



MdDS Balance Disorder Foundation
Dedicated to finding a cause and a cure for
Mal de Debarquement Syndrome
Vol. 43 - February 2011

Research Updates

Update from Dr. Cha - University of California at Los Angeles

This is going to be a big year for MdDS research. We've made great headway on our functional neuroimaging study which is showing really significant differences in brain activity in patients with MdDS. We're approaching this in various ways by looking at brain metabolism, perfusion, oxygenation, volume, and connectivity. This data will guide the form of neuromodulation therapy most likely to work. The study has progressively gained momentum in the last several years through a combination of efforts from the Foundation, patients, the UCLA Brain Mapping Center, collaborators, the NIH, donors, and media. None of the work would have been possible without each and every player, particularly the patients who volunteered for the study, many of whom who used their own resources to fly to California to participate. The current community of people interested in furthering the understanding of MdDS did not exist even one year ago and there are now two other investigators looking at different aspects of MdDS (Brian Clark in Ohio and Christine Dancey in the UK). This disorder



is devastating to those who are affected and understanding these different facets, like the physiological markers and impact on cognition and quality of life are all vital to promoting awareness of MdDS, preventing it, and treating it. From a purely scientific point of view, it is a fascinating example of neuroplasticity. Essentially, prolonged vestibular stimulation can trigger a persistent network of brain activity in an otherwise healthy person under the right physiological circumstances. The associated symptoms of cognitive slowing, fatigue, headache, and anxiety are not there by chance. This disorder is going to shed light on how these many symptoms are tied together and how the vestibular system is related to them. Advancing the understanding of MdDS is going to be team effort. It is too big of a disorder for any one person, foundation, or institution to tackle. But, the effort has to be made for all of the patients who currently suffer from MdDS and for those who may develop it in the future. We really need to be able to return quality of life to the people affected by this disorder.

Yoon-Hee Cha, MD

Visiting Assistant Professor

UCLA Department of Neurology

WE NEED YOU: Scientists at Ohio University are Conducting Research on Mal de Debarquement Syndrome and Study Participants are Needed - They are ready to begin testing as soon as qualified test subjects are found.



A team of scientists with the Ohio Musculoskeletal and Neurological Institute (OMNI) at Ohio University are conducting a study on the pathophysiology of MdDS. This study is led by Brian Clark, PhD, Director of OMNI, and seeks to understand the neurological basis of MdDS. The scientists are actively recruiting subjects with MdDS for their study. In brief, the study would require you to visit Athens, OH and complete two testing sessions that take about 3 hours each (these can be performed in a single day or on two separate days). One of these testing sessions involves us performing transcranial magnetic stimulation to study the portion of your brain that controls your muscles (specifically, we will see how "excitable" this part of the brain is). This procedure is non-invasive (*i.e.*, no needles). Most people describe this by saying it feels like someone is tapping you

on the head lightly. The other testing session involves quantifying your balance (by having people stand on a sensitive force plate that can quantify the “sway”) and measuring your heart rate and blood pressure responses to some simple tasks (e.g., rotating the head certain directions and standing up quickly). It should be noted that the study investigators do not have funds to offset the costs of travel associated with the research study (this would have to be covered by yourself). Participants will receive a small stipend funded by the MdDS Balance Disorder Foundation. If you have questions or would like further information please contact:

Brian Clark, Ph.D.

<mailto:clarkb2@ohio.edu>



Race To Rare Disease Day - Stop the Rock!

Each year the last day of February is designated as *Rare Disease Day* all over the world. It is a joint effort between NORD, the National Organization for Rare Diseases, and Eurordis, Rare Diseases Europe. The MdDS Balance Disorder Foundation joins with others living with rare, under diagnosed, and undiagnosed diseases and syndromes to participate in educational activities. Members participate in activities such as writing to their governors' to obtain Rare Disease Day proclamations, sending out brochures, and raising funds for research. Also, the MdDS Foundation would like to update its "*Faces of MdDS*" section of the website. Please send you picture and story to newsletter@mddsfoundation.org.

Check the [Rare Disease Website](#) to tell your story or help with the efforts.

Click [here](#) to make a donation. Or visit the [Foundation website](#) for other options.

Support groups and Foundation pages can be found at Yahoo groups and on Facebook.

