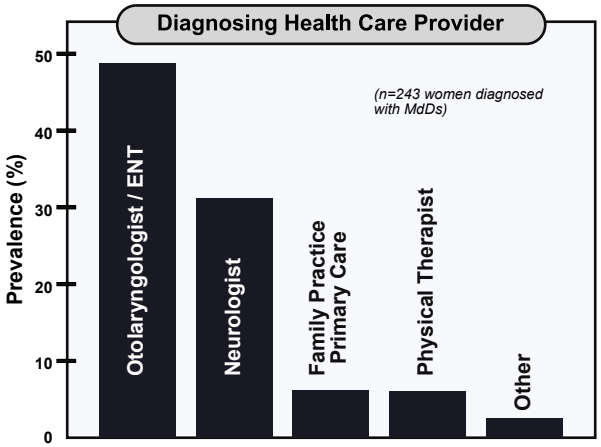

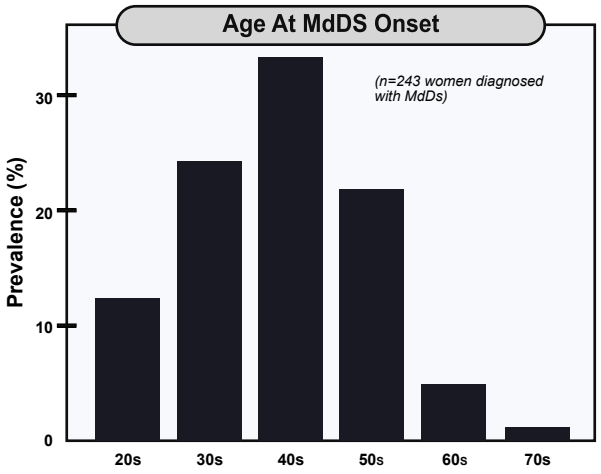

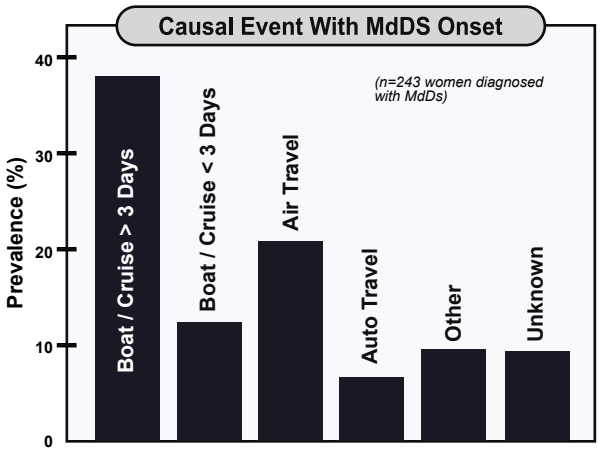

This brochure is provided as an educational service by

The MdDS Balance Disorder Foundation
22406 Shannondell Drive, Audubon, PA 19403

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www.mddsfoundation.org

OUR MISSION

To promote education and research on Mal de Débarquement Syndrome (MdDS), a rare and poorly understood disorder of perceived motion.

- **To provide support and education for patients and families of those with this rare balance disorder**
- **To facilitate clinical studies designed to improve the diagnosis and treatment of MdDS**
- **To promote basic and clinical research to better understand the cause(s) of this unique syndrome**
- **To collect, collate, and distribute demographic and other information from those with MdDS via online surveys (at present, our findings represent the world's largest available database of results about this patient population)**
- **To update professionals who provide medical care and treatment of MdDS patients**

We are an all-volunteer PA 501(c)(3) nonprofit foundation. We seek to promote awareness of, find a cure for, and assist patients suffering from Mal de Debarquement Syndrome (MdDS). All tax-deductible donations are directed to (1) informing health care professionals, patients, and the general public about MdDS, and (2) facilitating research towards more effective treatment, diagnosis, and prevention of this little understood disorder. Find us on

Find us on: facebook twitter GUIDESTAR

If you or your family seek support or additional information relating to MdDS, you may visit our website and learn about our online support groups: http://bit.ly/MdDS-Support, http://www.facebook.com/mddsfoundation.org, and follow us on twitter @mddsfoundation.org

Other Resources:

National Institutes of Health/Office of Rare Diseases Research
http://rarediseases.info.nih.gov

National Organization for Rare Disorders (NORD):
www.rarediseases.org

Vestibular Disorders Association (VEDA):
www.vestibular.org

www.MDDSFOUNDATION.org

MdDS
Mal de Debarquement Syndrome

PHANTOM MOTION PERCEPTION
ROCKING, BOBBING, SWAYING?

