

MdDS Support News

A Newsletter for International Members of the Mal de Debarquement Syndrome (MdDS) Support Group and the Professionals Who Treat Them

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How One Doctor, Who Has Recurrent MdDS, Helps to Educate Medical Residents

I am an obstetrician-gynecologist with multiple recurrences of MdDS. In an effort to educate new physicians, I take the opportunity when interacting with the family practice resident physicians in Boise, Idaho, to inform them about a medical condition of which they may not be aware. Most of the time, the contact is one-on-one while the resident physician rotates through the residency gynecology clinic. Occasionally there is a small conference meeting where the main subject is related to obstetrics and gynecology, but I also include MdDS. Thus far none of the residents has been aware of MdDS, but they usually seem very interested in the subject. As well as presenting MdDS definitions, symptoms, and theories of acquisition, I discuss the frustration of people who have MdDS with the medical community's lack of awareness of this condition. Rather than giving a lot of explanation about diagnosis and treatment, I give each of them the brochure the MdDS Foundation publishes.

Darrell J. Ludders M.D.

Since the last newsletter was published we had 26 new membership requests.

From Championship Golfer to MdDS Sufferer

Four years ago I won the Texas Amateur Golf Championship, now I golf when I can. About 3 years ago, I was traveling to Louisiana to golf and gamble, and I woke up dizzy at 2:00 AM in my hotel room. I called my doctor and he told me to find a drug store open and get meclizine. We turned around and came home and I went to the doctor. He said I had BPPV (Benign Paroxysmal Positional Vertigo.) He did some head maneuvers and sent me to an ENT. The ENT ran several tests and also said I had BPPV, but not a classic case because I was dizzy all the time. He also tried some head maneuvers and could not fix me. I came home and did some research on my own and did some head maneuvers and in three weeks all my dizziness was gone.

About a year later, I felt like I had some type of virus or the flu, just felt lousy and I have stayed dizzy and rocking and swaying ever since. That was 2 years ago. I went to many doctors, two ENT's and a neurologist. Nothing they did helped me. At this point I was diagnosed with endolymphatic hydrops. Finally, after 6 months, many tests, allergy shots, MRI's, CT's, 3 spinal taps in 10 days, endless blood work and following all the protocol for endolymphatic hydrops I was not getting any better. I was in a total vegetative state at this point. I lived on the sofa and wanted to die. My husband got on the Internet and everything he read on dizziness and imbalance referred to a doctor in Chicago. So I made an appointment to see him. In the meantime a friend of mine in Michigan got me an appointment with a world renowned clinic in Rochester, MN. As soon as I got there, I was diagnosed with MdDS. I was there for 4 days and then I saw the doctor in Chicago on the fifth day. He diagnosed me with MdDS agreeing with the previous doctors. They all feel that I got the MdDS from the original dizzy episode when we were on our trip to Louisiana. I was put on Klonopin right away and it was like a miracle. I went from a level ten to a two or three. If the first doctors had only known about MdDS, the amount of testing, doctors, drugs and negative experiences would have been a mere fraction of what I ultimately went through.

It is also a very expensive disease to have because I went through so much to be diagnosed correctly. During the first six months, even with insurance it cost about \$5,000.00 per month for all of the testing and medications.

My life has changed drastically. The symptoms I live with are: dizziness, rocking, swaying, brain fog, headaches, body tremors, tingling and numbness in my extremities, blurred vision, and fatigue.

I live with fear, I have never been afraid of anything before. I can't drive far or fly. I used to play golf daily, now I play when and if I can. I am unable to exercise, water ski, or play the games with my grandchildren that I would love to.

Many days I feel like a prisoner in my own body and suffer from feelings of guilt that I have ruined my husband's life. The feelings of worthlessness overcome me since often all I can do is grocery shop and keep my house clean. I could go on and on. (WD)

Nonprofit Status

As a result of the Pension Protection Act of 2006 changes had to be made to our Foundation. We are now certified as a Pennsylvania nonprofit corporation and we have obtained an official TIN (Tax Identification Number) from the IRS. A checking account has been established in the name of "MdDS Balance Disorder Foundation".

Please send contributions to:
Marilyn or Roger Josselyn
255 Copper Beech Drive,
Blue Bell, PA 19422.

*If you are a new member take a few moments to complete the Questionnaire that is posted periodically by Judy, and the databases located at the Support Site.

**If you are interested in volunteering to assist with our programs, please email: Roger at rjosselyn2@comcast.net or Marla at mcrnor@msn.com.

ICD-9 780.4, Indexed

<http://mddsfoundation.org/>

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

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

Quotes about Causes:

My MdDS began in the summer of '04 when I walked across a floating dock/bridge that was approximately 1/4 mile long. I've been on a boat ever since! (RR)