



MdDS Balance Disorder Foundation

Dedicated to finding a cause and a cure for Mal de Debarquement Syndrome
Volume 39, February 2010

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

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Meeting of the Board - 2010 Initiatives

The Board of Directors of the MdDS Balance Disorder Foundation held its first teleconference of the year to plan its 2010 initiatives in support of its mission:

- To provide support and education for patients and families of those with this rare balance disorder
- To promote basic and clinical research to better understand the cause(s) of this unique syndrome
- To facilitate clinical studies designed to improve the diagnosis and treatment of MdDS
- To collect, collate, and distribute demographic and other information from those with MdDS *via* online surveys (at present, our findings represent the world's largest available database of results about this patient population)
- To update professionals who provide medical care and treatment of MdDS patients

The Foundation has great news to share. The MdDS Balance Disorder Foundation received another major anonymous donation of \$50,000 this year to support and expand Dr. Cha's research efforts. The same donor expressed interest in the work that Dr. Cha started with the original funds in 2009. Those funds allowed Dr. Cha to begin her serious and focused study of MdDS in the clinical setting using neuroimaging techniques. We would like to express our gratitude to this donor and staff for making this continued donation possible.

In addition, this year Dr. Cha will be working on research of MdDs with funds from the NIH. Her study received three years of support, at \$100,000/year. Relative to Dr. Cha's progress, her findings are very encouraging towards defining a target in the brain...but, these results remain preliminary and must be confirmed with more MdDS patients in comparison to control subjects. As soon as we learn that her results can be provided to the public or receive information from her regarding further patient recruitment, we will provide this to the Support Groups. We are all anxious about her work as we hope for a consistent treatment or cure.

Immense brainstorming took place during the recent three hour teleconference call of the Board. There are wonderful things that are (and have been) happening. We are constantly working behind the scenes on behalf of everyone who participates in the Yahoo support group as well as the Facebook groups. We have many, many daily communications between board members which deal with the variety of issues related to the foundation, i.e., coming up with new ideas for awareness, expanding fund raising and donations, recruiting corporate sponsorship, reaching out to medical professionals, scheduling attendance at conventions and conferences, and doing major resource mailings.

The Foundation has some great campaigns planned for this year:

February's Fundraising Challenges - Donate in Honor of Someone You Love
and

Rare Disease Day - Alone we are Rare. Together we are Strong!
What a great way to start off the year.

June will bring us "MdDS Awareness Month" We are planning many events to bring about awareness and further donations for the foundation. Dr. Tusa, Advisory Board member, will present a course which includes MdDS at the University of Southampton in the United Kingdom at the end of the month. He has invited Jane Houghton, MdDS Balance Disorder Foundation Board Member, to join him.

During *October* we will again run the *Macy's campaign* and hope that all you will join the effort this year. What a great fundraiser that turned out to be last year. We hope to expand it to Bloomingdales as well.

Also, we want to encourage all of you to participate in foundation events, remember they are here for all of us. Please don't forget we have a Foundation Facebook page, if you are not a member of Facebook, please consider joining. Then you can do a search to find the foundation under Mal de Debarquement (MdDS) Balance Disorder Foundation, please get your friends and family to join the foundation as well. We constantly update news on the foundation page.

Also, please join the Foundation Causes page (a tab is available on the MdDS foundation page). This is a great way to raise money with the Birthday Challenges. Two of our members have recently used the Birthday Challenge and have raised over a \$1000.00. Just think if everyone did this. This brings in friends and family that might not have an opportunity to donate, or be aware of how to donate. Causes on Facebook makes it so easy. Also, as mentioned by a member recently, don't forget to shop iGive. It costs you nothing to join and nothing to shop, and a percentage of all purchase proceeds goes to the MdDS Foundation.

Every penny counts!

As always volunteers are needed to help with every growing commitment we are taking on. And, of course, your ideas and suggestions are always welcomed!

We live in hope!
Cathy Helowicz
Secretary
MdDS Balance Disorder Foundation

February Donation Challenge



*Don't get me flowers, chocolates, or wine
Just donate to the MdDS Foundation to be my Valentine.*

In this season of love, please consider donating to the MdDS Balance Disorder Foundation on behalf of or in memory of someone you love. Instead of sending flowers that will wilt and fade, or giving chocolates that add to one's waistline, give a gift that could change a life. No matter how large or small your donation is you are giving the gift of hope to someone whose life has been touched by this misunderstood, life changing syndrome. This syndrome not only affects the patient but each member of that person's family including young children, parents, and partners.

No donation is too big or too small.

We encourage you to share our appeal with your Facebook friends, all those people who you forward jokes to on your e-mail list, co-workers and of course to your close family and friends. Remember MdDS is a syndrome that can and does effect people of all ages.

