



## MdDS Balance Disorder Foundation

Dedicated to finding a cause and a cure for Mal de Debarquement Syndrome  
Volume 43, May 2011

### Information for Those Living with MdDS and the Medical Professionals Who Support Them

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### News and Awareness

**In the News** - Recently, [the Daily Globe and Mail in Vancouver, BC](#) published an article "Imagine being seasick for years - on land" by Ariana Barton. Dr. Yoon-Hee Cha, of UCLA; Dr. Brian Clark, of Ohio University; Marilyn Josselyn, Foundation president; and Cindy Balayewich, MdDS sufferer; explain life with MdDS and the research that is currently in progress.

**Japanese Earthquake Hangover** - Have any of you heard of "Japanese Earthquake Hangover?" This April 14, 2011, Wall Street Journal entry, [How to Treat an Earthquake 'Hangover,' Chester Dawson](#) describes another obstacle for the Japanese people to endure. Earthquake 'Hangover' has many of the same descriptors as MdDS. A number of people have attempted to make contact with the Japanese doctor quoted in the article and with those at the University of Tokyo to share information. One Board member has been in contact with the author but if you are a doctor with Japanese contact, perhaps they could use your help.

**MdDS Talk in Southampton, England** - On March 15, Jane Houghton, of the MdDS Balance Disorder Foundation Board of Directors, spoke at Southampton University to twenty-five Masters Students in Audiology. The talk lasted about an hour during which she told them "her MdDS story" and struggle to get diagnosed. Jane Burgneay, the organizer, produced some slides that displayed Dr. Ronald Tusa's understanding of this disorder from a clinician's point of view. He is affiliated with the Emory University School of Medicine. At the end the students asked some intelligent questions which showed they were thinking about the condition. Many of them took copies of the February newsletter and signed up to receive future editions.

**June is Mal de Debarquement Syndrome Awareness Month** -The MdDS Balance Disorder Foundation is hosting fundraising and awareness events to bring information about MdDS to the forefront as we search for a cause and a cure for this rare disorder.

**Art Rocks** - One such event will take place on June 8, 2011 in Jupiter, Florida, entitled "Art Rocks." Two local business women came up with the idea to give back to locally affiliated non-profit organizations. Therefore, Unique Glass Art and Unique Art Gallery, sponsor an Open House on the second Wednesday of each month and donate a portion of the proceeds. A portion of the proceeds from the "Art Rocks" Open House, sales and raffle, on June 8th, will be donated to the Foundation. It will be hosted by Cathy Helowicz, MdDS Balance Disorder Foundation Board member. Light refreshments will be served. The event is from 5:30-7:30PM at Center Park Plaza, 226 Center Street, Jupiter, FL. For information call: Susan at (954) 588-7275 or Carolyn Austin at (561)-747-2024.



**Other Awareness and Fundraiser Activities** - As other awareness and fundraising activities are planned, they will be posted at the [MdDS Balance Disorder Foundation website](#) and the [firstgiving site](#). In addition, support group members are planning to raise awareness through the social networking sites [Facebook](#) and [Twitter](#). Donations made to the MdDS Balance Disorder Foundation support research efforts (currently at Ohio University and UCLA), awareness campaigns and education about this rare disorder.

**Professionally Printed Brochures** - As part of MdDS Awareness month, professionally printed brochures are available to use

in your office or to take to your medical professional. Send a request to [newsletter@mddsfoundation.org](mailto:newsletter@mddsfoundation.org). A number of medical professionals are providing these pamphlets to their patients as they are diagnosed with MdDS. They are also available for use as educational tools and for people living with MdDS.

To find out more about this rare disorder, go to [www.mddsfoundation.org](http://www.mddsfoundation.org). The MdDS Balance Disorder Foundation is a 501(c) (3) all volunteer nonprofit foundation.

