

# ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION



INFORMATION

SUPPORT

AWARENESS

ADVOCACY



## My Ménière's Story

By Gary Breitbord

Ménière's sucks. I apologize if I offend anyone with my language, but I bet people who have a vestibular disorder are nodding their heads vigorously in agreement. Well, maybe not too vigorously, because they can't without risking a vertigo attack.

My story began in February 1994 at a trade show in Las Vegas. I'd had a few beers, but the disequilibrium I felt was not the same as my normal reaction to alcohol. I sat for a little bit and it went away. I didn't think anything of it until a few months later when it happened again. It began to occur more and more frequently. I then embarked on a journey many of you are all too familiar with – fluctuating hearing loss, fullness in the ear, "brain fog," tinnitus, and random episodes of debilitating vertigo.

I'm fortunate to be living in the Boston area where we have some of the world's best medical facilities. My primary care physician referred me to an Ear, Nose and Throat specialist who immediately diagnosed

CONTINUED ON PAGE 2

## IN THIS ISSUE

Diagnostic Tests for Balance Problems	3
Balance Awareness Week	6
Patient Involvement Strategies in Diagnostic Error Mitigation	8
ABC's of Meniere's	9
Professional Member Spotlight	12



PHOTOS: GARY & THE BREITBORD FAMILY, LIVING LIFE TO THE FULLEST DESPITE HIS MÉNIÈRE'S

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#### **MY MÉNIÈRE'S STORY CONTINUED FROM PAGE 1:**

it as Ménière's. From there I went to VEDA to find out as much as I could about the disease and treatments. I tried many of the potential remedies including: salt free diet, acupuncture, exercise, losing weight, endolymphatic shunt surgery, aspartame free diet (helped), no caffeine, CPAP machine for mild sleep apnea (triggered the symptoms!) and replacing all my amalgam fillings (no effect). I find it is worse for me in the winter months and better in the summer. Plenty of sleep, exercise and eating right seem to be the most helpful. Staying otherwise healthy helps by giving me the energy to deal with whatever Ménière's throws my way.

While none of the symptoms are fun, the vertigo attacks were life altering. I always had to have a "bail out" plan. What happens if I get an attack now? Where will I be safe? Will my kids be safe? Where can I lie down for 2 hours until it passes? Where do I get the energy to overcome the physical exhaustion coupled with the mental strain of just trying to manage my day-to-day life? At my nadir about 3-4 years into it, I was curled up in the fetal position on my bed blubbering like a baby because I'd reached my limit. I saw a behavioral therapist/counselor for help in dealing with it.

I'm extremely grateful to my family and friends who know I have this unseen enemy I struggle with. They provide me the most important things they can – love, support and understanding.

In my work life, I'm pretty competitive. I vowed this disease would not beat me. It won its share of battles, but it hasn't defeated me. Colleagues would sometimes ask what was up when they saw me lying down on the floor in a darkened conference room, or talking on the phone with my head on my desk, or asking them to repeat something for the 2<sup>nd</sup> time. I was able to not only survive, but also thrive in my career even with the Ménière's albatross around my neck, or should I say nesting in my ear. One story in particular stands out. I told Dr. Dennis Poe that I was unhappy in my job as a sales executive for a large company and was thinking about joining a start up, but was concerned about the extra risk of Ménière's. We then talked about the "bad stress" in my current job and the "good stress" of doing something risky, but enjoying it. So I took the leap and it worked out.

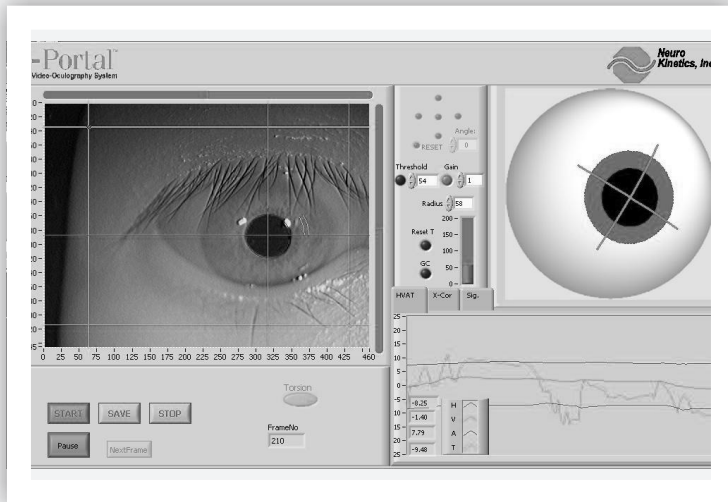
The good news for me is that the worst part of the disease has eased. Except for tinnitus and the occasional dizzy spells, it doesn't impact my day-to-day life.

