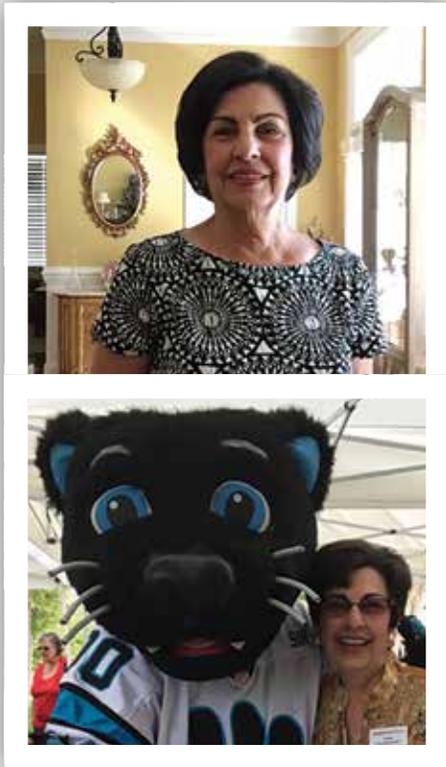


# ON THE LEVEL VEDA

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION

LIFE REBALANCED



## Of Brain Fog and Flying Pillows

By Catherine Hellner

It was February 23rd and I was lying in bed on my right side, like any other day. Except today, when I opened my eyes, the throw pillows that were lying on the floor next to my bed seemed to be floating in the air. Disoriented and confused, I rolled over on my back, which stopped my apparent hallucination. But deep inside I knew it wasn't a hallucination - something was definitely very wrong.

Finally I rolled out of bed and made it to the kitchen. Thinking I was dehydrated I drank 4 cups of water, but this didn't help, so I called my doctor and he recommended that I go to the emergency room.

All they seemed to care about was ruling out life-threatening conditions like stroke or brain tumor. They performed an MRI, an MRA, and cardiac tests. The good news is that there was no sign of Alzheimer's or dementia. While I was grateful those tests turned out negative, it still didn't answer the question of what WAS wrong with me. The ER doctors told me I had vertigo and sent me home without a diagnosis or any clue as to cause of my scary symptoms.

CONTINUED ON PAGE 2

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"MY FAMILY HAS BEEN VERY SUPPORTIVE AND UNDERSTANDING," SAYS CATHY. PICTURED ABOVE WITH HUSBAND, CLAY SR., AND SONS, CLAY JR. & CLIF

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## BRAIN FOG & FLYING PILLOWS...CONTINUED FROM PAGE 1:

The following week I still couldn't clearly focus and continued to feel unsteady, so my neighbor drove me to see an ENT. As the doctor was raising me up in his exam chair everything went black and I felt like I was falling through the air. I started to scream and then cry. It was the most horrifying experience of my life!

The ENT performed an ENG that showed nystagmus, but said it was nothing to worry about. He said that my symptoms were due to a central nervous system problem, not a peripheral vestibular disorder. He diagnosed me with vestibular neuritis and put me on a steroid pack and Valium. After taking the steroids for five days I began to feel better, but a couple hours after I began cleaning my house the symptoms returned with a vengeance.

I went on to see this doctor again, a physician's assistant (PA), and then another ENT, but none offered any additional insight into my continued attacks or hope that I would ever recover. One even said, "What is it you expect me to do?" I thought, are you kidding me? You're the doctor. It was bizarre and unbelievable to me that he had no interest in helping me or validating my feelings.

Through VEDA I found Jon Morrissette, a physical therapist, and started vestibular rehabilitation therapy (VRT). He diagnosed me with BPPV and vestibular hypofunction. During our first session he had me put my legs together, cross my arms over my chest, and close my eyes. Within seconds I was falling to the right. I could not believe that no one else had thought to perform this simple diagnostic test. We continued VRT twice a week for two months, and now I do my exercises at home.

VRT made all the difference for me. Dr. Morrissette said I may have to do these exercises for the rest of my life. The PA initially told me that vestibular problems wouldn't affect my vision, but I knew something wasn't right because while I could see things, I couldn't really "see" them (if that makes any sense). Vision therapy has made a world of difference.

I can go some days and feel OK and then it hits me. It's such a strange feeling and so hard to describe - if you've ever been through this you'll know what I mean.

I'm better now, but not 100%. That weird, floating feeling is always kind of there, but worse at times.

This has also affected me



CATHY STRUGGLED IN HER JOB AS A WEIGHT WATCHERS SECRETARY AFTER HER ATTACK.

cognitively. My memory plays bizarre tricks on me. When I really have to focus it makes it worse. I often feel foggy, and, oh, the fatigue!

I'm a secretary at Weight Watchers. I had just gotten this position when the vestibular issues hit me. I continue to work, but sometimes I know that my abilities are affected.

