



Mal de Debarquement Support News

A Newsletter for the International Members
of the MdDS Support Group
And the Professionals Who Treat Them



Volume 21

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WASHINGTON D.C. CONVENTION OBSERVATIONS - AAO EXPO - 9/2007

The following reflects our observations while present during the September 16 four day OTO EXPO sponsored by the AAO-HNS Academy (American Association of Otolaryngologists), at the Washington DC Convention Center.

Since the statistics for the Toronto convention are similar to those for Washington, we'll skip details. The Washington, DC convention had over 7000 attendees, consisting of doctors, professors, nurses and physical therapists, plus almost 300 exhibitors. Our little booth, manned by ourselves and three other volunteers competed with 299 other exhibitors, some larger than your first floor, but we signed up 101 people while distributing over 172 survey summaries, some 250 brochures plus business cards and newsletter copies

As last year at Toronto, we spent the first day getting to DC and setting up the booth. We welcomed visitors over the next 3 1/2 days. While we struggled to hold the attention of some visitors, many others generously exchanged their experiences, ideas and questions. Over and over, we were asked what treatments we could recommend; we could only give them the survey data and urge them to make their patients aware of the support site. We were constantly on the watch for their ideas and for their interest in research. Some of these professionals showed deep interest and may prove very valuable allies in the future. Where promising, we offered to launch a survey of their own design. Many were impressed with the fact that they were talking to MdDS patients. Similar to last year, a surprising number stated that their patients had had MdDS only for weeks or months and supposedly had been cured because they did not return. We wondered how many failed to return because they were not cured and either gave up or sought another doctor.

This year, we had a new handout which proved very popular: a summary of our three recent surveys (provided in the following pages). This gave them a quick overview of the demographics, symptoms, and clinical data, and they were able to take it with them. We displayed the 3' x 5' poster from last year's Toronto Expo. It stressed such words as: - Misdiagnosed - Vestibular. Brain - Forever Rocking - Rare - Persistent - Motion Experience (e.g., a cruise). - GOALS were stated as: - to Increase Patient & Physician Awareness - Promote Research. - The two side posters stressed: - Key Differentiator is Feeling Better in a Moving Car - Diagnosis by Exclusion through Negative Test Results. - Our placards covered: - Age at Onset - Gender Distribution - Related Motion Events - Increasing patronage at our foundation website.

At times it was slow, and at times we were stressed to handle several visitors at one time; that's when we really performed as a team. - We missed seeing our five Advisors, but we saw some very surprising others. - This was an international gathering; some obviously struggled with the English. Several from Scandinavia came up with unique but simple therapy approaches. - Some promoted the migraine theory, but most supported the brain theory.

We made a significant contact with the NIDCD (NIH) booth where we applied to be included in the upcoming bi-annual issue of their "Resources Directory". We were advised that a little known segment of the huge NIH budget is set aside for disorders too small or too unusual to join the major NIH grants to large institutions. We intend to pursue this.

So, as we know, there's a lot of education that we must continue to get out there. And there's much follow-up work to be done. We will look carefully for those who seemed to show enough interest that we may be able to enlist them further. And we'll hope to have made an impression on those who just grabbed a brochure or exchanged only a few words with us as they hastened past. Who knows what was absorbed by those who just paused long enough to scan our main poster and move on !

Roger & Marilyn Josselyn

Please see the Survey Summary which was handed out at the OTO-EXPO by scrolling to the next page.



The MdDS Balance Disorder Foundation is now listed at www.goodsearch.com



Simply access the website; choose **MdDS Balance Disorder Foundation** as the organization you search or shop for, and use it each time you search or shop the Internet. The foundation receives a donation or a percentage each time you do this. Thank you.

Please send tax deductible contributions to:

MdDS Balance Disorder Foundation
Marilyn Josselyn
255 Copper Beech Drive
Blue Bell, PA 19422

MdDS is ICD-9 78.4, Indexed

If you are interested in volunteering with our programs, please email either:

Roger at: rjosselyn2@comcast.net
Marla at mcmor@msn.com

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

For more information visit the **Mal de Debarquement website** at

www.mddsfoundation.org

Survey Results – 100 Diagnosed Patients – **© MdDS Balance Disorder Foundation** **(Mal de Debarquement Syndrome)**

The following information is a summary of our latest survey findings (as of 9/2007). - For more details, contact editor@mddsfoundation.org. - If you use this information, please reference the MdDS Balance Disorder Foundation and its website at www.mddsfoundation.org.

DEMOGRAPHIC SURVEY - 111 diagnosed females- September, 2007

Age at onset

- 11% - age 20-29
- 22% - age 30-39
- 34% - age 40-49
- 23% - age 50-59
- 10% - age 60-69

Precipitating event for females

- 45% - Cruise
- 22% - Boat
- 15% - Airplane
- 12% - Other
- 6% - Auto

(Of 125 total diagnosed persons, 111 or 89% were female.)