## Two Perspectives of Life with Mal de Debarquement Syndrome

By  
Mike and Krystal

### Mike Nelson - Initial Onset at 45 Years Old

January 28th, 2011 was a day my wife and I had been looking forward to for the previous seven months. It was the day we would be leaving on a cruise ship—our first cruise ever—for a week-long journey into the warm, tropical, clear blue waters of the Caribbean. Our cruise would take us to islands that promised lush rainforests, historical sites, and sandy, sun-kissed beaches. It would be a week away from the dry, skin-cracking, cold winter of the high desert. Indeed, the seven day adventure did live up to what was promised. It also brought on a completely unexpected and unwelcome surprise.

Prior to January 28th, I was physically well balanced, active, athletic, and full of energy. I rode my bike regularly, swam weekly, loved going to the grocery store, enjoyed a fairly active social life, took long walks, hiked in the mountains when I could find the time, and loved to take long drives. My wife and I talked endlessly about all the places there are to see in the world, the places we most wanted to see, and the ways we would get there.

After the cruise, life, for now, has a whole new, bizarre, terrifying, confusing, almost all-encompassing component to it. Here's what happened.

As the ship departed from Port Everglades, we were inside, listening to a presentation. Not thirty minutes into the voyage, I began to notice that everything around me was beginning to shift in my vision. Though I had been on much shorter water voyages, like ferry rides, kayaking expeditions, and such, this was a new sensation to me. The room began to rock and bob and make quick but subtle shifts every which way. And upon standing after the presentation, I noticed my sense of balance felt compromised; walking a straight line was suddenly quite a challenge. I was sure I was simply feeling the motion of the sea, and gradually became "used to" the motion over the ensuing seven days. I can even say I came to sort of enjoy the motion; it felt like I was being gently rocked—soothed and comforted by the ways of the ocean. Now, more than two months later, I truly find myself wondering if I would have been better off had I not enjoyed the motion. Did I become so "used to it" that I can't get it out of my head now?

When, upon disembarking from the ship on February 4th, the feeling of being at sea continued, I assumed I was simply "getting my land legs back." I had been through similar experiences after many a train ride. But when the feeling persisted for a couple days, I began research on the Internet, and could not pinpoint anything specific, other than references to a "rare, often chronic syndrome for which there was no cure," which I largely ignored, for obvious reasons. The only other mention I saw of something that described my symptoms referred to a common post-water-voyage condition that could possibly last two days—four at the most. I just assumed

"Hope is the feeling you have that the feeling you have isn't permanent."

-Jean Kerr

My appreciation for the value of good health vastly deepened beginning in March of 2007. I had just come home from a great vacation where I was able to do so many fun things that I enjoy. I would later realize that these activities that I did without any thought or reservation, would be the things I would have to carefully avoid in the future. Within a two week period I had the opportunity to fly to three different locations, spend a day at a huge amusement park, and get the chance to go skiing. I was happy, full of life, and in my late 20's unaware how life was about to change. I still remember that morning with such detail as I took my first few steps out of bed. The ground no longer felt safe and stable. I was now walking on what felt like a trampoline. I found myself having to hold onto walls. Laying down offered little comfort either. It felt like my body was free falling, similar to the feeling you get on a roller coaster. My ears were experiencing pressure changes like that of being on an airplane. I had heard the term brain fog tossed around before and admittedly thought it was an over exaggerated term. I was proven wrong. Trying to put together thoughts and words, which before came effortlessly, suddenly became an increasingly difficult task. It was a confusing period of time, to say the least, trying to explain to others these weird sensations that had invaded my body.

After winding up in the ER, like so many others in this situation- I was sent from doctor to doctor, specialist to specialist, even went through vestibular rehabilitation therapy...before being told that they did not know what I had or how to help me. For the first time, I truly felt helpless, in its rawest form. I was determined to figure this out, I wasn't going to accept that as my answer. After many nights of researching, I was able to find the MdDS Yahoo support group site and within minutes of reading people's stories, I felt in my gut that this is what I had. It was such a validating feeling to have finally found people that knew what I meant when I said I was experiencing G-forces in my head or how my body felt like I was in the middle of the ocean riding enormous waves. Thankfully they had a list of doctors that were familiar with this rare and little known condition. I was able to find a neurologist that confirmed all of this and diagnosed me with Mal de Debarquement Syndrome. It's amazing how just being given a name had the ability to bring some sense of relief, even when there was no end in sight.

