



### Ronald Tusa, MD and Jane Houghton at Southampton University

On June 27, 2008, Dr. Ronald Tusa spoke about *his experience* in diagnosing and treating Mal de Debarquement Syndrome at the "Advanced Balance Course, 2008". This course was held at the University of Southampton in England. More than sixty medical professionals from as far away as New Zealand attended the three day conference.

Dr. Tusa made it clear that the etiology of MdDS is unclear but that it usually appears after some type of passive motion, most likely a cruise or air travel but can occur in an idiopathic manner. During his presentation, Dr. Tusa discussed a 36-year-old female who experienced rocking and swaying after rail travel and a cruise. He stated that the MdDS devastated her life because she felt the symptoms relentlessly especially when sitting or standing still and when lying down. Because of these symptoms, she was forced to give up her profession as an attorney.

Using slides based on a survey which was conducted by the Mal de Debarquement Balance Disorder Foundation, he indicated that boat travel accounts for the highest number of MdDS occurrences. This survey included responses from 337 people with 277 being positively identified as having Mal de Debarquement Syndrome. The survey and Dr. Tusa's professional experience demonstrated a greater frequency of the syndrome in females, but he noted that this could be because women seek medical treatment more readily.

When Dr. Tusa is faced with a patient who presents with rocking and swaying after a passive motion experience, he treats it as an emergency by seeing the patient within one week. According to his presentation, he told the participants that he attempts to have his patients feel that they are actively involved in their treatment by having them take medication that masks some of the symptoms, take part in gentle exercise, read the MdDS Balance Foundation's newsletter, and participate in the available surveys.

After Dr. Tusa completed his presentation, he asked Jane Houghton, who has had MdDS for a number of years, to join him in speaking to the course participants. She spoke of her experiences and lack of treatment. In addition, she answered queries from the doctors in attendance. Jane and her husband Neil have devoted a great deal of time to supporting others with MdDS, seeking better care, and looking for a cause and cure for this syndrome that struck Jane after a sailing trip to Spain.

You can watch parts of this presentation at the following links.

<http://www.youtube.com/watch?v=l2BXoT9b4Iq>

<http://www.youtube.com/watch?v=Vs1wwDztTOc>

### A One Day Cruise Changed My Life



A little over one year ago, I was a very active and healthy twenty-five year old on a great vacation in the Bahamas. Then, I went on a one-day cruise. When I awoke on June 7, 2007, life the way I knew it changed. For some reason, my world was rocking, swaying, and bouncing. Of all the success stories that I have heard, everyone seems to get over this in the first year; otherwise, they are probably stuck with MdDS forever.

I am feeling pretty defeated and helpless since I feel so bad at my 1-year mark. Over the last year, I have had episodes where I have had relatively tolerable symptoms (Level 1-2, [see symptom scale](#)) and then for any unknown reason, it will hit me, and my symptoms will elevate to a 9 or 10. For the last couple of months, my symptoms have been at a 3-4 level, but then more recently, I am back to having increased rocking, swaying, and this constant heavy feeling in my legs. When I get up to walk, it feels like I have chains tied to my ankles making it incredibly hard to pick up my feet and walk and balance. It is to the point I almost want to crawl instead of trying to walk. These awful symptoms make it so incredibly difficult to function around the house let alone trying to tackle going to the grocery store or out for dinner.

The doctors tell me that I have to stay active and continue doing my balance exercises. I have continued to stay as active as I can and still I am not showing much improvement. I have tried different medications, chiropractic, acupuncture, physical therapy, etc. These methods have helped with my anxiety and tension in my neck and shoulders but nothing seems to help the rocking, swaying, dizziness, heaviness, bouncing, and floaty feeling that I live with everyday. I just do not know how people live with this awful condition for so very long. I do not have one positive thing to say about my situation at the moment. I feel like I am a different person now and the life that I once knew, is now just a memory. All the dreams and goals that I once had for my life seem so unattainable at this point. All I can hope for is research that will find a cure for this unbelievable syndrome.

AW

Female, 26 years old  
One year with MdDS

**\$2,000 by Labor Day!!!  
(September 1, 2008)**

We appreciate all contributions in the past but we need your continued help to achieve our goals.

- Donations are fully tax-deductible.
- All contributions are used by the Foundation to promote biomedical research and improved awareness about MdDS.



Please do your part, however big or small, and help to make this Summer plan a realized goal. Thank you for your help. Together, we are making a difference!

For **online** donations *via PayPal*, visit <http://www.mddsfoundation.org/>  
There, you will find easy-to-use PayPal buttons for one time and/or monthly donations.



**Important for all in the  
United Kingdom:**

**UK Petition to Increase Research into Balance Disorders**

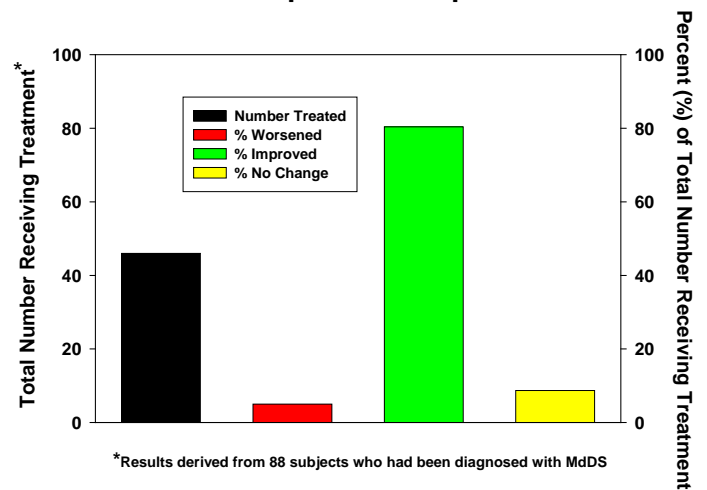
<http://petitions.pm.gov.uk/balancedisorders/>



**The Dilemma in MdDS Treatment**

When faced with the discomfort and life-changing symptoms that are the hallmark of MdDS, most turn to their physicians for relief. Very often, the prescribed drug is klonopin or clonazepam. Results from a recent survey by the MdDS Foundation documented that approximately half of patients diagnosed with MdDS were treated with this drug and that the majority were improved by this treatment.

**Klonopin/Clonazepam**



Despite the above, many worry that the use of this addictive drug will be associated with difficulties of withdrawal. In addition, many find that the drug loses its initial efficacy or stops reducing MdDS symptoms altogether even at higher doses. More studies are clearly required to carefully document the benefits/risks of this form of pharmacotherapy for MdDS.

\*\*\*\*\*

For further information about the Foundation or to learn more about MdDS, please visit our website at [www.MdDSfoundation.org](http://www.MdDSfoundation.org)

Send comments, questions, or suggestions to the [Newsletter Editor](#).