



**Information for Those Living with MdDS
and the
Medical Professionals Who Treat Them
Volume 41 - August 2010**

Mal de Debarquement Syndrome - A Neurological Disorder

[Research](#) | [Medical Conferences](#) | [Survey Results](#) | [June Awareness Month](#) | [Honor Donations](#) |
[Face of MdDS](#) | [Donations](#)

UCLA Motion Perception Study Continues

An UCLA research study on properties of motion perception is underway but *currently placing subjects on a waiting list*. This study is focused on subjects over the age of 21 who suffer from a motion perception problem such as mal de débarquement or spontaneous onset of self-motion perceptions like episodic vertigo, severe motion sickness, or sensitivity to visual motion. The study is also recruiting control subjects ages 21 years and older who do not suffer from any kind of motion sickness or motion perception problem. **Please see the [MdDS Balance Disorder Foundation web site for contact information and to be put on the waiting list](#).**

- Medical Conferences -

June 2010 - University of Southampton, UK

Advanced Balance Course, University of Southampton, United Kingdom

**Dr. Ronald Tusa, Director of Dizziness and Balance Ctr, Emory University, Atlanta, Georgia, USA and
Mrs. Jane Houghton, Board Member, MdDS Balance Disorder Foundation**

At the Advanced Balance Course there were two workshops about Mal de Debarquement Syndrome back to back. The first one lasted a good hour and then the second one was about fifty minutes (attendees had to be at their next and final lecture by 4pm) Out of the five workshops, the one about MdDS was the second most popular. Out of a total of 58 medical professionals in attendance, thirty of them split into the two MdDS workshops. Even those who did not attend had a section in their folders on MdDS and also received a brochure. The participants included ENT's, physiotherapists, and audiologists who came from America, Australia, Israel, Saudi Arabia, Greece, Switzerland and all parts of the UK including the Irish Republic.

Dr Tusa began explaining how MdDS occurs, the need to see these patients quickly, and to get them moving and active (still no treadmill or stationary bikes) but *moving forward* as he put it. Also in his opinion the use of Klonopin/Clonazepam in the early stages can be beneficial. He used [MdDS Foundation surveys](#) in his presentation and spoke about how pro-active the Foundation is. Also, he said that the support group was not all doom and gloom but again very positive and pro-active, as well as supportive.

Then Dr. Tusa invited Jane Houghton to speak about her experience with MdDS. Jane explained how she experienced MdDS after a weekend sailing trip and how it has lingered for nine years. At the start of each workshop Dr Tusa asked those there how many had heard of MdDS before, not necessarily come across it in a patient (which some had) but actually just heard of it. In the first workshop sadly there were only a couple who had heard of MdDS but in the second group only one had not heard of it! There was then a question and answer section which went well. The participants were keen to ask questions, which both Dr Tusa and Jane answered. "We are making slow progress," said Dr. Tusa.

July 2010

MdDS Foundation at the 61st Annual Meeting of the Texas Academy of Family Physicians

The MdDS Balance Disorder Foundation was an Exhibitor at the recent annual conference of the *Texas Academy of Family Physicians* ([TAFP](#)). This conference, held at the San Antonio Convention Center, was attended by ~400 physicians as well as numerous nurse practitioners and physician assistants who were seeking credit for required continuing medical education (CME).



The Foundation was represented by Terri and Mike Gibson and Linda McManus who occupied the booth on Friday and Saturday. The booth was in an ideal location at the end of the primary entry aisle into the exhibit area and just across from the area for the display of research posters. Almost all attendees visited the exhibit area and strolled around the booths during breaks (for breakfast on Friday and coffee/cookies at regularly-schedule breaks throughout the meeting days). **MANY stopped at our booth to learn about MdDS.**

Most conferees:

- had never heard of MdDS
- listened attentively to our descriptions of the disorder
- asked appropriate questions (including, "what's the treatment?")
- picked up brochures and our letter, [Understanding MdDS](#)



As they completed their booth visit, many thanked us and remarked that they had "actually learned something new this year"; most seemed genuinely appreciative that we were there.

Included in the conferees and our booth visitors were physicians (primarily Family Practice but also an emergency room doctor, psychiatrist, and a cardiologist or two) as well as nurse practitioners and physician assistants. We also found that many had sought our booth because we placed a quarter-page, black-n-white ad in the Official Program; this \$125 investment was a good one (especially since the ad as well as our brochure and letters went home with many conference goers). From this experience, we'd recommend that we seek to determine if advertising space is available in the Official Program of professional conferences that we canNOT attend in the future.

Another interesting conference event: we shared breakfast with a promising pre-med student Friday morning (at 6:30AM). This young woman hopes to someday become a Family Practice physician. She was very polite and curious as she learned about MdDS. We were delighted to witness and share her realization that she received the 1st place award and recognition in the student competition for her research poster.

