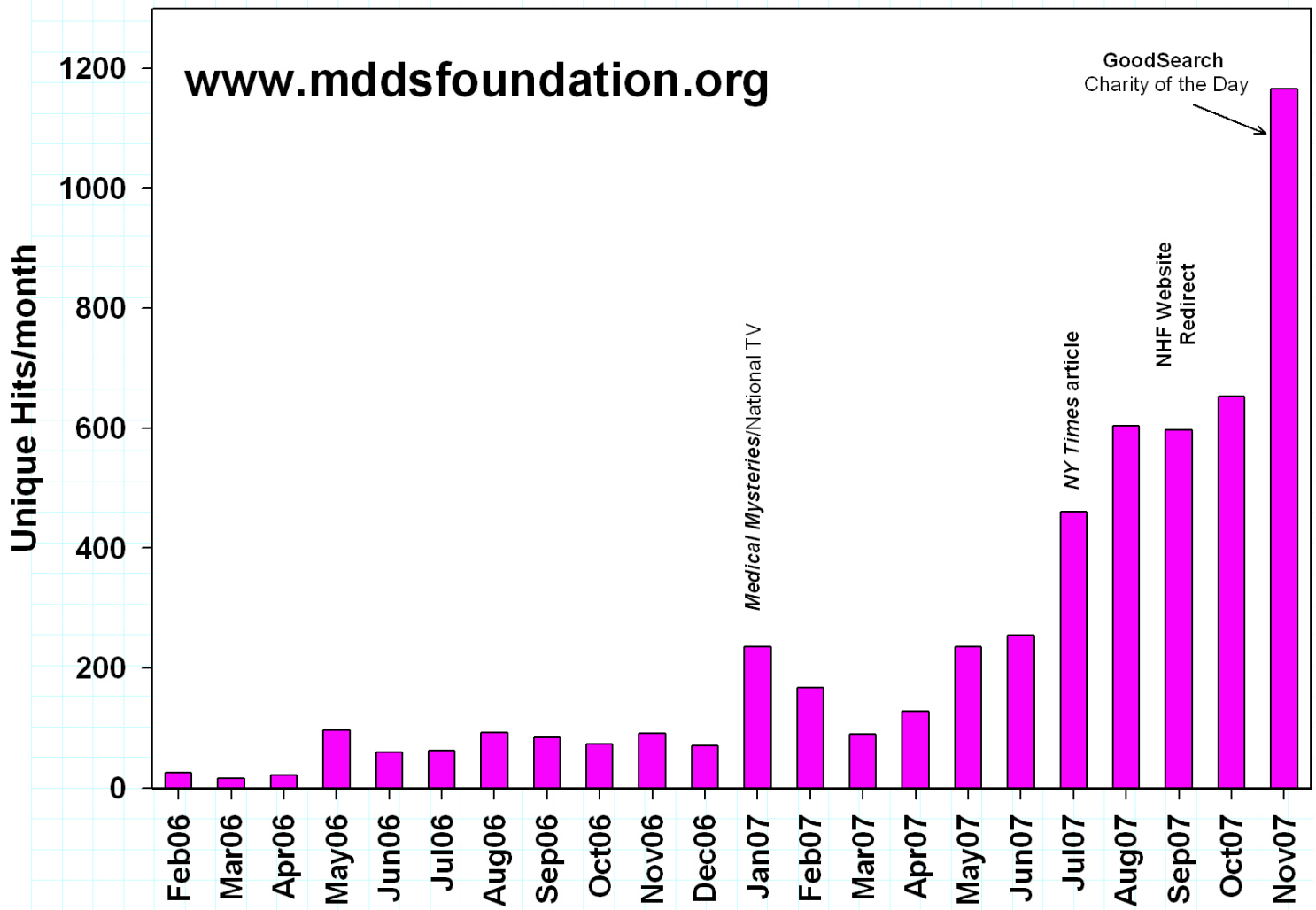
Once again as one year bounces, rocks, and sways into another, we offer thanks to all of the medical professionals who have assisted our efforts. We wish only the best in health and prosperity to our support group members, their families, and our extended MdDS family.

The Board of Directors
MdDS Balance Disorder
Foundation



Personally, I find solace in the friendships I have made on this extended journey and bid each who reads this, peace of heart, soul, and mind.
Thank you, Deb

Use of our Public Website



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