

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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Preliminary Data from the Symptoms Database

The on-going collection of data by the MdDS Foundation expands the world's largest single set of data about those with MdDS. The new "Symptoms" database has yielded interesting preliminary correlations*. #1: *the level of initial symptoms is inversely correlated with age (i.e., younger folks have higher symptoms in the beginning)*. #2: *age is positively correlated with duration of MdDS symptoms, $r=0.44$, $p=0.008$ (i.e., the older you are, the greater the duration of symptoms; calculations are pending to determine if this relates to the age of onset)*. #3: *the intensity level of current symptoms is related to the duration of symptoms, $r=0.37$, $p=0.03$ (i.e., those with a longer duration of MdDS have greater current symptoms)*. Curiously, there is no relationship between initial symptoms and current symptoms. But, taken altogether, these findings suggest that duration is a more important predictor of current symptom levels than the initial level of symptoms. *These findings are based only on results provided by 36 individuals who have been diagnosed with MdDS, 36 women (average age of 52) and 2 men (average age of 59.5). Expansion of this database will verify and extend these preliminary findings. Since the MdDS Balance Disorder Foundation is dedicated to an improved understanding of this disabling syndrome, it is hoped that these efforts will contribute to better approaches to the treatment and prevention of MdDS.

During the month of October there were twenty requests for membership at the support site. We have even found next door neighbors with MdDS. **Is it really so rare?**

Thirty Years of Mal de Debarquement Syndrome

I have had MDSS for over 30 years. I had not been on a boat for years before I acquired it. I flew to Hong Kong as I had done regularly my entire life. I was a teenager when I developed MdDS symptoms and it was completely debilitating. I remember sitting on a crowded street in Hong Kong while my mother protected me from being trampled as she waited until I thought I could walk to the car.

I have spent most of my life being tested for brain tumors and MS. I was finally diagnosed by a German doctor who did not know the name for MdDS. A couple of years later I was diagnosed by a doctor in Denver who did know the name which led me to Evan Torrie's Website and this group.

I had been given fertility drugs for years before being told I would never have a baby. I had a biological child a few years after giving up fertility treatments. Pushing to get him out changed the course of my MdDS. It intensified dramatically and has truly changed my life. This happened at 39 after I had already reared 2 stepchildren. My children are now aged 5 and 9 and I spend all my energy caring for them and wish I had more stamina to play with them. At one point in my life, I ran a small Aerospace Company as my husband was a rocket scientist and I have my Master's degree in Human Resources. Also, I loved being an x-ray technician especially when working in the operating room.

Now, I have become a recluse but I walk with a cane most of the time when I can get out of the house. The last of my friends seem to have disappeared since they can no longer accept my "imaginary" illness. Tragically twenty months ago my husband died, he was the only one among my friends and family that understood why, at times, I would flee from a busy supermarket leaving a full cart of food at the checkout line. I do sometimes have a good day but this only seems to serve as proof to friends and family that "it's all in my head." I hide behind sunglasses to avoid as much Fluorescent and bright sunlight as possible. I'm sure many people think I'm drunk as I stagger down the street....

My doctor considers me completely disabled. I continue to see him often as I fall frequently. I also need every moment my children are at school to sleep. I can no longer read for more than a few minutes at a time. I cannot take any anti-depressant medication; I'm allergic. I cannot collect Social Security disability widow benefits because you cannot be considered a disabled widow until you are 50 and I'll turn 49 later this month.

I feel this disease has stolen so much from me, but more importantly, from my children. I know it is a syndrome and some hear the word syndrome and think "well that's not really so bad." My brother is now dying from Acquired Immune Deficiency Syndrome. He has had AIDS for 20 years and he understands how devastating a "syndrome" can be.

Many thanks to Terri G. (Texas, USA), and Barbara (Kamloops, Canada), for getting articles placed in their local newspapers. Linda L. (Scotland) had an article published in CHAT, a popular magazine in the United Kingdom, explaining her MdDS experience.

*****Please help us collect information about the MdDS experiences of our Support site members. If you are a current support group member please be sure to visit the site to fill in the Geographic and Symptom Databases. Also, if you are a new member take a few moments to complete the Questionnaire that is posted periodically by Judi.**

Your Contributions Count!

Donations to the MdDS Balance Disorder Foundation in support of educational and advocacy programs are encouraged and should be made by sending them to:
MdDS Balance Disorder Foundation,
255 Copper Beech Drive,
Blue Bell, PA 19422
(For logging/ acknowledgement).

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

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