

ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION

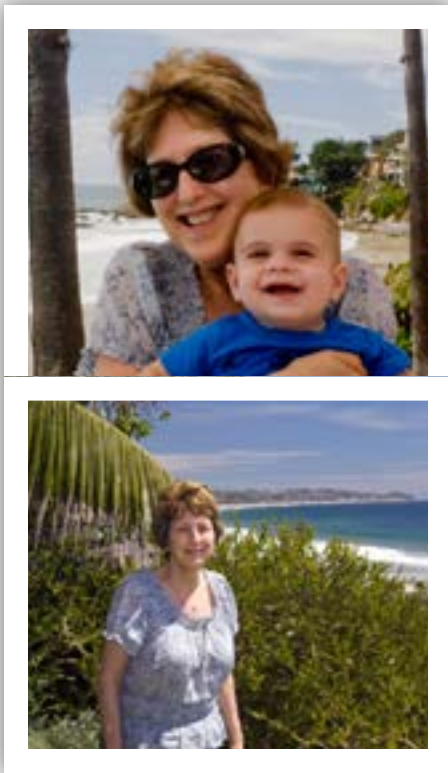


INFORMATION

SUPPORT

AWARENESS

ADVOCACY



Cruising to Dizziness

By Elaine Schlissel

I am 65 years old and live in Atlanta, Georgia. In June, 2010 Mal de Debarquement (a.k.a. "MdDS") changed my life.

My symptoms started while my husband and I were aboard a ship waiting to disembark from a long anticipated one week Alaskan cruise to celebrate our 40th anniversary. During the month before our trip I experienced vague and intermittent symptoms of dizziness and headaches. The headaches were no big surprise; I am from a family of migraneurs and had previously had a few episodes of migraines. The dizziness was odd, but I thought maybe it was a virus. No need to cancel the trip of a lifetime for a few mild symptoms!

Alaskan cruises provide an opportunity to see amazing scenery and wildlife through a variety of motion experiences - trains, buses, seaplanes, dogsled rides, helicopters, ferries, and fishing boats. A dream come true for most passengers, a nightmare for a passenger whose souvenir is Mal de Debarquement Syndrome.

CONTINUED ON PAGE 2

IN THIS ISSUE

Social Security Criteria	4
Symptom Checker	5
Social Media Update	6
Sleeping Tips	8
Mal de Debarquement	9
Research Update	12



(TOP LEFT) ELAINE & GRANDSON ELI (BOTTOM LEFT) ELAINE
(BOTTOM RIGHT) ELAINE WITH HUSBAND, EDWARD

On the Level is a quarterly publication of the Vestibular Disorders Association (VEDA), published in Portland, Oregon, USA and distributed to national and international members. Information in this newsletter is not intended as a substitute for professional health care. VEDA does not recommend any particular course of treatment, clinic, or health care practitioner. The opinions expressed in articles in On the Level are those of the authors and not necessarily those of VEDA's staff, medical and scientific advisors, or Board of Directors. The publisher reserves the right to accept, reject, or edit any materials received for publication. No part of this publication may be reproduced without written permission. © All rights reserved.

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CRUISING TO DIZZINESS CONTINUED FROM PAGE 1:

Minutes after my ship docked I sensed that it was still moving. Within a week, I was dizzy, confused, my head ached, and I could barely walk.

I was fortunate that my internist quickly referred me to a neurotologist. At the neurotologist's office I was asked some very strange questions. Had I recently been on a cruise? Did I feel that I was still "on the boat"? Was I dizzy? Was I rocking? After the fourth "yes" I was diagnosed with an illness I had never known existed.

My pleasant life as a young, active retiree and grandma quickly vanished. Before MdDS I was taking adult education classes, enjoying a book group, participating as an active member of a women's organization, exercising at the gym, and spending time with my granddaughters. After the rocking began I dozed most of the day, tripped on stairs, walked into walls, and suffered from unbearable headaches. Instead of looking forward to my son's wedding and later the birth of his son, I worried about not being able to enjoy his wedding, and not being able to carry his baby safely.

"MY PLEASANT
LIFE AS A YOUNG,
ACTIVE RETIREE
AND GRANDMA
QUICKLY
VANISHED."

My first bout of MdDS lasted five months. Early diagnosis, compliance with prescribed eye and balance exercises, medication, and good luck brought about a remission. The vestibular migraine headaches that often accompany MdDS have been more difficult to treat.

After being rock-free for two years, the physical stress of an unrelated illness set the stage for a second bout of MdDS. This bout lasted for eight months.