My family has been very supportive and understanding. I am not one to ask for help if I can do something myself. They would tell you I am hard-headed and a bulldog, pushing through, despite it all! I am always grateful because I know no matter how bad something may be, it can always be worse.

Nothing in my life has ever laid me so low. I don't know if I'll ever be over this, but I know that I can deal with it. I was

a sinking ship, and VEDA was my life-preserver. Thank God for Cassey (VEDA's Patient Support Coordinator), who held my hand (virtually) and reassured me that I was not alone. If Cassey hadn't been there to connect me to Dr. Morrisette, I don't know what I would have done.

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LIFE HAS EVER  
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To those of you who are still struggling to find a good doctor, don't give up! And don't let it get you down. Continue to live your life, even if sometimes the activities you used to take for granted make you uncomfortable.

This is the craziest thing that has ever happened to me, and sometimes I have to remind myself that I'm NOT CRAZY!

Thank you to Cassey and VEDA for being there when I was at the end of my rope and did not know what to do or where to go!



"It helped me to write about my experiences with healing - my symptoms, frustrations, insights, all of it. When I reread what I wrote, I got a better perspective about my progress or the pitfalls I kept repeating." - Sue Hickey, Finding Balance.

## A Different Way to Give

Your donations mean that a patient who is scared and alone can get connected to qualified vestibular specialists and essential support networks.

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For more information, contact VEDA at 503.294.9085 or [veda@vestibular.org](mailto:veda@vestibular.org).



# Jumpstart Your Attitude

By Sherron Laurrell

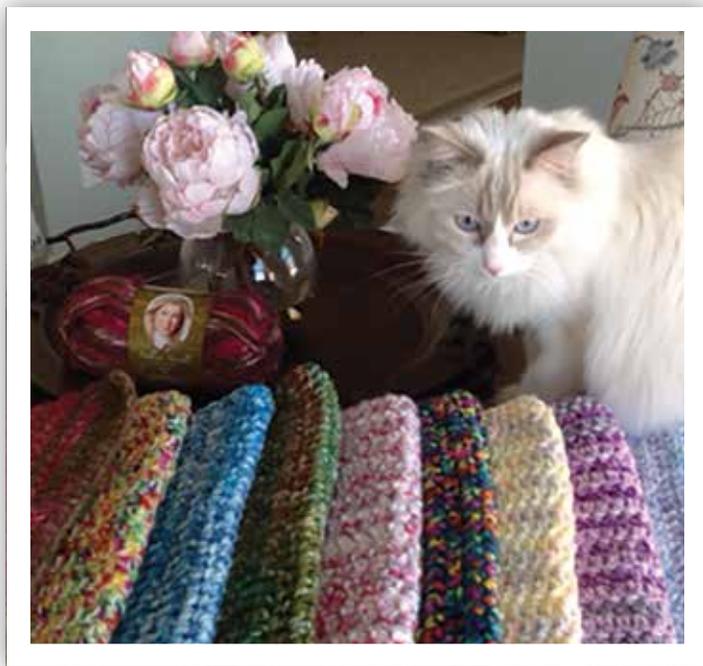
I have to admit, it annoys the daylights out of me when I hear someone say “you need to adjust your attitude and everything will be better.” They usually say it in a sing song voice with a slightly condescending smile on their face. Maddening. Always well-intended. Usually ignored.

But my feelings on this advice have evolved over the past few years. Now I am the one suggesting it.

In May 2013, I woke up dizzy. A sense that the floor was moving and furniture around me was vibrating. I thought I must be sick. Maybe I had eaten something bad. I held on to the walls as I made my way around my house, certain it would clear up soon. It didn't.

It took seven months to find a doctor who could diagnose (unilateral vestibular hypofunction) and help me, someone who understood how scared I was and could prescribe vestibular rehabilitation therapy (VRT). It took another year before I was able to fully accept that I had a chronic vestibular disorder that would keep me dizzy for life.

My whole world changed during that time. I was always nauseated and lost 45 pounds. I stopped doing social things. I dropped out of all my community activities, except my



**SPENCER INSPECTING A BATCH OF CROCHETED MATS FOR SHELTER CATS.**

writers group. Writing has always been a kind of therapy for me. I had trouble committing to events of any kind because I never knew how I would feel. It was a miserable, frightening time.

My home became my safe space. I knew my world was getting smaller and smaller. I knew I had to do something to create a new “normal” for myself. And in the end, I learned, it came down to attitude.

A member my writers group suggested that I write an article about how I had reinvented my life in light of this chronic and disruptive disorder. My hope is that this story helps someone else who is struggling through the early days of a “chronic illness.” In my definition, a “chronic illness” is very different from an acute illness like a heart attack or broken leg or a life threatening illness like cancer. Chronic illnesses, for the most part, are not life threatening but they are life altering. It is my hope that this story will spark some ideas to help those who are in need of a reboot.