VEDA has helped me with not only informational resources, but also a "human network" of doctors and patients with Ménière's. Recently, I joined the VEDA Board of Directors and I am looking forward to helping give back to VEDA for all they've done for me.

# It's All in the Eyes: Diagnostic Tests for Balance Problems Track Eye Movements

Patients seeking medical help for dizziness or other balance and equilibrium problems might be asked to undergo one or more of a number of possible diagnostic tests, including some that are uncomfortable to endure. One battery of noninvasive and patient-friendly tests preferred by a growing number of GPs, audiologists, otolaryngologists (ENTs), neuro-otologists (doctors who specialize in the neurologic component of the ear) and others involve tracking how the eye responds to a stimulus, such as a laser dot projected on a screen.

"The eye is the portal to the brain," says Dr. Alex Kiderman, chief technology officer of Neuro Kinetics, Inc., a manufacturer of neuro-otologic diagnostic devices used worldwide. "By precisely measuring oculomotor (eye movement) function, our systems help doctors detect a broad range of vestibular and neurological pathologies. The concept is as old as asking a patient to follow a pen being waved across his or her line of sight, but updated with highly accurate digital measuring and advanced analytics that provide keen insight to a patient's condition."



The refined eye-tracking capability is generated with the company's I-Portal® platform technology. When combined with stimulus equipment and command and analysis software, I-Portal produces detailed, high-resolution analysis of eye movements, with real-time reporting of results. Armed with that knowledge, doctors can make more accurate and timely diagnosis and develop effective treatment programs.

One of the company's products is its I-Portal NOTC (Neuro-Otologic Test Center) system featuring its renowned Barany chair. Tests that medical specialists carry out include VNG pursuits, optokinetics and



saccades. The NOTC generates measurements of the eye's horizontal, vertical, pupil and torsional responses or reflexive reactions to stimuli.

"Quality diagnostics require quality data, and that's what we aim to deliver," Kiderman said.

Many of the medical specialists employing Neuro Kinetics devices and data analysis software offer the tests in their offices. Others refer patients to nearby Balance Centers.

Neuro Kinetics has been offering its balance and equilibrium tests for almost 30 years and has developed what it believes is the world's leading eye-tracking technology. More recently, the company has expanded its focus to include developing new tests and analysis for brain injuries stemming from battlefield explosions and concussions from athletic competitions. The company is under contract with the U.S. Department of Defense to carry out clinical trials using its technology.

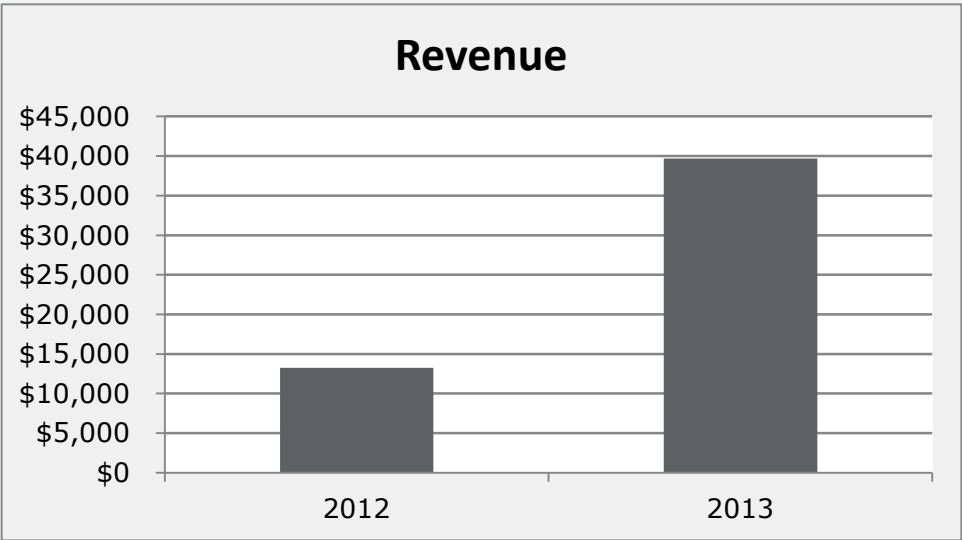
"Eye tracking holds great promise in a number of urgent medical fields," Kiderman says. "For patients with balance problems, our technology generates sensitive clinical data. We're helping doctors help patients every day, all around the world." For more information, please visit [www.neuro-kinetics.com](http://www.neuro-kinetics.com) or e-mail [info@neuro-kinetics.com](mailto:info@neuro-kinetics.com).