MdDS is an insidious illness. Outgoing, active, productive members of society can quickly become housebound. Cognitive abilities are often diminished, and can become further diminished by medicines used to treat the disorder. Automatic tasks turn into nearly impossible chores. Severe exhaustion sets in. Some people spend years dealing with weird symptoms and being shuffled from specialist to specialist. Since most ENT's and neurologists have never seen a case of MdDS, they order many expensive tests that reveal nothing. No wonder anxiety and depression often come into play!

MdDS has taught me that both patients and their medical providers have responsibilities.

FOR DOCTORS:

LISTEN TO US CAREFULLY.

Don't dismiss our symptoms. Many of us have severe depression and/or anxiety, adding an additional layer of difficulty and complication to our lives. Please remember that we've been blindsided by a vestibular disorder that has significantly altered our quality of life.

BELIEVE US WHEN WE DESCRIBE OUR DEBILITATING SYMPTOMS.

Understand the desperation that comes from not being able to do the things we used to do easily, from complete exhaustion, and from having an illness that is poorly understood by our families, friends, employers and physicians.

DON'T GIVE UP ON US WHEN OUR MEDICAL PROBLEMS ARE NOT QUICKLY RESOLVED.

We also wish that our condition required less of your time. Since little is known about MdDS, there is no accepted protocol for treatment. Work with us to develop a treatment plan, and be prepared to try other approaches when appropriate. Please don't dismiss us by saying "there is nothing I can do," or "just live with it." If you cannot help us, please try to help us find another viable option for treatment.

FOR PATIENTS:

PARTICIPATE IN THE PROCESS.

Keep a medical journal with your health history, symptoms, and notes from previous appointments. Bring it to all appointments, and use it to jot down questions that occur to you between doctor's visits.

BE YOUR OWN ADVOCATE.

Read peer-reviewed studies by well-respected medical researchers and bring them to your doctor's attention. You don't have to be a scientist to understand the abstract and the conclusion of a study.

GET SUPPORT.

Look into traditional face-to-face support groups and online support groups. Listen to advice that seems right to you, but realize that each case is unique.



After all, metaphorically, we are all in the same boat.

VEDA WANTS TO HEAR FROM YOU!

Your experience matters to us, and your passion for our organization helps keep this cause alive. Anyone who has firsthand experience with VEDA, such as donors, members and Facebook followers, can write a review about us on GuideStar. Your review will appear in our profile on both GuideStar and GreatNonprofits. Writing a review is a free, easy way to support our work without even leaving your home! Your honest feedback is critical to our continuing good work and overcoming the obstacles that stand in the way of our achieving success.



HELP US SPREAD THE WORD ABOUT OUR COMMITMENT TO OUR MISSION!

To write a review, visit [Guidestar.org](http://www.guidestar.org) and search for "Vestibular Disorders Association" or go directly to: <http://www.guidestar.org/organizations/93-0914340/vestibular-disorders-association.aspx>

VEDA Advocates for Changes to Social Security's Criteria for Evaluating Vestibular Function

The Social Security Administration (SSA) recently requested comments on whether and how they should revise the criteria in their Listing of Impairments for evaluating hearing loss and disturbances of labyrinthine-vestibular function in adults and children.

VEDA was thrilled to have an opportunity to provide feedback that could help improve vestibular patients' ability to qualify for disability benefits.

We compiled input from a team of VEDA medical advisors and wanted to share with you some of the key points within our recommendations:

HEARING VS. VESTIBULAR

VEDA emphasized the need to distinguish hearing loss from vestibular dysfunction. Many vestibular patients do not experience hearing loss. Putting emphasis on hearing loss diminishes the impact of other vestibular symptoms (e.g. dizziness, visual disturbances and cognitive impairment).

MOTION EVOKED SYMPTOMS

A patient's vestibular symptoms should not have to be evoked by motion. A patient can experience symptoms when perfectly still.

JOB ACCOMMODATION

It is important for the SSA to recognize that secondary effects of vestibular disorders make it difficult or impossible for affected individuals to work. These include: cognitive dysfunction, spatial disorientation, anxiety, and nausea. Even if a person can perform a job with accommodation, can they actually transport themselves to such job, considering that driving or taking public transportation can be difficult because of a patient's lack of stamina to stimuli such as oncoming headlights, windshield wipers, the movement of passing cars, etc.

COMMON SYMPTOMS NOT NECESSARILY THE RULE

Many disabling vestibular conditions do not necessarily present with frequent attacks (the condition may be constant, and may increase with movement, position, visual stimulation, fatigue, etc.), tinnitus, or hearing loss.

