

# MdDS Support News

Newsletter for Members of the Mal de Debarquement Syndrome (MdDS) Support Group and the Professionals Who Treat Them

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## TORONTO OBSERVATIONS

The following are Marilyn's and my observations while present during the four day (September 17-20) OTO-EXPO Convention sponsored by the AAO-HNS Academy (American Association of Otolaryngologists - Head and Neck Surgery).

**STATISTICS** - Approximately 6000 physicians, fellows, residents, nurses, and associates were in attendance for some or all of the convention. - There were about 300 exhibitors, including 12 nonprofit organizations such as ours. - The exhibit booths were open over a 4-day period covering 25 hours. - About 310 AAO members visited our booth at an average rate of one every five minutes. An equal number of brochures were distributed - 80 physicians signed our register sheet with 28 asking to receive newsletters, 44 requesting 600 brochures, 37 asking for "selected survey data," and 33 expressing "interest in future studies" or research. One physician offered to become an Advisor.

**VISITORS TO OUR BOOTH:** (if we were able to identify their location)

*COUNTRIES (19):* Australia, Belgium, Canada, Columbia, Denmark, France, Italy, Israel, Ireland, Jordan, Mexico, Nigeria, Philippines, Portugal, Scotland, So. Africa, Trinidad W.I., United Kingdom, USA, Venezuela.

*STATES (25):* AL, AZ, CA, CO, FL, GA, IL, KY, MA, MD, MN, MO, NH, NJ, NV, NY, OH, OR, PA, RI, SC, TX, UT, VA, WI.

**EXPENSES** - Estimated \$2800 for booth rental, booth equipment rental, poster printing, business card printing, convention parking, exhibitor travel/lodging/meals, etc. - The booth and equipment expenses were highly discounted through nonprofit discounts and "negotiated discounts." It was not cheap, folks, but we think we hit pay dirt! We are putting your (and our) contributions to work!

**CONVENTION DATA:** Visit <http://www.entnet.org/> for more info on the event.

Our primary interest was in the physicians' reactions to our booth messages. Our posters stressed such words as - Misdiagnosed - Vestibular vs. Brain - Forever Rocking - Rare - Persistent - Motion Experience (e.g., a cruise) - Key Differentiator is Feeling Better in a Moving Car - Diagnosis by Exclusion through Negative Test Results - Age of Onset - Gender Distribution - Associated Motion Events.

**GOALS** were stated as: - to Increase Patient & Physician Awareness - Promote Research.

It is hard to generalize after conversing with 310 people, but we will take a stab at it. There was an overall sincere interest expressed. The majority professed that they had heard of MdDS, had maybe one or two patients a year, but were frustrated with not being able to propose effective treatment or a cure. We cringed somewhat as many asked if we could recommend a method of treatment. Many perked up when they learned that we were a support group rather than a

company peddling a product. They were glad to learn of our Support site as at least some positive information they could provide to their patients (We would point out that some 19,000 messages had passed through the site). Most surprisingly, many said their patients had had it for only a few months before being cured; they were often surprised when Marilyn mentioned her eight-year duration. Those not familiar with MdDS were surprised to hear of cruises as a cause. Those more knowledgeable expressed surprise at the span of other motion experiences that could cause MdDS. The bar charts caught their attention, particularly the ratio of females and the age ranges. Many appreciated our new business card with the exact internet address for our ICD-9 code. Most agreed that MdDS is a CNS (brain) problem rather than an ear/eye problem.

A most important **follow-up** remains. We have to respond to those who asked for newsletters and brochures. We have to seek out the more promising people who came to us, especially those who showed an interest in data or studies. In addition, most importantly, we must personally follow up on the few who indicated an interest in involvement with research. There is much work to be done before these contacts cool off - we will need help from our heavyweights.