SYMPTOM SURVEY - 110 diagnosed persons - July 2007

Motion symptoms at first diagnosis - (more than one choice per responder)

- 93% - Rocking
- 85% - Swaying
- 78% - Floor movement up/down
- 69% - Bobbing
- 46% - Bouncing
- 87% - Imbalance experienced
- 85% - Unusual fatigue
- 82% - Trouble remembering words
- 81% - Anxiety experienced
- 77% - Concentration problems
- 74% - Multitasking problems
- 73% - Confusion experienced
- 72% - Short-term memory loss
- 70% - Imbalance worse in the dark
- 69% - Word use incorrect
- 67% - Ataxia experienced
- 67% - Organization problems
- 65% - Depression experienced
- 62% - Dizziness experienced
- 56% - Typing errors: scrambled letters or out of sequence words
- 20% - Long-term memory loss

(results from this survey continued on the next page)

Symptom Survey (cont)

Headache experienced - (more than one choice per responder)

- 50% - Tension headache
- 41% - Migraine headache
- 32% - Sinus headache
- 12% - Cluster headache

Ear problems - (more than one choice per responder)

- 45% - Fullness
- 45% - Tinnitus
- 26% - Pain

Vision problems

- 35% - Objects appear to be moving
- 30% - Blurred vision
- 22% - Nystagmus (Confirmed by a doctor or by testing)
- 7% - Other
- 5% - Double vision

Heaviness experienced - (more than one choice per responder)

- 48% - Heavy head
- 39% - Leg heaviness
- 36% - Body heaviness
- 8% - Other heaviness

Gravitational forces felt - (more than one choice per responder)

- 61% - Body pulled in one direction
- 44% - Pulling felt inside skull
- 13% - Other pulling sensations

Initial symptoms - (more than one choice per responder)

- 42% - Nausea
- 28% - Body tremors
- 20% - Titubation (visible head bobble)
- 18% - Other
- 15% - True spinning vertigo
- 13% - Aphasia
- 11% - Dysphasia

Increased feeling of motion was felt when subjected to the following - (more than one choice per responder)

- 87% - Stress
- 78% - Sudden movement
- 75% - Crowds
- 71% - Loud noises
- 67% - Wild patterns
- 66% - When bending down
- 65% - When startled
- 64% - When looking up
- 61% - Computer screen
- 60% - Fluorescent lights
- 58% - Bright lights
- 57% - Strobe lights
- 48% - Small spaces
- 45% - Stores with high ceilings
- 33% - Other

CLINICAL SURVEY - 101 total - May 2007

Those who have primary MdDS symptoms

- 97% - Feel like I'm rocking, swaying or bobbing
- 95% - Feeling decreases when in motion such as a car or boat
- 95% - Symptoms have been persistent for at least 30 days

Age at onset

- 14% - age 20-29
- 17% - age 30-39
- 34% - age 40-49
- 25% - age 50-59
- 10% - age 60-69

Triggers for persistent rocking - (more than one choice per responder)

- 36% - Boat travel, 4 days or more
- 32% - Other: 5-elevator, 4-flulike symptoms, 3-spontaneous, 2-amusement park, - plus: waterbed, unstable trailer, exercise equipment, travel combinations.
- 17% - Boat travel less than 4 days
- 13% - Airline travel 4 days or less
- 10% - Airline travel more than 4 hours
- 7% - Car travel more than 3 hours
- 5% - Car travel 3 hours or less
- 1% - Train travel 3 days or less

Duration of rocking sensation

- 57% - Continuous except when in motion (walking, riding in vehicle, etc.)
- 29% - Continuous
- 5% - 12 hours or less per day
- 5% - 6 hours or less per day
- 3% - Not daily

Who made the diagnosis? - (more than one choice per responder)

- 44% - Otolaryngologist
- 28% - Self diagnosed
- 25% - Neurologist
- 20% - Other
- 5% - Audiologist
- 4% - Physical or Occupational Therapist
- 3% - Primary care physician
- Others = Psychiatrist, Head & Balance Center, Neurological Chiropractor

What treatment helped the most?

- 32% - Other: Time, Inderal, combination of exercise & medication, lots of sleep, chiropractic, massage therapy, laying in recliner.
- 21% - None of these
- 15% - Benzodiazepam (Valium, Ativan, Xanax)
- 11% - Klonoopin
- 7% - Exercise
- 5% - A tricyclics (Eavil, Nortriphiline)
- 4% - Physical activity
- 3% - An SSRI (Paxil, Zoloft, Prozac)
- 1% - Meditation, biofeedback, or other relaxation technique