February culminates with ***Rare Disease Day: Alone we are Rare. Together we are Strong!*** around the world. On February 28, 2010 organizations around the world hold events to bring awareness to Orphan and Rare Diseases. The members of the MdDS Support site wrote to their state governors to have a proclamation read in each legislative session on that day.

Your donations to this non-profit organization are tax deductible.

There are many ways to donate to the Foundation:

- Access www.mddsfoundation.org and use the Pay Pal button.
- Visit the [Facebook Causes Page](#)
- Send a check or money order to:

MdDS Balance Disorder Foundation
c/o Mariyn Josselyn, President
22406 Shannondell Drive
Audubon, PA 19404

In Recognition of our Honor Donations

Donor	Honoree
Joan Dreux-	Carol Havlin Robert Westpheling
Laura Albrecht-	Kathy Yu
Andrea Nightingale-	Miranda Ravin
Judy Messenheimer-	Roger and Goldie Sample
Deb Russo-	Dutch and Pat Welch Mike Russo
Greta Rubinow-	Lynn Whitaker
Don Tiefke-	Chris Tiefke
Terri Gibson - Birthday Challenge	Mike Gibson Glenda Gibson Sue Ratliff Cathy Helowicz Debra Brill Deb Russo Barbara Wiedman Irene Hartman Dennis Grimland Molly Bedrich Carla Mahle Janis Sonntag Donna Hooper Linda McManus Brenda Melder Emily Bradley Tommy Tompkins Cheryl Allen Marilyn Josselyn

Many thanks!!

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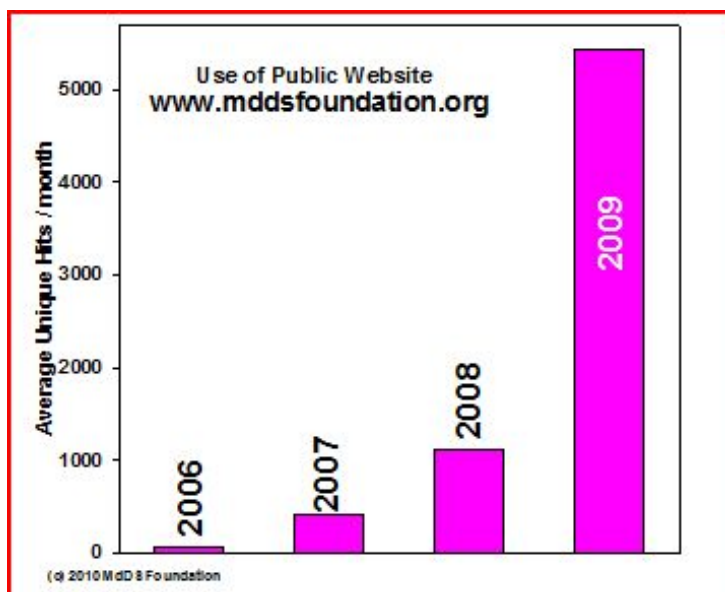
Public Website Updated

Site Continues to Gain Use / Exciting Plans for Health Care Professionals

The Foundation's public website, www.mddsfoundation.org, has recently undergone a "facelift" for improved viewing and use. In combination with a Google AdWords grant to our non-profit Foundation to expand search engine links to the website, the past year has seen record activity.



Among other improvements implemented, a Google-based language translator has been added to each website page. Hopefully, this addition will benefit those with MdDS who do not have English as a primary language. In review of the annualized record of website use, there has clearly been a significant increase in website usage during 2009 and there are currently 1130 members of the online support group. It is expected that this activity reflects success in educating the lay public as well as health care providers about MdDS. In the near future, the website will be further enhanced to provide even greater information for health care professionals who seek expanded knowledge of this unique and rare disorder.



Patient Perspectives

Two Different MdDS Experiences With the Same Concerns for the Future

Late January of 2009 is when my first symptom of Mal de Debarquement Syndrome began. Unfortunately, I wouldn't be officially diagnosed until December, 2009. My first symptom was a heavy feeling in my head and arms. My head would involuntarily droop. The very first time I felt this was when I was stopped at a red light in my car. I also felt weakness in my legs while walking. In addition, I would get "brain fog" at work. I would be looking at something on my computer and I couldn't process it. On another occasion, I had trouble speaking. I couldn't think of the words to form a simple sentence. My Primary Care Physician scheduled an MRI of the brain and spine and an EEG. Both of these came back normal and I was prescribed Lexapro and diagnosed with Generalized Anxiety Disorder. Another symptom began, which was intense pressure in my head, as if there was a tight band around it. I had migraines periodically. Then, one morning in March 2009, I woke up feeling unbalanced and dizzy. This feeling has not left me since. However, some days are better than others. When I walk, I feel like the ground is moving. When I sit, I rock back and forth. When I stand, I sway. And when I'm lying down, I feel like I'm floating. At times, there is also a sensation of a gravitational pull from one direction, then another. Being in closed in places with lots of visual stimuli (eg. grocery stores) makes my symptoms skyrocket. By October, my symptoms were severe enough that I could no longer work. At this point, I had seen my PCP, a Psychiatrist, two ENTs, an Endocrinologist, an Ophthalmologist and a Neurologist and none of them had an answer. I was determined to find out what was wrong with me. I went to a second Neurologist. Within two minutes of me describing my symptoms and seeing that all my tests were normal, he asked me if I had done any traveling at the time of the onset of my symptoms. I told him no. Nevertheless, he said he thought I had MdDS. Finally getting a diagnosis was bittersweet. I was relieved that there was a name for what I had been experiencing for so many months, but sad of what this mysterious illness meant for my future. Maria, 44