MdDS is a persistent and long-lasting disorder of perceived motion and related imbalance that most often develops after an ocean cruise or other type of travel motion experience.

Do you know a person who has returned from an ocean cruise and feels like they are still on the boat - months or years later?

Perhaps they returned from a plane, train or lengthy car ride and now it feels like they are on a ship at sea.

They may be suffering from Mal de Debarquement Syndrome (MdDS), a rare and poorly understood persistent sensation of motion and imbalance.

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ICD-10-CM Diagnosis Code R42 : Dizziness and giddiness
http://www.icd10data.com/ICD10CM/Codes/R00-R99/R40-R46/R42-/R42

What Is Mal de Debarquement Syndrome (MdDS)?

MdDS is a rare and life-altering disorder of perceived motion that most commonly develops after an ocean cruise or other type of water travel. MdDS is also known as disembarkment syndrome or persistent landsickness. MdDS also occurs following air/train travel or other motion experiences or spontaneously/in the absence of a motion event. MdDS is a syndrome because it often includes a diverse array of symptoms.

The characteristic symptom of MdDS is a persistent sensation of motion such as rocking, swaying and/or bobbing.

Other MdDS Symptoms:

- Disequilibrium - a sensation of unsteadiness or loss of balance
- Extreme or unusual fatigue
- Cognitive impairment - difficulty concentrating, confusion, memory loss
- Anxiety, depression
- Ataxia - unsteady, staggering gait
- Sensitivity to flickering lights, loud or sudden noises, fast or sudden movements, enclosed areas or busy patterns
- Headaches, including migraine headaches
- Heaviness - sensation of gravitational pull of the head, body or feet
- Dizziness
- Ear pain and/or fullness
- Tinnitus - ringing in the ears
- Nausea

Many MdDS patients feel relief while driving/riding in an auto, airplane, train or with other motion activities. However, the abnormal sensation of motion returns as soon as the motion activity is suspended. This is an important feature in the diagnosis of MdDS.

Most individuals with MdDS appear normal, have normal results in clinical tests, and visit many health care specialists prior to diagnosis. Collectively, this may increase stress/anxiety levels, which can lead to increased MdDS symptoms. Prompt diagnosis may improve recovery.

How Is MdDS Diagnosed?

No tests can provide a definitive diagnosis of MdDS. Health care providers commonly perform tests to rule out other disorders with similar symptoms. MdDS is primarily diagnosed on the basis of patient history (such as a recent boat, air or train travel or other motion experience) and the elimination of other disorders.

It is common for test results to be normal for those with MdDS. Perhaps as a consequence, patients suffering with MdDS frequently are not readily diagnosed and often feel discouraged. Clinical tests to exclude other disorders may include:

- Audiogram
- Blood tests (e.g., CBC, glucose, ANA, TSH)
- Caloric Stimulation
- Dix Hallpike Maneuver
- ECOG (electrocochleography)
- ENG test (electronystagmography)
- MRI and/or MRA of the brain stem and neck
- Neurological examination
- Posturography
- Rotary chair test
- VEMP test (vestibular evoked myogenic potential)

How Long Will It Last?

Many people transiently experience sensations of floating or imbalance after a cruise or other motion experience. However, these sensations usually continue for only a few hours or days. This is more commonly referred to as “landsickness” or “regaining your land legs.” In striking contrast, **with MdDS, these symptoms persist for months to years.** MdDS symptoms may or may not diminish over time and after remission may reoccur following another motion experience or during periods of stress or illness.

The cause of MdDS is unknown. The majority (~90%) with MdDS are women, but no hormonal connection has been identified. Some believe that MdDS is a variant of motion sickness and related to inappropriate vestibular adaptation after a motion experience. Another theory is that it is a variant of migraine. More biomedical research is needed.

What Are Treatment Options?

Most anticholinergic or antiemetic medications that work for other forms of dizziness or motion sickness, such as scopolamine and meclizine, are not effective in either the prevention or treatment of MdDS.

While there is no known cure, benzodiazepines and amitriptyline have been beneficial in the treatment of MdDS. Additionally, some patients benefit from vestibular therapy, and many are improved with exercise.

Rigorous clinical studies have not been performed to examine the prevention of MdDS through the use of medication. Nevertheless, some MdDS patients who travel utilize benzodiazepines prior to and during travel to keep MdDS symptoms in check.

An increased awareness among physicians may help lead to the clinical knowledge necessary to develop effective treatment strategies. Further research is required to gain a greater understanding of this disorder.

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Mal de Debarquement Syndrome