To join the support group at Yahoo, sent an e-mail to:
mdds_support-subscribe@yahoogroups.com

Look for us on Facebook by clicking [here](#).

International News -

Jane Houghton was invited down to Southampton University to speak at a Hearing and Balance Seminars on March 15th. A senior teaching fellow and Jane will address Masters students and staff about the symptoms and ramifications of living with MdDS.

If you would be willing to share your story with a media source in the UK, please contact Jane at jane@mdds.org.uk . She has media contacts ready and waiting for the opportunity to interview you!!!

If you live in the United Kingdom and would like to receive brochures to share with medical professionals, please request them directly from Jane by contacting her at jane@mdds.org.uk. Leave her a message that includes your contact information and the number of brochures that you will need.

Rocking and Swaying After Childbirth

Pamela Kelley's MdDS History

My first and only child was born in June, 2006. Four to five months later, out of nowhere, I started having a strange body sensation comparable to being on a boat. I went to my GP, who put me on meclizine, but it did nothing. He then ordered a brain MRI, which ended up in a referral to a neurologist. The neurologist performed some tests on me. Unsure of an answer, he referred me to an ENT physician. After the ENT Dr. looked me over, and I described my symptom, he said he believed I had “the French term for disembarkment”. He suggested I look it up online and that was my introduction to Mal De Debarquement Syndrome. He also wanted to run further tests, but for a few reasons, I didn't follow up at that time. Frankly, I was just happy to know I didn't have a brain tumor.

Over the next 3 years, I experienced mild rocking and didn't feel it was affecting my life. Then in late 2009, I started noticing that my concentration was lacking and I had more fatigue. I went online to the MdDS Foundation site and saw that my new symptoms were in fact part of having MdDS. At the beginning of 2010, I saw a different ENT doctor who specializes in dizziness. After all the tests were run, I was officially diagnosed with MdDS.

Early 2010 brought on new symptoms such as the ground moving sensation, stronger fatigue, leg weakness, visual sensitivity, and increased cognitive impairment. If it wasn't for the support of the MdDS

support group and a fellow MdDS sufferer, my dear friend Maria L., I would have been lost in anxiety wondering what was going on with my body. Since then, the levels of my symptoms have been up and down. From one day to the next, I don't know what to expect.

The absolute hardest part of having this disorder is not being the Mom I want to be for my now 4 year old son. He's not old enough to understand why Mommy gets tired and doesn't have the energy to play with him as he desires, or why Mommy can't run a lot with him out of fear that she will get off balance and fall. Like most of us with this disorder, I didn't think this would happen to me. Health issues like this aren't supposed to happen until much later in life.

With all that said, I do my best to focus on the positive and contribute to a solution. There are many others out there in the world with worse problems, and while MdDS can alter your world as you used to know it, it's not terminal. I have a new perspective on life which sometimes only comes from going through an experience such as this. Compassion and Understanding have become even larger words in my vocabulary than they were before.

In August of 2010, I participated in the MdDS research study with Dr. Cha at UCLA. Within the limits of being a stay at home busy Mom, I do what I can to contribute to the cause through donations, talking to others with MdDS, spreading awareness, or backing programs that help our cause. This disorder being so rare, it's vital that everyone gets involved. We are all ready to step off the boat and feel solid ground.

Surprise Remission After 10 Years-

I am a 58 year old woman who is experiencing a remission from my second episode of MdDS. This episode lasted 10 long years; I never thought I would feel stillness again. My first experience occurred after a family cruise 12 years ago which gradually faded away after 18 months. Unfortunately, we cruised again and I came home with the rocking and swaying once again. After a time of inactivity, I found that I felt better and had better balance if I participated in kickboxing activities and took low doses of daily anti-anxiety medication. I felt better but the motion never went away. After ten years of feeling that I would never recover I was put on a low dose of an anti-depressant and I underwent hip replacement surgery for which I had spinal anesthesia. After the surgery, I was placed on Warfarin, iron and Celebrex. As I recovered at home from the surgery, I realized that I was no longer rocking and at this time it has not returned.

Honor Donations: Thank you to all of our donors!