I very much wish I could report that in the last 4 years my symptoms have dissipated or have improved greatly. The truth of the matter is I have become fairly skilled at coping. Forgetting what it feels like to be still, my body and brain have

that the nightmare I'd been living through in our post-cruise Fort Lauderdale hotel room would vanish after we flew home.

At that point, the main way I could have described my symptoms was that I felt like I was still on the boat, pure and simple. My balance felt "off." I still felt as if I, and all around me, was in constant motion. When leaning to reach for something, I had to brace myself by holding onto (or leaning against) something solid for support. It did not matter what I was doing; I felt off kilter all the time. Walking and squatting seemed to exacerbate the symptoms. Also, I felt abnormally tired, and attributed this to recovering from a long week at sea.

Little did I know that the flight home, three days after disembarking from the ship, would only further aggravate my condition. We had a short, hurried transfer in Phoenix to make our connecting flight home. As we rushed through the terminal, the rocking and bobbing was intense, making me feel as if I had to be really careful not to fall. Back home, picking up our truck from the airport parking lot, my first time back in the driver's seat since the cruise, I felt as if I was in a floating boat. When I described the sensation to my wife, she offered to drive. I told her I wanted to try driving; we were both tired and I just wanted to get home. Half a mile down the road, I told her I was going to stop because I thought we had a flat tire...the ride simply did not feel "right." Upon inspection, all four tires were fully inflated. How strange this all was! The rest of the drive home was rather unremarkable, but I noticed that each time we came to a stop or rounded a corner, the sensation of being in water would start again.

[continued](#)



been forced to adapt the best way they know how. I have become familiar with which activities or environments are triggers for me and do my best to avoid those while still trying to find a sense of normalcy amongst everyone around me. This condition is not terminal thankfully, but it certainly is life altering. Not only must you adjust to feeling as if you are on a boat 24/7, but you also have to think through *Everything* that you do ahead of time and how it may exacerbate your symptoms. MdDS has changed my life in a multitude of ways. I've lost a few people along the way who couldn't accept that I had to alter the life I once knew. Perhaps they expected the *exact* same Krystal as beforehand. In essence I was still me (same heart and mind), but I now had a few things going on that required an extra little dose of understanding and patience. With that being said, I also gained other people along the way that I would never have found otherwise! I have learned through this experience how alienating it can be to have an invisible illness and unfortunately how some people are very black and white when it comes to things that they can not see. I have also learned a deeper compassion through this and to take what people say and do nothing more with it but believe them. Judgment placed on others is only a reflection of yourself.

I have acquired a new sense of HOPE through this experience and it has placed a new-found perspective in my life. I hope more than anything to one day be able to feel STILLNESS again. I have realized that living with this condition became a bit more manageable when I stopped living with the 'why did this happen to me' attitude. I also had to step out of the fantasy notion that everything was going to go back to normal tomorrow. I learned to accept that right now this is my reality and I can choose to stop living and remain in fear or choose to learn to live with it the best to my ability. I chose the latter. This in no way means I have surrendered the fight in me to overcome this. It just means that while searching for answers (and hopefully a cure) and learning more about this puzzling condition, I am still adamant to do as much with this current life that I possibly can. MdDS is a part of my life (certainly not by choice), but it by NO means defines who I am. Surely some days it firmly grabs a hold of me (and I will admit it can get pretty dark), but there are many other days where I am able to rise above it and find a new strength in me that I never knew existed.