TESTING REQUIREMENTS

We recommended improvements to the SSA's examination and testing requirements to include a comprehensive physical examination, ENG/VNG (to measure involuntary eye movements), radiology (CT, MRI), vestibular ocular reflex (VOR) function, and a functional exam by a physical therapist.

CENTRAL VS. PERIPHERAL VESTIBULAR DISORDERS

VEDA recommended changing the phrase "disturbances in labyrinthine-vestibular dysfunction" to "disturbances in central or peripheral vestibular dysfunction" to differentiate between peripheral vestibular disorders (related to the inner ear) and central vestibular disorders (related to one or more parts of the central nervous system that process balance and spatial information).

"SECONDARY EFFECTS MAKE IT DIFFICULT OR IMPOSSIBLE TO WORK."

CONFUSING FORMAT

VEDA pointed out that the format of the SSA's document is cumbersome, especially for a vestibular patient who may be struggling with visual and/or cognitive problems. We recommended adding simple formatting changes such as a table of contents, section headers and diagrams.

Recognizing that the SSA needs some way to evaluate a person's physical ability/disability, VEDA pointed out that vestibular testing has severe limitations, so you cannot always say that "normal" vestibular function testing equals a normal vestibular system.

Isabel Symptom Checker Helps Narrow Diagnosis Possibilities

WHAT IS THE ISABEL SYMPTOM CHECKER?

Diagnosing a vestibular disorder can be challenging, even for medical professionals with specialized training. Even more disheartening is the lack of knowledge some general practice and emergency physicians have about the vestibular system. If you or someone you know is suffering from an undiagnosed condition, you may want to research possible causes that you can discuss with your physician. Enter the Isabel Symptom Checker.



The Isabel Symptom Checker is a highly sophisticated medical knowledge system. Its job is to take a set of symptoms and present back a list of possible diagnoses that could be the cause of those symptoms. Each diagnosis is linked to knowledge to help you read up on the disease and learn more about it. The intention is not that you should bypass the doctor and diagnose yourself but to become more informed and be able to have a more balanced and productive discussion with your doctor or healthcare provider about your diagnosis.

WHEN SHOULD ISABEL BE USED?

Isabel should be used when you have doubt about the diagnosis that your doctor has made about you. Everybody will have a different threshold before they have doubt but a good rule of thumb is that your doubt and concern should be based on the number of symptoms you have and how long you have had them. If you have had just one mild symptom for 2 days then it is far less likely to be anything serious than if you have had 2-3 symptoms lasting for 3-4 weeks, for example. You are the person who knows most about your symptoms, such as how long you have had them, how painful they are and whether they are getting worse or better so, if you feel concerned that you are not being listened to by your doctor, then that is a perfect time to use Isabel.

You can access the Isabel Symptom Checker via VEDA's website at vestibular.org.

VEDA ANNOUNCES NEW VICE PRESIDENT



VEDA is excited to announce the appointment of Sheelah Woodhouse, PT BScPT as Vice President of our board of directors.

Sheelah is a certified Vestibular Physiotherapist and National Director of Vestibular Rehabilitation with LifeMark and Centric Health, with locations across Calgary, Canada. She has been a VEDA member since 1999. Sheelah brings a wealth of knowledge about vestibular rehabilitation therapy combined with the business savvy of an entrepreneur, as well as a passion for educating the public, medical community and insurance industry about the assessment and treatment of those with vestibular disorders.

Get social with VEDA!

VEDA'S FACEBOOK FOLLOWING
GREW 26% IN 2013 TO 6,261!

VEDA's active Facebook community educates vestibular patients with research updates, health and wellness articles, and uplifting quotes and stories. By sharing through social media, you can help VEDA raise awareness about vestibular disorders.

THANKS TO OUR LOYAL FACEBOOK
FOLLOWERS, WE REACHED 23,687 PEOPLE
WITH OUR FACEBOOK POSTS DURING
BALANCE AWARENESS WEEK.

Here are some of our most popular posts:

- RESEARCHERS AT UNIVERSITY OF COLORADO SCHOOL OF MEDICINE MAY HAVE FIGURED OUT WHAT CAUSES MENIERE'S DISEASE AND HOW TO ATTACK IT. ACCORDING TO CAROL FOSTER, MD, FROM THE DEPARTMENT OF OTOLARYNGOLOGY AND ROBERT BREEZE, MD, A NEUROSURGEON, THERE IS A STRONG ASSOCIATION BETWEEN MENIERE'S DISEASE AND CONDITIONS INVOLVING TEMPORARY LOW BLOOD FLOW IN THE BRAIN SUCH AS MIGRAINE HEADACHES.