Several other unanticipated items of interest from the meeting: First, there was a representative from

a VA hospital who asked if we would be willing to present information about MdDS at one of the meetings of the local Medical Society...we didn't hesitate to say yes!. Second, the military had booths (to recruit into the Army or Air Force); in casual discussions with the Air Force recruiter, he indicated a close contact in the Houston area that just happens to affiliate with NASA (as a flight surgeon) to provide care for astronauts on their return from outer space!!! We are hopeful that we will get to meet this health care provider in the future. And, finally, we spoke with representatives of several pharmaceutical firms and were encouraged to seek out neuroscience investigators and contacts at their firms.

All-in-all, Terri, Mike, and Linda deemed this conference a tremendous success...shortly after the first break on Friday!!! We believe that this is a good target of our awareness efforts. We wish everyone could have been there!

[Back to the top](#)

New MdDS Survey Results Indicate Increased MdDS Duration with Sequential MdDS Episodes

Using online [surveys](#) to collect data, the MdDS Balance Disorder Foundation continues to seek self-reported information from those who suffer from MdDS. Two separate surveys conducted between July 2008 through March 2010 have provided interesting, new insights. One survey with over 700 responses included 262 individuals who were diagnosed with MdDS, 93% were female; the majority of these women (80%) were diagnosed by otolaryngologists or neurologists.

[*Click here to access the complete article and graphs](#)

June Awareness Month Activities -

Sponsored Run for Godmother Jane



Jane Houghton's eleven year old godson, Sam Fielding, completed a sponsored run for the MdDS Foundation and posted a donation to www.firstgiving.com/mddsfoundation. Thank you, Sam. Your time and donation are appreciated by all who live with MdDS not just your Godmother Jane.

Catch the Chocolate Wave

On Friday, June 18th, the Mdds Foundation held a fundraising and awareness event, Catch the Chocolate Wave, at The Chocolate Lounge in Old Town Spring, Texas. Approximately 30 people were in attendance and the evening was successful and fun for all involved. A dessert buffet of cupcakes, cream puffs, lemon bites and a chocolate fountain with fruit, pretzels, oreos, marshmallows, and other tasty items to cover in chocolate were enjoyed by all. Coffee donated by Starbucks and wine donated by Crescent Moon Wine Bar were also served. The evening included live music by [Gary Floyd](#) and a silent auction with some great donated items that helped raise funds for the foundation. Terri Gibson addressed the crowd briefly and told of her experience as a Mdds sufferer for over four years post-cruise. YouTube videos about Mdds were also available for viewing during the event.



This event would not have been possible without the support of the following volunteers: Mike and Terri Gibson, Rick, Tracine, Keely and Summer Gibson, Matt and Avery Smith, Breanna Larsen, and Victoria Patton. A very special thanks to our sponsors for the venue, food, and beverages: The Chocolate Lounge, Crescent Moon Wine Bar, Starbuck's, Grafix Emporium, Postal Annex, Costco, Sam's Club, Walgreen's and Walmart. Our successful silent auction was made possible by the following donors: Curtis & Molly Bedrich, Marla Cruise, Barbara Edmondson, Gary Floyd, Mike & Terri Gibson, Rick & Tracine Gibson, Deb Russo, Kathy Wortham LMT, Angela Grimland – Southern Living at Home, Karen Hobgood – Creative Memories, Carolyn Rohrer – Creative Memories, Patti Marek – BeautiControl, Brix Wine Cellars, CR Collectibles, Dave's Pepper Palace, La-ti-da Boutique, and Zen Salon & Day Spa.

The event alone netted almost \$1,200 with an additional \$1,280 in donations to the foundation so almost \$2,500 was raised in one fun-filled evening. Overall, everyone enjoyed a great time of food, fun, friends, music, and shopping the silent auction. Hopefully, we can make this an annual event.

Some Statistics for June Mdds Awareness Month Activities:

~Hayley Wilkinsons's, "Rock the Boat" YouTube video had 3,200 views. As a result of this video, Jane Houghton's story traveled throughout the United Kingdom and thanks, to the Internet, around the world. Her story appeared in the [Daily Mail](#), The Express, The Telegraph, The Sun, and The Metro newspapers. and on the front page of Yahoo News. Also, she did a live radio show for [BBC](#) Oxford then that evening the BBC drove her to their BBC Studios in Manchester to be on their late night Radio Five show. Also, her local TV news station, Northwest Tonight, did an interview for the evening news. Finally, she was on the Radio Four show "Saturday Live" at 9am.

Each time Jane appeared or spoke about Mdds the Foundation received numerous inquiries from people who are living with the syndrome but were unable to get a diagnosis.

~Terri Gibson's YouTube video explaining life with Mdds had almost 1,000 views.

~The [Mdds Balance Disorder Foundation](#) website has registered over 163,000 hits. The [Faces of](#)

[MdDS](#) page was updated to show the how people of all ages and both genders are affected by the syndrome.