# Balance Awareness Week 2013 Highlights

Thanks to our donors, sponsors, and all the people who created personal campaign pages, we raised \$40,709 during Balance Awareness Week to support VEDA’s programs! These much needed funds will be allocated toward **building** a larger support group network, **launching** an advocacy program, and **expanding** our outreach efforts to educate people about vestibular disorders, including where to seek help, and how to cope with the physical, mental and emotional impacts of this debilitating illness.

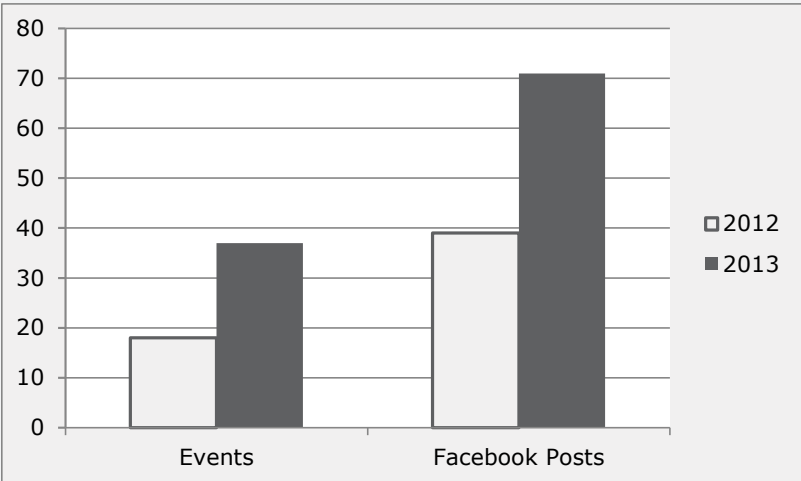
## Fundraising Summary

TOTAL RAISED	\$39,683
DONATIONS (#)	341
PERSONAL CAMPAIGN PAGES (#)	37
SPONSORS (#)	9



## Spreading the Word to Raise Awareness

The goal of Balance Awareness Week is to increase awareness about the impacts of living with a vestibular disorder, especially among people who may not know what “vestibular” means. We do this in many ways, including through social media (e.g. Facebook), mainstream media (e.g. articles in local, regional and national newspapers, magazines, blogs, etc.), eblasts, events, and posters. We’re very excited to report that our outreach efforts were hugely successful!



FACEBOOK	
POSTS	71
REACH	115,999
LIKES	2,178
SHARES	783
COMMENTS	230

EBLASTS	
SENT	28,397
OPENED	8,758

A PRESS RELEASE HIGHLIGHTING THE TOUCHING STORY OF 13-YEAR OLD MICHAEL MCDEVITT WAS PUBLISHED BY 337 MEDIA OUTLETS, WITH OVER 22 MILLION TOTAL AVERAGE VISITORS.

# What People Are Saying About Balance Awareness Week

"We are delighted to be able to partner with VEDA and Meniere's Australia this year to raise awareness of vestibular disorders and make a difference globally. We look forward to continuing our work together throughout the year and for Balance Awareness Week 2014."