Janet McIntyre - In honor of Marilyn J.
Paula Epstein - Seeking a cure for my mom, Marilyn J.
Robert N. Sidewater - Seeking a cure for my sis, Marilyn J.
Cris & Michael Epstein - Seeking a cure for Mom, Marilyn J.
Carol Thomas - Happy Birthday, Virginia
Joe & Barbara Parrish - For our best friend Maria Lavelly
Terry & Ken D'Amico - In memory of my grandmother, Anne Ackelitis
Susan C. - Happy Birthday, Jane.
Linda McManus - Happy 21st Birthday, Jamie.
Barbara Hawbaker - In honor of my sister, Marla C.
Maria Lavelly - Happy Birthday, Marla!
Marilyn Josselyn - Happy 60th Birthday, Marla!
Cathy Helowicz - Happy Belated Birthday, Terri!
Cathy Helowicz - Happy 60th Birthday, Marla!
Jane Houghton - Happy 60th Birthday, Marla.
Maria Agnoli Reardon - Happy Birthday, Marla!
Carmen Hawes - Happy 60th Birthday, Marla. Thanks for all you do.
Irene - Happy, Happy Birthday Marla!!!
Elaine Sola - Happy 60th Birthday, Marla!
Kimberly Bohlman - Happy Birthday, Marla!
Linda McManus - Happy Birthday, Marla. May the next 60 be great!!!
Deb Russo - Happy 60th Birthday, Marla.
Cheryl Kinner - Terri's Birthday Challenge
Carolyn Rohrer - Happy Birthday, Terri.
Glynis Brown Fletcher - Hope you have a wonderful birthday! And, may they find a cure for your rare disease this year!
Patty Boyd - Happy Birthday, Terri! Hope our wishes come true this year!
Deb Russo - Happy Birthday, Terri. Hope this is a wonderful year for you.
Marilyn Josselyn - Happy Birthday, Terri! May all your days be calm and your wishes come true.
Maria Lavelly - Wishing you the best year ever, Terri.
Pamela Kelley - Happy Birthday, Terri.
Renei Ybarra Sewell - Happy Birthday, Terri.
Elaine Sola - Terri's Birthday Challenge
Devon - for Pamela Kelley
Carole & Alan McNeil - For all of your relentless work over the last 9 years, Jane.
J. Meadows - For all of the Aussie rockers out there
Doris M. - For Marilyn Josselyn
Susan C. - Happy birthday, Jane H.
Gail Modugno - Thinking of you, Deb!
R. Abrams - For our daughter, Laura.
Nelle & Harvey Jenkins - In honor of Terri G.
Ben Houghton - Happy Birthday, Mum (Jane H.)
Hayley Wilkinson - For Jane
C. Addison - For Holly, my mentor
Uri Yaval - For Virginia

Donating to the MdDS Balance Disorder Foundation

Please [click](#) here to see all those who have made a recent donation and to see what your donations are used for. All donations are applied to the goals of educating the public and professionals to the symptoms and ramifications of living with MdDS, and to support research into the etiology and treatment of the syndrome.

Research is costly especially when a syndrome is considered to be rare, less than 1 in 200,000 people are affected. As we gather more information, MdDS seems to be less and less rare but often misdiagnosed.

You can donate by sending a check to:

The MdDS Balance Disorder Foundation
c/o Marilyn Josselyn
22406 Shannondell Road
Audubon, PA 19403

or you can visit: www.mddsfoundation.org to find all of the options. Annual overhead costs are less than 4%.

Update from the Board of Directors:

The Board of Directors of the MdDS Balance Disorder Foundation is continuously working to promote research on MdDS. You already know that we turn to our Support group, family, and friends to help raise funds to make research possible. Please also know that you are appreciated by the researchers we support. This brief report is designed to summarize what we have accomplished in supporting them.

*Yoon-Hee Cha, MD, UCLA Medical Center. In 2011, the MdDS Foundation will provide a **third** year of support (Fifty thousand dollars) for Dr. Cha's MdDS research studies.* She continues her research efforts to determine if there are unique features in the brains of those with MdDS (in comparison to age-matched normal subjects). Dr. Cha uses state-of-the art, expensive equipment to "image" brains, *i.e.*, fMRI and PET scanners. The cost for these scans is high, *i.e.*, \$300 (fMRI) and \$2,000 (PET). Once scanned, the analysis of data is incredibly sophisticated, time consuming, and costly. But, in the end, specific regions of the MdDS brain will be defined. This will then allow predictions about the altered brain mechanisms associated with MdDS. But, more importantly, Dr. Cha hopes to identify

brain targets for patient treatment with TMS (transcranial magnetic stimulation).