~During the month of June, thirty new Facebook members joined the [Official MdDS Foundation](#) page. We have people from Italy, Japan, Mexico, Australia, the UK and the USA seeking information about MdDS.

~The [Doctor's Channel](#) posted the "Rock the Boat" video and it received over 1,800 views (mostly doctors). They even did a special emailing for us to doctors associated with the channel.

~ The *ABC Medical Mysteries* video, "Disembarkquement Syndrome, posted 300 new counted views during June.

~ Hundreds of brochures and informational letters were sent out or delivered to doctors.

[Back to the top](#)

~Honor and Memorial Donations~

**In memory of James Herbert Brown,
father of Terri Brown Gibson (Board Member)**

Jane Houghton

Linda McManus

Michael and Deb Russo

Roger and Marilyn Josselyn

Cathy Helowicz

Harvey & Nelle Jenkins

Dr. Robert Slater

In memory of Mike Blazejowski - Michael and Deb Russo

In honor of Jane Houghton- Sam Fielding

In honor of Theresa Weiland - Helen & Roger Weiland

In honor of Terri Gibson - Mark & Cynthia Denney

In honor of Marilyn Josselyn's Birthday

Susan Barnes

Carolyn Housewert

Cathy Helowicz

Irene & Tim Hartman

Linda McManus

Mike & Deb Russo

Judy Messenheimer

Mike & Terri Gibson

*****Once again the foundation will be participating in the [Macy's Shop for a Cause Day](#). Look for more information to come or contact Terri at mdsdfoundation@yahoo.com. For a \$5 donation you will receive a Macy's shopping pass that will entitle you to a discount on Saturday, October 16, 2010.*****

The Face of MdDS- Mikael - Twenty-two years old and feeling robbed of his youth...



As I step on the escalator, a wave of relief hits me; I am normal again, if only for a couple of seconds. My name is Michael, I am 22 years old and I live in Sweden. I have suffered from Mal de Debarquement syndrome for two years now. It started the third of July 2008 after a month of backpacking across Europe via planes, trains and boats... I had experienced some strange episodes of dizziness during the trip – such as waking up in the middle of the night feeling like I was falling through the ground – but I didn't think too much of it as each dizzy spell faded quickly. Then I woke up rocking one or two days after coming home and it basically hasn't stopped since.

Symptoms:

I don't want to go into too much depth describing the symptoms as there really is no way of doing justice to the horror of never feeling like you're being still – ever. My brother at one point said: “but what's so bad about feeling like you're on a boat (the typical description of MdDS)? I like being on boats!”. Well he wouldn't like being on this one... Your brain is in constant turmoil because it knows something's wrong, and hence constantly sends out signals of immense distress, but the only question it seems to come up with is “is the world moving, or am I moving?”. It's as if the answer “I am still and the world is still” no longer exists. The only time I get relief is when I am in passive motion such as in a car or bus – or an escalator for that matter; sadly I often pay with higher symptoms afterwards. The worst time of the day for me is when I lie in bed at night hoping I can fall asleep as I'm constantly feeling like I'm being tossed around.

Diagnosis:

Unfortunately very few are aware of this condition here in Sweden, and even fewer accept that the symptoms don't always come on immediately upon cessation of motion-stimuli (such as when you step of the boat onto solid ground). Hence it's been a struggle every step of the way for me, and I still haven't received a formal diagnosis. After going from doctor to doctor, one being more clueless than the other (especially the part of me feeling completely normal while in passive motion seemed to confuse them), I started searching through the internet. It didn't take me long to find the MdDs foundation's webpage, and the symptoms matched a hundred percent. I finally knew what I had; reading that there was no cure and that treatment-options were very scarce, I stopped bothering about doctors.

How has this affected my life?

It has and continues to take away my youth. After months of bad symptoms it calmed down for me and continued to calm down the following year. I was at a place where symptoms were really low and though bothersome at times, they were not debilitating; suffice to say I was incredibly thankful as I could resume my life... Then I went to Turkey on vacation, and now symptoms are worse than ever before. This is extremely tough because when symptoms go up your life's basically taken away from you. You are constantly fatigued from having to balance, you feel horrible all of the time because of the symptoms and you can't think straight due to the cognitive effects.

However the worst part of this horrible illness must be the constant disbelief and the way you're treated as a consequence. Doctors do their tests and when they can't find something they conclude you must be mad and that you're making it all up, and when you go from doctor to doctor without finding any answers your family starts to think you might be too...

I've never felt more alone in my life. The emotional wounds have healed now but the scars are still there, and they will be till the day I die.

Michael Heller – July 8th 2010

Donations: To make a donation to the non-profit MdDS Balance Disorder Foundation:

1. Go to www.mddsfoundation.org to see all of the options.
2. www.firstgiving.com/mddsfoundation
3. Use PayPal
4. Send a check to:

MdDS Balance Disorder Foundation
Marilyn Josselyn, President
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Audubon, PA 19403

[Back to the top](#)

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Dedicated to finding a cause and a cure for MdDS