



MdDS Support News

A newsletter for members of the Mal de Debarquement Syndrome (MdDS) Support Group and the Professionals Who Treat Them

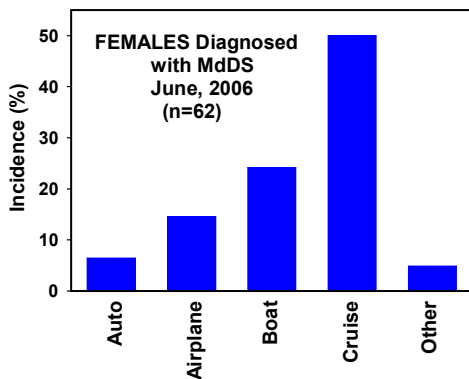
July/August 2006

Major Motion Events Associated with the Onset of MdDS

MdDS or Mal de Debarquement Syndrome is now recognized as a rare disorder with mild to profoundly disabling sensations of motion (e.g., rocking, bobbing, or swaying). Concurrent symptoms often include imbalance and cognitive impairment.

Little is known regarding the cause(s) of MdDS. As a result, treatments are lacking. Commonly, the onset of MdDS follows a motion experience such as after a cruise.

The MdDS Foundation continues to collect information to assist health care providers and researchers in efforts to better understand MdDS. Our worldwide database of 94 individuals in the [MdDS Support Group](#) includes people from Australia, Canada, Lebanon, New Zealand, Switzerland, the UK, and USA; Data from 62 women who were diagnosed with MdDS provide new insights regarding the event(s) preceding the development of this disorder. 50% developed MdDS after a cruise, ~24% after boat travel, ~15% after air travel, and ~6% after auto travel (below).



A major MdDS Foundation goal is to educate and help identify cause(s), treatments, and cures for MdDS. Our database will continue to be an important aid in this effort.

Jane Houghton Contributes to a Presentation by Advisory Council Member Dr. Robert Tusa of Emory University

Imagine traveling four and a half hours from your home to a Medical Conference in Southampton, England where you are to present along with Dr. Robert Tusa of Emory University, Atlanta, GA, USA. There will be 65 doctors from all over Europe in attendance. For the past five years, post cruise, you have been rocking, bobbing, and swaying with no true medical answers. You are hoping to be able to tell a sufferer's perspective of Mal de Debarquement to a professional audience. For Jane Houghton this became a reality on June 27, 2006.

Dr. Tusa began the first of his two lectures on MdDS to the 37 delegates who chose this topic by making it known that although he sat on our MdDS Balance Foundation Advisory Council he was not on our payroll. Dr. Tusa asked those in attendance how many of them had heard of or seen a patient with the symptoms of MdDS and received a 45% positive response. He gave his perspective of MdDS as a true medical entity and described his criteria for diagnosis. After which, he talked about his current methods of treatment to the medical delegates in attendance. During his lecture, he used slides prepared by Dr. Linda McManus under the auspices of the MdDS Balance Foundation.

Then, he invited Jane Houghton to tell her story from the time she realized that something was amiss when she went ashore during her cruise to her lengthy search for a diagnosis, and the effects MdDS has on her life each day. After this, the delegates were free to ask questions of Mrs. Houghton which she

answered purely from a sufferer's point of view. The group of professionals who asked her many questions and showed empathy for her situation received her well. Therefore, there are now 37 more professionals throughout Europe who have a better understanding of life with MdDS and the reality of the disorder. In addition, all 65 delegates received brochures in their welcome packets and the Houghton's left 50 more upon their departure. Jane feels that Dr. Tusa is a true advocate for those of us who live with MdDS. He stressed that he includes it in his lectures to further knowledge of its existence and the serious life challenges that it causes.



Since our last newsletter, we have welcomed a 63-year-old gentleman from Switzerland, a 23-year-old young man and a 49-year-old man from the US, along with approximately 10 others.



Publicity efforts in the UK have been aggressive. Heather told her MdDS story in a colorful spread in "Pick Me Up" magazine. Rachel published a letter at [Dive.com](#), an online magazine for scuba divers. As a result, Jane was approached by a free-lance writer to do another magazine article on MdDS.

Your Contributions Count!

Donations to the MdDS Foundation in support of educational and advocacy programs should be made to **MdDS Balance Disorder Foundation** and sent to the address below (for logging/acknowledgement) or to the National Heritage Foundation 6201 Leesburg Pike, Suite 405 Falls Church, VA 22044

If you are interested in volunteering to assist with our programs, please email: Roger at rjosselyn2@comcast.net or Marla at mcrnor@netzero.net