Natasha Harrington,  
Director - Meniere's UK



"Joining VEDA and participating in Balance Awareness Week has given me a sense of community coming together to defeat dizziness. Through VEDA I have learned more about vestibular disorders and broadened my community of people who understand what it is like to have one. Thank you, VEDA!"

Mandy Heaton, vestibular  
patient - Portland, OR



"Pacific Balance & Rehab enjoyed participating in Balance Awareness Week. We engaged the Seattle community during our Open House, featuring balance screenings, healthy cooking demonstrations, and balance equipment exhibitions - including the Fitterfirst balance board and Urban Poling's nordic walking poles. It was great to team with VEDA and their sponsors - they

made it easy for us to set up our event, provided support and publicity, and included some awesome prizes and giveaways to attract folks. With this help we had an excellent turn out and definitely guided some people in need of assistance for balance and dizziness issues. We plan to participate again next year!



Chris Morrow, PT, NCS - Founder Pacific Balance & Rehabilitation Clinic

## VOLUNTEER SPOTLIGHT



VEDA would like to thank Jody Connell for her time and dedication as a volunteer for Balance Awareness Week. Jody's vestibular symptoms first began in 2009. After being misdiagnosed initially, she ended up at the Atlanta Ear Clinic. She attended a support group meeting at the clinic, where she met VEDA development director, Tony Staser, and enthusiastically asked what she could do to help raise awareness for vestibular disorders. She organized the "Picnic in the Park" event held in Atlanta during Balance Awareness Week, secured sponsors, and created a personal campaign page where she raised \$1000. It's committed volunteers like Jody that have made this year's Balance Awareness Week VEDA's most successful fundraising and outreach event yet!

\*READ JODY'S FULL STORY AT [HTTPS://VESTIBULAR.ORG/JODY](https://vestibular.org/jody)



# BALANCE AWARENESS WEEK to **DEFEAT** *DIZZINESS*

EV

ROCKVILLE,  
MD

## WALK IN THE PARK



VEDA board member, Stacey Buckner, and the Balance Center of Maryland, invited patients to join them for food, friendship and fun. Stacey demonstrated Urban Poling's nordic walking poles and FitterFirst's balance board to audiences of all ages!



BOSTON,  
MA

## TAI CHI FOR BALANCE

Dan Kleinman, director of Brookline Tai Chi, hosted a Tai Chi class customized for vestibular patients. Tai Chi is a martial art characterized by its flowing movements, which can be used to improve balance.



SEATTLE,  
WA

## OPEN HOUSE - PACIFIC BALANCE CENTER

Chris Morrow, founder and physical therapist at Pacific Balance Center, held an open house, with free fall risk screening assessments and cooking demonstrations focusing on foods that support vestibular health.



# EVENT HIGHLIGHTS

VENTURA,  
CA

## 2K WALK

Equilibrium Balance

Performance Center hosted their first annual 2K walk to raise awareness about vestibular disorders. A special thanks to their local presenting sponsor, SCAN Health Plan.



ATLANTA,  
GA

## PICNIC IN THE PARK

Volunteer extraordinaire, Jody Connell, organized a picnic in the park for the Atlanta Community. Attendees included VEDA board member, Louise Geib (a vestibular patient), former board member, Gaye Cronin (an occupational therapist), and Michael McDevitt (a 13-year old patient featured in VEDA's national press release about Balance Awareness Week).



PORTLAND,  
OR

## BALANCE & HEARING FAIR AT OREGON HEALTH SCIENCES UNIVERSITY



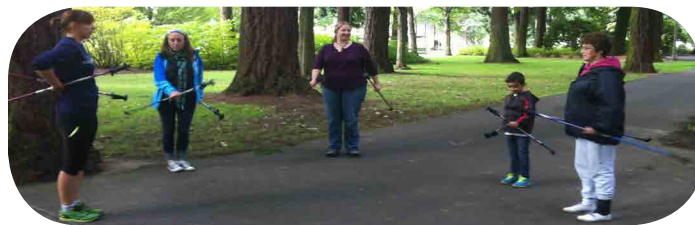
Dr. Anh Nguyen-Huynh with OHSU's Vestibular Clinic held a Hearing & Balance Fair, where they screened over 150 people for hearing & balance problems. VEDA Executive Director, Cynthia Ryan, and Development Director, Tony Staser, educated attendees about vestibular disorders.