Gerry Connolly was an inspiration for me to look at how I was approaching my illness. Gerry was working at his desk in May 2013, when his wife Nancy said “Your hand is shaking. Why is your hand shaking?” Gerry didn't know. Already managing a bout with prostate cancer and a chronic heart condition, he didn't even notice that his right hand had begun shaking involuntarily. It took several doctors' visits to get a neurologist's diagnosis of “essential tremor,” a chronic neurological disorder that progresses over time.

Anyone who knows Gerry knows that he was blessed at birth with a calm, “glass half full” perspective on life. Another chronic disorder was an additional burden to manage but it wasn't going to slow him down. He is very active



**SHERRON WITH HER CAT, SPENCER, AND “NIECE DOG,” RIVER.**

and they travel a lot. Gerry's constant shaking hand, his chronic heart disorder, the cancer problem (which is in remission) require attention, monitoring and follow up. He is grateful that the shaking hand is not his primary hand. All of this affects his life, but it doesn't slow him down. He has adjusted. He attributes a great deal of his coping capabilities to his positive, calm outlook, his wife, his family, and keeping busy.

So here you have two different people who both discovered that they would have to live with, learn about and work around chronic illnesses. One person withdrew and paused for two years. The other figured it out and moved forward more quickly. Why?

I believe that it was our attitudes. I am a worrier. He is not. I tend to live in the "what if" corners of life. He does not. Some would say he is extra fortunate that he has a spouse. I am not married. What I believe really matters is that one has friends and family they can depend on, not necessarily a live-in partner. Heaven knows there are lots of partners who are not empathic or attentive to a chronically ill person's needs.

Over and over again over the past four years I have thanked my siblings and friends. I would have been lost without their relentless support, even when I avoided them.

And I finally figured out how to do things that brought



**GERRY AND NANCY SNORKELING IN COZUMEL, MEXICO**

normalness back into my world. I can't shop in grocery stores or the mall anymore because I get overwhelmed with "visual vertigo." So I use a grocery store "shop at home" service and the online services of my favorite department store. I love to write, so now I volunteer with VEDA to write feature articles for their newsletter, *On the Level*. In that role, I interview dizzy people and tell their stories to educate and inspire other people who suffer with the same life-altering conditions. I love cats, so I crochet mats for shelter cats, and I am an administrator for an online Facebook auction that raises money to help pets in need. I joined the local pool and I walk back and forth to help with my balance and arthritic joints. I am in my fourth year of yoga lessons twice a week, which helps me with my balance and anxiety. I have a renewed lease on life. It surely is different than my "old" life, but it is full and satisfying.

I wish I had my friend Gerry's calm, adaptive attitude. I don't. But I have evolved into believing that your attitude directs your life. I hope that you will be able to adjust your attitude when adversity strikes and relaunch your life as you move forward.

Best of luck!



**GERRY AND NANCY CONNOLLY ENJOYING A PUB BREW IN BELFAST, IRELAND.**

# Evaluating Your Vestibulo-Ocular Reflex (VOR)

By Cammy Bahner, Au.D., CCC-A



CAMMY BAHNER, AU.D., CCC-A

The vestibular-ocular reflex, commonly referred to as VOR, is an important part of our balance system. The primary function of the VOR is to help us maintain visual acuity during motion by moving the eyes in the direction opposite to the head. For example, when the head moves to the left, the eyes move to the right. When walking, running, or turning the head, the VOR helps us

to stabilize images and maintain a clear view of the world. When the VOR is not functioning well on one or both sides due to a vestibular impairment, it may result in a number of different symptoms, such as difficulty reading signs while walking, dizziness, blurred vision with head movement, and a sense of imbalance. The human VOR functions over a very wide range of head movements, from very slow movements, such as those made while reading, to very quick movements, such as head turns made when changing lanes while driving. We will explore two of the more common tests that your care providers may use to evaluate various aspects of your VOR.

The caloric test is the most common test for evaluating your VOR. During caloric testing, your eye movements will be monitored while your vestibular system is stimulated with cool air or water. This is quite simply accomplished by utilizing a set of goggles that you will wear over your eyes. The cameras that are imbedded into goggles will allow the examiner to monitor and measure your eye movements. The examiner will put warm or cool air (or water) directly into one ear at a time, during which you may experience a “spinning” or “floating” sensation. The examiner will perform this procedure a total of four times, each ear with warm irrigation and each ear with cool irrigation, to evaluate your VOR and to determine if your inner ear balance organs are functioning equally when compared to each other. The caloric test allows the examiner to see how your VOR functions for very slow head movements. The entire procedure takes approximately 20 minutes to complete.