Krystal - onset late 20's

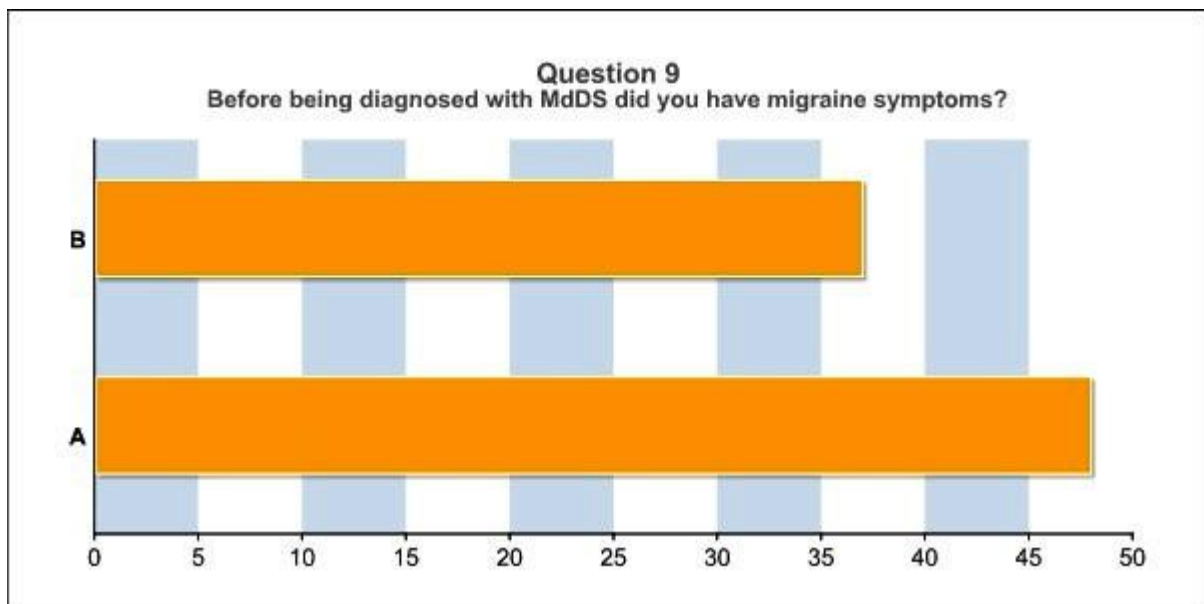
### Preliminary Results of the Mal de Debarquement/Migraine Association Survey

The follow results are based on the responses of 85 participants, all of whom have a confirmed diagnosis of Mal de Debarquement syndrome from a medical profession. They answered an on-line survey between 02/24/2011 - 04/18/2011.

Of the 85 people who responded to the survey, 83 were female and 73 are currently experiencing MdDS symptoms. The average age of the initial onset of MdDS was 47 years. Seventy two people, 84.7%, reported that their MdDS started as a result of a motion experience; ten, (11.8%), reported spontaneous onset; and three, (3.5%) answered "other" which include gaming system use, both spontaneous and motion induced, and onset weeks after air travel. Forty-eight people(57 %) state that they experienced migraine symptoms prior to MdDS and forty-one (47%) have a migraine diagnosis from a medical professional. The most frequently reported migraine symptoms were headache and sensitivity to light.

Of the seven people who reported have a spontaneous onset of MdDS, all were diagnosed with migraine by a medical professional.

This is obviously a preliminary survey. The topic needs further investigation on a larger sample size.

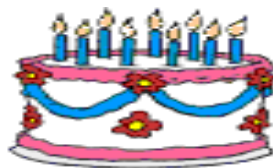


A - Yes = 48

B - No = 37

To see recent birthday and honor donations please go to our donation website by clicking [here](#).

We would like to wish a very Happy Birthday to Roger and Marilyn Josselyn who both celebrated special birthdays in the month of April. We owe them a debt of gratitude for having the foresight to begin the MdDS Balance Disorder Foundation.



Contact the MdDS Balance Disorder Foundation at [newsletter@mddsfoundation.org](mailto:newsletter@mddsfoundation.org)

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