## YOGA FOR BALANCE



The Julie Lawrence Yoga Studio held an "Adaptive Yoga" class to help vestibular patients strengthen the muscles responsible for balance.

## WALK FOR BALANCE



VEDA volunteer, Melissa Bosserman, taught attendees how to use Urban Poling's nordic walking poles to improve their balance. One attendee relied on a cane, but with two Activator poles her posture improved and she was able to walk with a natural gait pattern. She was beaming!

# The Patient is in: Patient involvement strategies for diagnostic error mitigation

By Kathryn M. McDonald, Cindy L. Bryce, Mark L. Graber

Diagnostic errors are increasingly recognized as an important and costly aspect of patient safety. This study advocates for engaging patients to improve diagnostic accuracy in their care and provides tactics to help patients prevent diagnostic errors, including a list of questions to ask their provider. These approaches aim to enhance clinician–patient communication and to help physicians avoid their own cognitive biases. The article also argues for the role of patients as a “crucial voice” in augmenting diagnostic delivery systems, research, and policy.

## CHALLENGES EXPERIENCED BY PATIENTS & FAMILIES DURING THEIR DIAGNOSTIC JOURNEY

### PATIENTS AND FAMILIES SOMETIMES:

- Fear complaining, being seen as difficult
- Feel powerless for many reasons
- Do not always take own problems seriously enough
- Are unsure about basics of the health system or involvement opportunities
- Have difficulty dealing with inexperienced doctors who are trying to appear experienced in the problem
- Are unsure how to get ‘the supervisor’ when issues are not resolved at frontline

### HEALTHCARE PROFESSIONALS SOMETIMES:

- Dismiss patients’ complaints and knowledge
- Do not listen to concerns about serious symptoms or deteriorations
- Give psychiatric, alcoholic or drug abuse diagnoses incorrectly

### HEALTH SYSTEMS SOMETIMES EXHIBIT:

- Disjointed care: lack of coordination and teamwork
- Breakdown in communication
- Lack of information passed to patient
- Test results not reviewed closely or followed up
- No disclosure or apology after diagnostic errors

SOURCE: SYNTHESIS GENERATED BY AUTHORS FROM THE DIAGNOSTIC ERRORS IN MEDICINE CONFERENCE

## PATIENT/FAMILY TACTICS FOR PREVENTING/DETECTING DIAGNOSTIC ERRORS

- Tell your story well
- Be a good historian
- Be a good record keeper
- Be an informed consumer
- Facilitate communication and coordination among different people involved in care
- Ensure test results are known
- Ensure follow-up (do not assume no news is good news)
- Encourage your doctors to think broadly
- Understand uncertainty in diagnosis (assume you have a ‘working diagnosis’ that may change)

SOURCES: ADAPTED IN PART FROM GRABER, 37 AND SYNTHESIS GENERATED BY AUTHORS FROM THE DIAGNOSTIC ERRORS IN MEDICINE CONFERENCE

## QUESTIONS TO ASK YOUR PROVIDER TO REDUCE DIAGNOSTIC PROBLEMS

- What are my primary concerns and symptoms?
- How confident are you about the diagnosis?
- What further tests might be helpful to improve your confidence?
- Will the tests you are proposing change the treatment plan?
- Are there findings/symptoms that do not fit your diagnosis?
- What else could it be?
- Can you facilitate a second opinion by providing me with my medical records?
- When should I expect to see my test results?
- What resources can you recommend for me to learn more about diagnosis?

SOURCE: GRAEDON AND GRAEDON

# The A.B.C.'s of Ménière's Disease

By Bonni Kinne

In the early stages of Ménière's disease fullness in the right ear is promptly followed by a spontaneous onset of severe vertigo (a spinning sensation), tinnitus (ringing in the affected ear), nausea, and vomiting. These debilitating symptoms persist for approximately four hours, after which a patient is extremely fatigued and sleeps for several hours. The patient continues to notice mild tinnitus and slight imbalance after awakening, but these symptoms resolve within a couple of days.