Amy's support group message #18936 lists some of the diverse opinions expressed as to cause and treatment; as she said, these often represented random opinions rather than showing a consistent pattern. - Our visitors were more interested in learning what we

could offer - and we could offer little. However, they were pleased with our promise to supply information from our upcoming Research Study - Very few offered any medications or therapies with conviction. Walking and a "stay fit" exercise regimen were generally offered as treatment. A few suggested migraine as the cause. We were surprised at the number who insisted that MdDS is quite common; yet often their comments did not seem to reflect knowledge of the disorder. A fair number expressed the opinion that MdDS cannot be cured if it has lasted over a year. It was always rewarding to hear a physician say either "I may not have recognized it in patients I've seen" or "I think a patient of mine demonstrates the symptoms you describe." In addition, a number were very frank in saying "I never heard of MdDS." One doctor spent ten or fifteen minutes lecturing that MdDS cannot occur without the parallel existence of other factors. Another insisted that Marilyn could not have MdDS if it has lasted more than a year. One doctor said he had just seen a patient who appeared to have gotten MdDS after walking across a pedestrian suspension bridge.

During several visits to the Wicab booth, it was a pleasure to meet Bob Beckman, CEO, and Kim Skinner and Sona Walter with whom we have been dealing for some time. Kim spoke warmly of her talks with Deb and regretted that she could not meet her there. Sona gave us a surprisingly in-depth proposal as a means to attract the attention of the research community. - We were unable to attend Dr. Stanley's brief talk at an early morning seminar in which he summarized his study of the BrainPort's effectiveness with our MdDS volunteers and others. He did us a favor by referring to our booth

number during his talk, and several people showed up as a result. The BrainPort had just been approved for distribution in Canada. As in Europe, the talking price is \$10,000; I believe there are alternate leasing arrangements. Wicab expects FDA approval soon, but only for vestibular disorders.

One more interesting observation. A U.S. Navy Lt. Commander and ENT came by in his uniform and could not escape my grasp. His answer to my question was "No, I've never heard of MdDS". To my dismay, instead of acknowledging that research for a cure should be pursued when such cases were identified, he replied that if people were found not to be adaptable to shipboard life, they would probably just be given a shore assignment!

**Random Observations-** Here are a few random observations, not of great significance. - As you saw above, there was a startling collection of countries, states, and provinces represented. - Tim Hain was there briefly during our booth set-up day but our paths did not cross. Our signup list was entitled "How can we help you?" - Two or three members asked for the brochure in French! Amy has offered to do the translation. We expect to receive both a full listing of attendees and a complete AAO membership list. We already have a list of the exhibitors. VEDA's Balance Awareness Week coincided with the conference dates. We had a poster for it. -Our stuffed little Teddy Roosevelt with bandana, mustache, eyeglasses and hat was a great attraction, to the point that people were asking for one. The convention was held in the smaller but still large South Building of the MTCC (Metro Toronto Convention Center). As an indication of its size, Marilyn refused to complete the 10 minutes of escalators, elevators, and walkways from there

through the entire center to the front entrance to find a luncheon place. The entire convention, with registration, administration, educational meeting rooms, exhibit areas, etc. took up three floors of the center.

As for **credits**, we are thankful for the advice and assistance of a number of our people, including Marla, Deb, Linda, and Donna - and of course, Amy and Bryce - and Andrew, Marilyn's 15-year-old grandbrainchild who composed, altered, and digitized for Kinko the posters that Marilyn and I designed with your help. Paul, our physician neighbor provided assurance that we should not be concerned about doctors who might be offended with the word "Misdiagnosed"; and he lent us his poster carry-tube for the trip. Mike Carter of AAO was a wonderful and patient helper, nursing us through the many unfamiliar issues of exhibiting at a convention. He was available both from the Virginia AAO headquarters beforehand and at the convention itself, even to emptying an overfull wastebasket, which we found required a written order. And Delia Lapanese and Jody Diedrick of the Freeman Company were great helpers with keeping the booth equipment/rental costs to a minimum, including Delia's tip that I might ask Mike Carter to absorb some of the costs (which he did). -We thank Dr. Stanley and the Wicab people for their involvement and support. So this was a group action ranging from your tips on presentation, logos and handouts - to your blessings and thanks before and after. We thank everyone for your help. Finally, I thank Amy and Marilyn for persevering with these tasks in spite of the burdens of MdDS.

Roger and Marilyn Josselyn - Booth #193