



MdDS Balance Disorder Foundation

Volume 33, April 2009

Information for the International Members of the MdDS Support Group and the Professionals Who Support Them.

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American College of Physicians Internal Medicine Conference



For the first time the MdDS Balance Disorder Foundation will meet with primary care physicians and internists at the American College of Physician's Internal Medicine Conference in Philadelphia, PA. Surveys show that very few people are diagnosed with MdDS by internists. Members will share brochures, survey information, graphs, and personal experiences.

Roger and Marilyn Josselyn, Elaine Sola, and Irene and Tim Hartman will be available at booth 844 to discuss Mal de Debarquement Syndrome on:

April 23, 10:00-4:30

April 24, 10:00-4:30

April 25, 10:00-2:30

Please look for them near the "MdDS" banner.

Ronald J. Tusa, MD, PhD

is the first recipient of the

Clinical Educator Excellence Award of the MdDS Balance Disorder Foundation

Dr. Tusa has a long and distinguished career in academic medicine. He is a respected clinician with a commitment to excellence in clinical education. As such, he continues to routinely address international audiences in a variety of workshops and courses. Indeed, at the bi-annual UK conference on Balance, he includes a specific discussion of MdDS using results provided by our Foundation.

Dr. Tusa is presently a Professor in the Department of Neurology at Emory University in Atlanta, Georgia where he also serves as the Director of the Dizziness and Balance Center. Dr. Tusa also has joint appointments in



Great Day Houston



As a direct result of Rare Disease Day activities, *Great Day Houston* with Deborah Duncan, presented a whole show on rare diseases and syndromes which included a representative of NORD, the National Organization for Rare Diseases. One segment was devoted solely to Mal de Debarquement Syndrome. Terri and Mike Gibson, Liz Conerly, and Dr. Helen Cohen, of Baylor College of Medicine, participated in an interview with Deborah Duncan. Terri, who has been living with MdDS for three years, took center stage while describing the symptoms of MdDS, during the discussion her husband, Mike, described his concerns for her future. Liz Conerly explained how she returned from a rather routine flight 15 years ago only to find out that she was rocking and swaying. It took her three years to receive a diagnosis. Click [here](#) to see the complete interview.

Balance Disorder Petition in the United Kingdom



A reminder to all who live in the United Kingdom, please remember to sign the petition (located at the link below) encouraging research into balance disorders . Also, ask your family and friends to sign the petition as we all know their lives are affected by living with a person with a balance disorder.

The last day to collect signatures is May 12, 2009.

<http://petitions.pm.gov.uk/balancedisorders/>



Thank you, Marla!

The Board of Directors of the MdDS Balance Disorder Foundation would like to thank Marla Cruise for her years of service. Recently, Marla decided to step down from the Board but agreed to retain her position as the [MdDS Support Site](#) Administrator and Moderator.

Marla was instrumental in the early development of both the Board and the [Support site](#) which now includes almost 900 members.

Recently, Cathy Helowicz was named to fill the Board vacancy. Welcome Cathy, we look forward to working with you as we move forward with our goals and objectives.

Hello everyone, I'm Kim and I want to share my story with you

I have suffered from what I now believe is MdDS for nine years. It was only after a friend saw "Mystery Diagnosis" featuring Roseanne Jensen in early January and told me that "someone else was rocking," that I researched and found out just how many have this syndrome. It was like being alone on an island for nine years and then finding a lot of others were on it too.

I had researched many years ago but kept hitting dead ends so I thought it was just my own problem that I had to live with. You can imagine my shock when I posted a message online and heard back from Cathy Helowicz who also lives in Jupiter where I live! Then I found the foundation website

My onset was spontaneous and sudden on Nov 17, 1999. I had not been on a cruise or done any traveling. It was six weeks after I had given birth which followed a year and a half of life altering events. In June 1998 both of my parents passed away, just three weeks apart, both from cancer. I know my mind and body were extremely tired.

On that day, while walking across the room I suddenly felt that the floor moved under my feet, as if I were on a floating dock. Then, when I would lie down and/or stand up I felt the rocking and swaying, which only got worse over the weeks. I thought I had a virus, but after three weeks when it didn't go away, I knew it was something more serious.

That following year I went to several doctors who prescribed antivert, xanax, and valium which I could not live on. I had all the tests, MRI's, ENG's, and went through vestibular rehabilitation.

My primary doctor put me on Celexa to help the ensuing depression/anxiety. I noticed after time my symptoms became minor and I was able to function. I almost thought the whole thing had gone away.

I went off of Celexa in September, 2008 and felt very good for a couple of months; however in December the symptoms of rocking/swaying returned and I felt horrible. Also, new symptoms appeared; fullness/heaviness in my head; feeling a lot of pressure with no pain.

I started using Celexa again January 7, 2009 and have had a pretty rocky month but am just now starting to feel some relief from the symptoms, and am feeling more like my normal self. The depression and anxiety these symptoms cause is horrendous.

Cathy Helowicz is doing so much to get the word out about MdDS and to get more research going on it. It is so wonderful to know that there is hope. I want us to find a cure for this horrible



syndrome that people know so little about, and so many people seem to have.

Here's to us all feeling much better real soon! ~ Kim



Rare Disease Day

Activities 2009

~ Honor Donations were made by ~

Alice and Eugene Skinner in honor of Marla Cruise

Helen and Roger Weiland in honor of Theresa Weiland

In order to make a donation to the MdDS Balance Disorder Foundation:
Use the PayPal Button at www.mddsfoundation.org and indicate the honoree on the PayPal form.

Send Cash and Checks:
MdDS Balance Disorder Foundation
c/o Marilyn Josselyn, President
22406 Shannondell Drive
Audubon, PA 19403



But we don't want too..

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Forward this to a friend.

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Forward-to-a-Friend