

Mal de Debarquement Support News

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

Volume 15

April, 2007

Initial Symptom Survey

There is a new "Initial Symptom Survey" at the MdDS Support site. Marla, who is a nurse, has volunteered to undertake a survey to determine commonalities in Initial Symptoms in order to better express them in the next version of the MdDS Balance Disorder Foundation's brochure. She is asking that only people who have been positively diagnosed complete the survey by April 30, 2007. Please return the survey to Marla at the e-mail address which she has posted at the Support Site. Once the results of this survey are tabulated, they will be shared in a later newsletter.

When filling out the survey, please check only the symptoms that were present at the time of your diagnosis as symptoms can change due to other health issues and medications.



From CPA to MdDS

Recently I saw a story on MdDS on ABC. It made me feel hopeful that there are others like me. Like many MdDS sufferers, my story started with a cruise. My parents took the entire family on a cruise for their 40th anniversary. It was only a four day trip out of Miami and to Mexico and back. We returned July 2006 and ever since stepping off that boat, I feel as if the whole world is rocking. I flew back to Maryland, and tried to go back to work. I am (was) a CPA at a National non-profit organization, but when I tried to look at the computer and my spreadsheets, everything was rocking and I could not do a thing. At a morning meeting, I could not focus on my financial statements, as the entire conference room was rocking.

I went to a doctor right away. This led to another doctor, and my Mom thought it was just stress or depression. I knew that was not it. Anyhow, I went to no less than a dozen doctors before I finally went to Johns Hopkins to see two doctors who listened and finally understood what I was going through. They prescribed Nortriptyline, Clonazepam, and Ziprasidone

So, to make a long, painful story short, here I am, many months later. I lost my job. My employer was very nice about it and did give me three months disability and sent a fruit basket. I harbor no ill will towards them at all, but I still have no job. I am on long term disability which I am lucky to have, even if it is at 60% of my former salary. I think maybe G-d is teaching me a lesson, because I used to say I wish I didn't have to work. Now, that I'm not working, I pray every day that I am able to work.

My wife has been very, very supportive and has seen me through a lot of sleepless nights. I am only 33 and was in perfect health. I was running marathons, and I had to stop that because the running made me feel worse. I only feel OK when driving or on the Metro. I run the gamut of going from sort of optimistic, when some days the rocking is not as bad, I think I am healing and may be back to my old self, all the way to the worse days when I feel that I'll never get better. If I never get better this is no way to live. I try to keep those thoughts out of my head, but it is truth; if I were guaranteed that I would never get better I am afraid that I would have to "cut my losses" and just be done with it. Again, I try to keep the thoughts out of my head but it has ruined my life. It has taken over and is pervasive throughout the day. I pray every day to get better. Scott, 33 years old.

The MdDS Support Group membership has grown from 35 in October, 2003 to over 500 in March, 2007 but the diagnostic techniques for a cause and a cure have not progressed. This is due to the lack of serious, clinical research into the cause of MdDS. Many of the new Support Group members are debilitated by this misunderstood syndrome. There are more doctors who are able to diagnose but there is little they can offer in the way of relief or a cure. We continue to seek a dedicated researcher!

Once again a matching fund donation challenge has been met. Thank you to all who donated to make this a success.

Please send tax deductible contributions to:

**MdDS Balance Disorder Foundation
Marilyn or Roger Josselyn
255 Copper Beech Drive,
Blue Bell, PA 19422.**

ICD-9 780.4, Indexed

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

**Roger at rjosselyn2@comcast.net or
Marla at mcrnor@msn.com**

mddsfoundation@yahoo.com

<http://mddsfoundation.org/>

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

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