- EVER FEEL LIKE YOU ONLY HAVE 15 MINUTES WITH YOUR DOCTOR AND SO MUCH TO ASK THEM, BUT ALL YOUR QUESTIONS FLY OUT OF YOUR HEAD WHEN YOU GET INTO THEIR OFFICE? VEDA HAS A NEW FORM THAT YOU CAN DOWNLOAD AND BRING TO YOUR DOCTOR'S VISIT WITH QUESTIONS THAT WILL HELP YOU GET CRUCIAL INFORMATION ABOUT YOUR DIAGNOSIS AND TREATMENT. VISIT US ONLINE AT VESTIBULAR.ORG FOR THIS AND MANY OTHER USEFUL EDUCATIONAL RESOURCES.

What would you like to see us post on our Facebook page?
Email us at info@vestibular.org.

IF YOU'RE NOT ALREADY FOLLOWING VEDA
ON FACEBOOK, WE ENCOURAGE YOU TO
CHECK US OUT:
[HTTPS://WWW.FACEBOOK.COM/
VESTIBULARDISORDERS](https://www.facebook.com/vestibulardisorders)



2,020 PEOPLE WHO FOLLOW VEDA ON FACEBOOK LIKED, COMMENTED ON OR SHARED THIS PEANUTS COMIC, WHICH REACHED 22,912 OF THEIR FRIENDS!



COMING SOON!

VEDA WILL BE RE-VAMPING OUR ONLINE MEMBERS' FORUM, AND INTRODUCING A FORUM FOR VESTIBULAR PROFESSIONALS.

TESTIMONIALS:

"VEDA'S MANY ONLINE MEMBERS WERE SO ENCOURAGING, SHARING THEIR STORIES AND TIPS. IT HELPED ME THROUGH THE DARK DAYS."

"WHEN I FOUND VEDA I KNEW THAT I WAS NOT ALONE AND THAT THERE ARE OTHERS LIKE ME. THANKS FOR ALL THE INFORMATION THAT YOU PROVIDE TO PEOPLE LIKE ME. I AM MUCH BETTER NOW AND VERY GRATEFUL."

"VEDA HAS IMPROVED MY QUALITY OF LIFE BY SUPPLYING KNOWLEDGE AND SHARING PERSONAL STORIES OF HOPE AND INSPIRATION. THANK YOU FOR ALL YOU DO!"

Sleeping Tips

From the VEDA Facebook Community

Many vestibular patients have difficulty falling to sleep. For some, tinnitus (a constant ringing sound in their ears) is the problem. For others, there is a panic that they may awake to find the room spinning.

VEDA believes that patients have valuable information to share about their experience living with a vestibular disorder, so we asked our members for techniques they use to help them fall asleep.

"Sleep is an issue I struggle with. A gal from one of my vestibular support groups sent me night lights, which I have found have been a great help. Having additional light sources, reduces the panic I used to feel when waking up in a dark room. Also, there are some really great apps on the iPhone such as "flashlight" that will help you when you need additional lighting."



"I am currently listening to soothing tapes, to help calm me down enough to get sleep. I am constantly



in search of new ways and techniques to make my sleeping experience less dreadful."

"I keep a fan (or air purifier) running in my bedroom at all times. It helps (reduce the sound of ringing in my ears)."

"When I've been particularly dizzy, I've slept on a wedge pillow. I don't know what I'd do without it!"

"I find using Resperate, a machine designed for high blood pressure, has helped take the edge off of nighttime dizziness. It involves deep breathing to tones sort of like biofeedback. Nothing makes it completely go away but I have found this to be somewhat helpful."

"I found that meditation helps, I listen to a stress reduction hypnotherapy CD as I relax and go to sleep. I also sleep in a bit of an upright position, propped up by pillows all around me."



"A contoured neck pillow can help some people depending on the type of vestibular disorder. Some physical therapists let you try these pillows before buying them as it's important to get the right one. It may also help if you avoid eating or doing any rehab training or exercise a few hours before bedtime."

"I know this sounds silly, but they have this "as seen on TV" pillow that is in shaped like a semi-circle and has a little hole where your ear goes. It helps the ringing and kind of cradles you. Makes me feel more secure."