Some time later the patient experiences a similar incident and decides to be evaluated by a family physician. Based upon the patient's subjective history and objective examination, the patient is referred to an otolaryngologist (ears, nose, and throat doctor). After undergoing several diagnostic tests, the patient visits a therapist who specializes in vestibular rehabilitation.

## WHAT IS MÉNIÈRE'S DISEASE?

In a normal situation, the fluid system associated with the inner ear operates independently of the fluid system associated with the entire body. In Ménière's disease (also known as idiopathic endolymphatic hydrops), the quantity and quality of the inner ear fluid are directly affected by the quantity and quality of the fluid throughout the entire body. Therefore, an increase in the volume and/or concentration of the fluid throughout the entire body causes an increase in the volume and/or concentration of the inner ear fluid (see Figure 1).

It is thought that this increased volume and/or concentration is responsible for the classic symptoms associated with an acute Ménière's episode (vertigo, tinnitus, nausea, and vomiting). These symptoms may occur spontaneously or may be preceded by fullness in the affected ear. Although the typical length of an acute episode is 20 minutes to four hours, the symptoms may persist for up to 24 hours. The interval of time between episodes is unpredictable, and this remission period may be completely symptom-free or it may include mild tinnitus and/or slight imbalance. The most distinctive

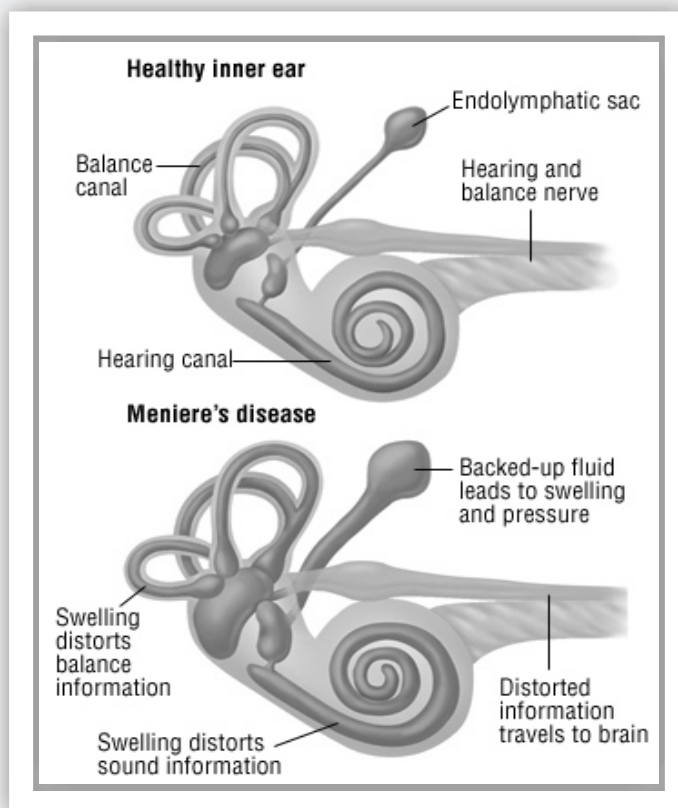
characteristic of Ménière's disease is the recurrent nature of the attacks.

Ménière's disease affects up to 2% of the population, and its incidence is equally distributed between males and females. Although this vestibular dysfunction may begin as early in life as the age of 20, it is an uncommon condition in childhood. In fact, most affected individuals are 40 years of age or older. In the early stages of the disorder, only one ear is usually affected. However, up to 50% of all individuals who have had Ménière's disease for more than 30 years report some bilateral involvement.

## WHAT CAUSES MÉNIÈRE'S DISEASE?

Although each acute episode of Ménière's disease is thought to be caused by an increase in the volume and/or concentration of the fluid in the inner ear, the underlying reason for this increase is unknown. The most popular reasons that have been proposed include viral infections, head injuries, an allergic reaction or autoimmune response, and/or a genetic tendency or hereditary trait. In fact, most researchers suggest that a combination of factors probably play a role.