MdDS Affects Families as Well as the Person Who Lives with the Syndrome

My name is Terry and I am a 43 year old woman currently living in the San Francisco Bay Area. I used to be super women – I own my own business, volunteered regularly at my children's school, and went on skiing/snorkeling/outdoor vacations with my family; spending my summers in canoes, motor boats, sailing, and going on snorkel trips. I even went on a seven day cruise in my twenties and never felt a single wave when I got off the boat. That all changed in July 2009 when my parents treated my sisters and my family to a seven day cruise to celebrate their 50th anniversary. Little did we know how this celebration would change my life and that of my family. I woke up with a headache every day on the boat and felt nauseous the days we were out to sea. I felt fine on land at our destinations. I was definitely ready for the cruise to end.

I felt some waves and had a hard time concentrating on my work the first two days off the cruise but these feelings did not affect my life. I flew from Florida to California, and once I was home I started to have other symptoms. I took the kids to a movie theater and felt motion sick and I experienced nausea which got worse in crowded places. In the beginning, the nausea was so bad I felt too sick to drive and could not feed my children. I became worried about being alone with my 6 and 9 year old during the day and have had my mother or mother-in-law with me for the past six months. It is hard seeing how this condition affects my children. My daughter told me she wanted her old mom back. My son was crying one night because he thought I was going to die because I could not eat much early on. Our entire family is on the east coast and we did not travel to see them over the holidays. The kids told me it did not seem like Christmas. It is difficult helping my six year old read because looking at the book and seeing him wiggle makes me feel like I am in a hurricane. I refuse to let MdDS effect going to my children's activities. I attend their soccer and basketball games even though watching the movement can make me worse.

I went to a PCP. The doctor said I had "land sickness" and told me to first try meclizine and then the transderm scopolamine patch. The meclizine did not help so I tried the patch. I felt pretty good on the patch until I woke up on day four and had very blurry vision. My doctor told me to take off the patch. Within twenty hours after removing the patch I experienced all of the withdrawal symptoms listed – nausea, vomiting, fatigue, dizziness, plus a more pronounced feeling of motion. Three days off the patch I saw an ENT. She said the patch had suppressed my vestibular system, to move around, and to come back if I did not feel better in two weeks. Two weeks later I had lost fifteen pounds and was no better. I personally believe that it is not a coincidence that my symptoms escalated after the patch removal and I believe that it pushed me over the edge.

I did a Google search of "land sickness after cruise" and found Dr. Hain's article on MdDS. I fit the description perfectly. I brought an MdDS brochure to my ENT who had not seen a patient with it in her career. She contacted an ENT at Stanford who said not to take medicine and it would slowly go away. Two and a half months after the cruise, I was not better and decided to drive 6 hours to see Dr. Cha at UCLA. She confirmed the diagnosis of MdDS. At this time, I still woke up with extreme nausea and vomited half of the mornings. The nausea seemed to go away around dinner and when it went away I really felt the rocking. I was reluctant to take medication due to my reaction to the patch and since we do not know if it prolongs MdDS, but I could not handle the all day nausea any more. Now, I take klonopin at bedtime and it seems to help reduce the vomiting, and the nausea is less severe on most days. I guess I am lucky that I found out early what was wrong with me, but not knowing when or if this will ever go away is not easy to live with.

Stores also make me feel worse therefore I cannot stand to be in them. I cannot watch television programs with a lot of motion. My husband bought a new flat

screen television and we have to reduce the screen size so I can watch it. My job entails being on the computer. It has been difficult because it feels like someone is pushing my head forward and then backwards. Luckily that has diminished, but now I sometimes get sick from scrolling and clicking between screens.

Over the past six months, I have learned some tricks on how to deal with certain situations and my limits. I have also seen an improvement in my symptoms. However, it is still frustrating to only be able to do a fraction of what I used to be able to.

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

Please join us on our **Facebook** cause page
or the Foundation page.



But we don't want to ...

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