**This information is not intended as medical advice. Please consult with your healthcare provider before making any lifestyle changes.*

Sickness of Disembarkment

By Bonni Kinne

I recently evaluated a 45-year-old female patient who went on a seven-day cruise over the holidays. Although this cruise took place over a month ago and she didn't experience motion sickness while she was on the ship, now that she is back she has been experiencing the following problems:

"I've been experiencing a rocking or swaying sensation, especially when I'm inactive or attempting to be motionless. Although I'm off balance when I attempt to walk, I feel better when I'm driving. In addition to these fairly constant symptoms I occasionally experience difficulties with my concentration, problems with my vision, ringing in my ears, fatigue, headaches, nausea, anxiety, and depression. All of these symptoms feel worse at the end of the day as well as when I'm ill or under a lot of stress, in a dimly lit or very bright environment, in a crowded shopping center, or when working on the computer. I'm extremely frustrated because I was in perfect health before I went on my cruise!"

WHAT IS WRONG WITH MY PATIENT?

The symptoms noted above are most likely due to a disorder known as Mal de Debarquement (MdDS) or "sickness of disembarkment." Most individuals, even professional sailors, experience temporary post-motion symptoms after disembarking from a ship. Mal de Debarquement is generally diagnosed if these post-motion symptoms last more than one month. Although the intensity of the symptoms tends to decrease over time, some individuals continue to be bothered by this disorder for several years. In addition, the longer the symptoms persist, the poorer the long-term prognosis.

Sea travel is the most common precipitating factor for the development of Mal de Debarquement. However, this disorder has also been known to occur after flying on an airplane, riding in a train, being on a space flight, dining in a rotating restaurant, and sleeping on a waterbed. Mal de Debarquement may be associated with a great deal of disability and is considered to be an under-diagnosed and under-researched condition.

WHAT CAUSES MAL DE DEBARQUEMENT?

Although there are a number of theories related to the possible cause of Mal de Debarquement, none has yet been proven. What researchers do know is that Mal de Debarquement appears to be a physiological, not a psychological, disorder.

The three primary physiological systems that detect where our body is in space are the vestibular system, the visual system or eyes, and the somatosensory system or muscles. When an individual is exposed to an unfamiliar passive motion (such as sea travel) these three systems adapt to this motion (i.e. the individual develops "sea legs"). When the unfamiliar passive motion is removed (such as during disembarkment) the three systems usually readapt to the stable conditions off the ship in a relatively short period of time (i.e. the individual redevelops "land legs"). Individuals who experience Mal de Debarquement have trouble readapting to the stable conditions back on land.

HOW IS MAL DE DEBARQUEMENT DIAGNOSED?

Although there are no objective testing procedures capable of definitively diagnosing an individual with Mal de Debarquement, physicians may order diagnostic tests that are designed to rule out brain abnormalities (such as an MRI), vestibular disorders (such as the caloric test, the rotational test, or dynamic posturography), hearing difficulties (such



CONTINUED ON PAGE 10

as audiometry), and autoimmune problems (such as laboratory tests). After these tests have ruled out other possible causes of the individual's chief complaints, Mal de Debarquement is diagnosed based upon the individual's subjective history.

The typical MdDS patient is a female between the ages of 40 and 50 who experiences a rocking or swaying sensation after having gone on a cruise and whose symptoms are decreased when she drives a motor vehicle.

HOW IS MAL DE DEBARQUEMENT TREATED?

There is no completely effective intervention for Mal de Debarquement. Vestibular suppressants traditionally used for treating vertigo and other motion-provoked symptoms (such as Antivert, Meclizine, and Scopolamine) are usually inadequate once the symptoms of Mal de Debarquement have developed. In addition, hormonal medications may actually increase the intensity of an individual's symptoms. The medications that have demonstrated the most promise for decreasing the intensity of an individual's symptoms are the benzodiazapines (such as Ativan, Klonopin, and Valium). Some individuals may also benefit from being referred to a vestibular rehabilitation specialist if they have an actual balance problem or if they are fearful of participating in normal activities of daily living as a result of their Mal de Debarquement. However, vestibular rehabilitation is often unsuccessful at alleviating all of the individual's subjective complaints.

Although Mal de Debarquement may become a permanent condition, most individuals eventually experience a spontaneous resolution of their symptoms. Therefore, intervention is often directed towards keeping patients as comfortable as possible

while they wait for their symptoms to subside on their own.

CAN MAL DE DEBARQUEMENT BE PREVENTED?