FIGURE 1



CONTINUED ON PAGE 10

## HOW IS MÉNIÈRE'S DISEASE DIAGNOSED?

A thorough subjective history combined with a comprehensive physical examination will often be sufficient to suspect a diagnosis of Ménière's disease. However, your family physician and/or otolaryngologist may request that laboratory tests, an MRI, and/or a CT scan be conducted as well. The purpose of these diagnostic tests is to rule out other possible reasons for your symptoms. In addition, common vestibular tests include electronystagmography (ENG), rotational testing, and dynamic posturography; common hearing tests include audiometry, electrocochleography (ECOG), and an auditory brainstem response (ABR) examination. Each of these tests is non-invasive, and all of them are commonly performed on an outpatient basis.

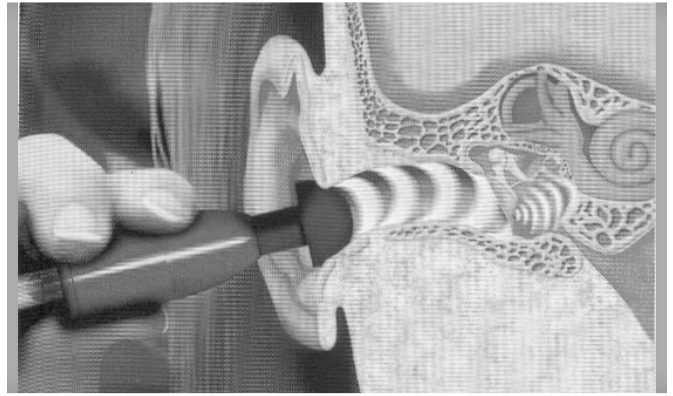
## HOW IS MÉNIÈRE'S DISEASE TREATED?

During an acute Ménière's episode, you should lie down and focus on a stationary object. If prescribed, Meclizine (Antivert) or Diazepam (Valium) may help decrease your vertigo and Promethazine (Phenergan) or Prochlorperazine (Compazine) may help decrease your nausea. Although there is no actual cure for Ménière's disease, the primary goal of a long-term management program is to prevent the occurrence of the acute episodes or to at least decrease the frequency at which these episodes occur. Long-term management is most effectively accomplished by taking diuretics (water pills) and by adhering to a low-salt diet. In addition, you should limit your intake of aspirin, sugar, caffeine, alcohol, nicotine, and foods that contain large amounts of MSG. You should also maintain a regular eating schedule and drink plenty of fluids.

A relatively new treatment approach is the use of a Meniett device (see Figure 2). After a ventilation tube has been inserted into your tympanic membrane (eardrum), this device is able to transmit tiny pulses of pressure into your inner ear. These pressure pulses are thought to decrease the volume and/or concentration of the inner ear fluid. In order to be most effective, the device should be used five

minutes at a time, three times per day.

FIGURE 2



If your acute Ménière's episodes are not adequately managed through the use of the previously described measures, more invasive treatment techniques may be considered as a last resort. One of these techniques involves the injection of Gentamicin (an antibiotic) or Dexamethasone (a steroid) into the middle ear. Although Gentamicin injections are very effective at alleviating the symptoms associated with Ménière's disease, they may also cause damage to the hearing apparatus. Dexamethasone injections, on the other hand, may preserve hearing but are less successful.

The other three techniques involve surgical procedures. During a labyrinthectomy, the entire inner ear is removed. During a vestibular nerve section, the balance portion of cranial nerve VIII is completely severed while the hearing portion of cranial nerve VIII remains intact. The third technique involves the placement of a shunt into the inner ear. The purpose of this shunt is to decrease the volume and/or concentration of the inner ear fluid.

## IS THERE ANYTHING ELSE I SHOULD KNOW?

Although Ménière's disease is not fatal, it can be a progressive condition if not properly managed. If you experience advanced hearing loss, you may need to wear a hearing aid. If you experience persistent balance problems, you may need to receive vestibular rehabilitation. Be sure to contact your family physician and/or otolaryngologist if any of the following symptoms occur during one of your acute

CONTINUED ON PAGE 11

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

## Your membership with VEDA helps us provide information on vestibular disorders to thousands of people every year. Thank you!