At this point, Dr. Cha has imaged ~15 MdDS patients and ~15 controls. She is currently in the process of data analysis. And, she hopes to begin TMS studies soon. Separately, she hopes to study more subjects with spontaneous-onset MdDS in order to learn if the affected regions of the brain are similar to those who develop MdDS following a motion experience, *e.g.*, cruise or plane, train, or car ride. As soon as the results from any of these research studies are available, we will share them with this group.

Brian C. Clark, PhD, Ohio University, College of Osteopathic Medicine, and Director of the Ohio Musculoskeletal and Neurological Institute (OMNI). In 2011, the MdDS Foundation will provide twenty thousand dollars in support for Dr. Clark's MdDS research studies. During this year, Dr. Clark will determine if there are unique characteristics of brain function (intracortical properties towards hyperexcitability) in subjects with MdDS. He has recently published a paper with the results of a single subject with post-cruise MdDS where differences were observed (as compared to healthy subjects). If he confirms this observation in others suffering with MdDS, it is conceivable that new, diagnostic testing, treatments, and preventions could be developed.

Brochures: During 2010 and early 2011, close to 1600 informational brochures were sent to medical professionals and MdDS patients in 24 states and internationally, to Canada, South Wales, Australia, Mexico, South Africa, and to the United Kingdom. Also, in the UK, brochures are included in the informational packets at Balance Presentations at the University of Southampton.

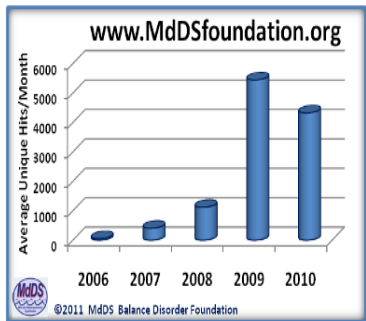
If you will be co-ordinating, presenting at, or attending an upcoming conference, please consider including brochures.

You can request brochures to share with your patients or doctors at newsletter@mddsfoundation.org.

Frequently Asked Questions (FAQ)

Click [here](#) to view the new "Frequently Asked Questions" section at the MdDS Foundation web site.

MdDS Website Continues to Inform



The public website maintained by the MdDS Foundation (www.mddsfoundation.org) remains a vital source of MdDS information. Website use has been steady throughout the past year with over 4000 unique hits each month. The site provides the most current information about MdDS including FAQ, patient surveys/survey results, fund-raising campaigns, as well as on-going research studies. Check it out and revisit regularly to remain *in the know* about MdDS.

Motion Sickness History NOT Prevalent Prior to MdDS

Motion sickness is associated with nausea and vomiting and involves a combination of inputs from vestibular visual, and proprioceptive systems. Some speculate that alterations in these same systems may be involved in the development of MdDS. *Not surprisingly, an often-asked question is whether or not a relationship exists between MdDS and the tendency to develop motion sickness.* Previously, we published the findings from self-reported surveys of women diagnosed with MdDS following a cruise (summarized in the adjacent text box). Further analysis of those survey results revealed that the majority (66%) of these women did not have a history of motion sickness. Thus, only 34% described a tendency to develop motion sickness (in cars or boats); this was consistent with the reported use of medication to reduce motion sickness during the cruise (38% of the entire group of women).

Survey Profile of MdDS Post-Cruise (152 women diagnosed with MdDS)

48.2 yrs = average age at MdDS onset
6.8 days = average cruise duration
2.7 days = average time after cruise for onset of MdDS symptoms

(from [MdDS Newsletter, December 2010](#))

Although these findings suggest that the development of MdDS is not related to a history of motion sickness, additional research is required. For instance, what is the relationship between motion sickness and those with MdDS who have not taken a cruise? Does a history of motion sickness relate to the severity or duration of MdDS symptoms? Does motion sickness play a role in those individuals who develop nausea as a MdDS symptom? Is there any relationship between the severity of cruise conditions, motion sickness, and the development of MdDS? Future studies to address these questions may provide new insights about MdDS, insights that could facilitate welcomed improvements in MdDS diagnosis, treatment, and prevention.

Direct comments and questions to: newsletter@mddsfoundation.org

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