Because there is no completely effective intervention for Mal de Debarquement, prevention is the key. The most obvious way to prevent the occurrence of this disorder is to avoid exposure

to unfamiliar passive motion. For those individuals who are unable or unwilling to avoid this exposure, there is some evidence that the use of specific medications before and during the passive motion activity may be helpful. The medications that have demonstrated the most promise in terms of preventing the occurrence of Mal de Debarquement include the benzodiazapines listed in the treatment section as well as certain medications used for anxiety, depression, and migraines.

"BECAUSE THERE IS NO COMPLETELY EFFECTIVE INTERVENTION FOR MAL DE DEBARQUEMENT, PREVENTION IS THE KEY."

For more information on Mal de Debarquement, visit the Educational Resources section of VEDA's website at <https://vestibular.org> and the MdDS Balance Disorder Foundation's website at www.mddsfoundation.org.

BONNI KINNE IS AN ASSISTANT PROFESSOR IN THE DEPARTMENT OF PHYSICAL THERAPY AT GRAND VALLEY STATE UNIVERSITY, WHERE SHE HAS BEEN CONDUCTING RESEARCH IN THE AREA OF VESTIBULAR REHABILITATION. BONNI ALSO WORKS PART-TIME IN A CLINIC WHERE SHE SPECIALIZES IN THE TREATMENT OF PATIENTS WITH VESTIBULAR DISORDERS. BONNI RECEIVED HER BACHELOR'S DEGREE IN BIOMEDICAL SCIENCES AND MASTER'S DEGREES IN EXERCISE SCIENCE AND PHYSICAL THERAPY.

"Always laugh when you can, it is cheap medicine. – George Gordon Byron"

YES! I WANT TO HELP PEOPLE SUFFERING FROM VESTIBULAR DISORDERS.

Your support helps VEDA provide information on vestibular disorders to thousands of people every year. Thank you!

You can renew your membership &/or make a donation to support VEDA's life-changing work online at vestibular.org, or send your payment to 5018 NE 15th Ave, Portland, OR 97211 with the enclosed self-addressed envelope.

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- Professional \$110 (*e-newsletter only-email required*)
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Thank you for supporting the Vestibular Disorders Association! With your help we can reduce the time it takes to accurately diagnose vestibular disorders and improve treatment outcomes, helping patients live happy, productive lives.

What Will Your Legacy Be?

Jeanette Welch—a founding VEDA board member—was dedicated to supporting the mission of the Vestibular Disorders Association during her lifetime, and beyond.

As a charter member of VEDA's "Balance Society," Jeanette left a legacy that will continue to help people suffering from vestibular disorders now and into the future.

When you make a planned gift to the Vestibular Disorders Association, you'll become a member of our "Balance Society" - a memorial to your commitment to improve the lives of people with vestibular disorders.

For more information about including VEDA in your Will or estate plan, contact development director, Tony Staser, at 503.294.9085 or via e-mail at Tony.Staser@vestibular.org.



VESTIBULAR
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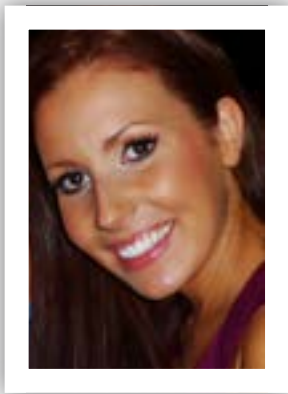
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Research Update



The role of acceptance in adjustment to Ménière's disease

For many chronic conditions, it has been found that the patient's level of "acceptance" is a critical factor in their treatment. Higher levels of acceptance have been found to be associated with positive outcomes, for example, in tinnitus and chronic pain patients. However, no research has yet been done to measure the levels of acceptance in people with Ménière's disease, and suitable questionnaires to carry out such work have not yet been developed.

Researcher Laura McGinn

A group of researchers based at the University of Southampton, Imperial College London, Kings College London, Linköping University (Sweden), and the Mayo Clinic (USA) have received funding from the Ménière's Society (UK) to create and pilot a questionnaire to measure "vertigo acceptance" and use it to assess the relationship between acceptance and adjustment in people with Ménière's disease. If higher levels of acceptance are found to predict better outcomes, in future research it may be possible to investigate the effectiveness of validated acceptance-based interventions in Ménière's disease, such as Acceptance and Commitment Therapy (ACT) and Cognitive Behavioural Therapy (CBT).

HELP VEDA RAISE AWARENESS...

SAVE THE
DATE!



BALANCE AWARENESS WEEK
DEFEAT *DIZZINESS*

September 15th - 21st, 2014