You can renew your membership & make an additional gift to support VEDA's life-changing work at [vestibular.org/membership](http://vestibular.org/membership), or send your payment to 5018 NE 15th Ave, Portland, OR 97211 with the enclosed self-addressed envelope.

### Annual Membership:

- ☐ Basic \$40 (e-newsletter only-email required)
- ☐ Professional \$110 (e-newsletter only-email required)
- ☐ I would like to receive your newsletter in the mail for \$5 US/\$15 International

### Donation:

- ☐ \$25 ☐ \$50 ☐ \$100 ☐ \$150 ☐ \$200 ☐ \$250
- ☐ Other \$ \_\_\_\_\_
- ☐ Charge my credit card monthly \$ \_\_\_\_\_
- ☐ Please make my donation anonymous

### Method of Payment:

- ☐ Check (payable to VEDA in US Dollars)
- ☐ Visa ☐ MasterCard ☐ American Express
- ☐ Please send me information about including VEDA in my Will or Estate Planning.

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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.

MÉNIÈRE'S CONTINUED FROM PAGE 11:

Ménière's episodes: (1) a severe headache; (2) a loss of consciousness; (3) visual problems; (4) speech problems; (5) weakness in one of your extremities; (6) numbness/tingling; and/or (7) chest pain. Finally, always keep in mind that there are many healthcare professionals and support groups available for individuals with Ménière's disease. You're not alone!

**For more information on vestibular disorders, visit VEDA's website at [vestibular.org](http://vestibular.org).**

BONNI KINNE IS AN ASSISTANT PROFESSOR IN THE DEPARTMENT OF PHYSICAL THERAPY AT GRAND VALLEY STATE UNIVERSITY, AND WORKS IN A CLINIC WHERE SHE SPECIALIZES IN VESTIBULAR DISORDERS. SHE RECEIVED HER BACHELOR'S IN BIOMEDICAL SCIENCES AND MASTER'S IN EXERCISE SCIENCE AND PHYSICAL THERAPY.

"VEDA HELPED ME THE MOST BY TEACHING ME HOW BEST TO HANDLE A MENIERE'S ATTACK, BY HOLDING ON TO SOMETHING STABLE AND STARING AT SOMETHING THAT IS NOT MOVING. A LOW SODIUM DIET ALSO HELPS." - NANCY SWEARENGEN

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# VESTIBULAR

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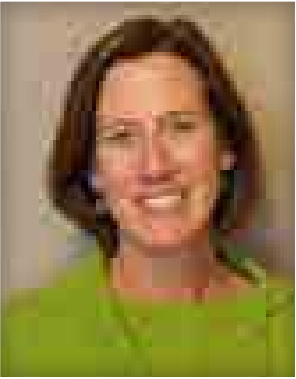
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"Wherever the art of medicine is loved, there is also a love of humanity." - Hippocrates

### Professional Member Spotlight



Gayle Hynes has been a physical therapist for 20 years, 17 of which have been spent working exclusively with vestibular patients. She became interested in vestibular rehabilitation after her husband began experiencing vestibular migraines. "I saw firsthand how debilitating and frustrating vestibular problems can be," says Gayle. "I knew that to be the best therapist I could be I needed to focus on vestibular rehab."

One of the things Gayle loves most about working with vestibular patients is that they are so appreciative. "The first time you treat a BPPV patient is so rewarding!" says Gayle. "I also appreciate that I have been able to see the growth of the Elks vestibular department from a handful of therapists to 5 clinics with balance centers."

**ELKS HEARING & BALANCE CENTERS PERFORMED 22 FREE BALANCE SCREENINGS DURING BALANCE AWARENESS WEEK.**

**VEDA WOULD LIKE TO THANK ELKS HEARING & BALANCE CENTER FOR SPONSORING BALANCE AWARENESS WEEK**



Located throughout Idaho in Boise, Eagle, Meridian, Nampa, and also Ontario, Oregon, Elks' staff of certified vestibular therapists uses computerized testing to diagnose disorders involving balance, dizziness, vertigo and a history of falls.