Video Head Impulse Test (vHIT) is another common test used to evaluate your VOR. Once again, you will wear a lightweight goggle with a camera and motion sensors built in. You will be instructed to focus on a target in front of you while the examiner will assist you in making small, quick, random head movements, called impulses. When your head moves to the left your eyes should move to the right. vHIT measures and analyzes this reflexive eye movement and provides the examiner with immediate information about whether your symptom of “dizziness” is caused by one (or both) inner ear vestibular systems. This test allows the examiner to see how your VOR functions for much quicker head movements. The entire process takes less than 10 minutes.

Since vHIT can be performed in much less time, many researchers and care providers have questioned whether or not we really need to include both calorics and vHIT tests in our assessment of the VOR. Some have proposed that we do not need calorics anymore and that vHIT is an alternative and superior tool to the caloric test, which has a long-standing reputation as the gold standard test for assessing the VOR.

vHIT is an exciting and relatively new tool for assessment of the vestibular system with certain advantages over caloric testing. For example, the amount of time to complete an evaluation is significantly reduced for vHIT. vHIT is also an effective test for evaluation of the VOR in the pediatric population and may be able to provide information when caloric testing is unable to be used. Yet another distinct advantage



CHILD WITH VHIT

of vHIT testing is that it stimulates the VOR using a more physiological high frequency stimulus than caloric testing. In spite of these advantages, caloric testing has been shown to have a high degree of sensitivity and specificity in the evaluation of unilateral vestibulopathy.

Advantages and disadvantages aside, the overwhelming conclusion is that calorics and vHIT do not provide the examiner with redundant information about your vestibular system but, instead, are complementary to one another. Although both tests do assess the VOR, they stimulate different frequencies of this reflex. Both calorics and vHIT are necessary parts of the vestibular assessment battery and both will ultimately help your care provider to better understand your individual vestibular system to make a good diagnosis and treatment plan.

Brought to you by Micromedical Technologies.



WOMAN WITH VIDEO GOGGLES

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# BALANCE AWARENESS WEEK 2017

## FLAT FLAMINGO PHOTO CONTEST WINNERS

## FLOCK YOUR FRIENDS

1ST PLACE



Fyzical Therapy & Balance Center  
North Andover

Together we flooded the Internet with flamingos!

3RD PLACE



Mrs. Robinson

2ND PLACE



Body in Balance

4TH PLACE



Deb Miller

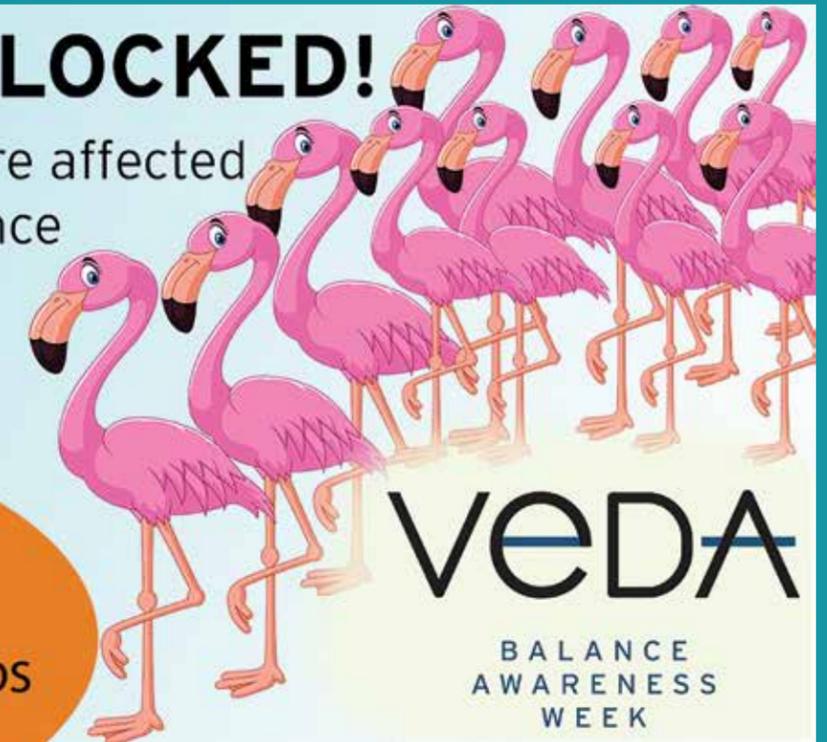
5TH PLACE



Sheldon Sugar

**You've been FLOCKED!**

64 million Americans are affected by inner ear/brain balance disorders, vertigo, and other vestibular issues.



When you're flocked, DONATE \$5 at [vestibular.org/baw](http://vestibular.org/baw) And then FLOCK YOUR FRIENDS

To raise awareness about balance and the challenge of living with a vestibular disorder, people flocked their friends' social media pages by posting this informational flamingo meme, and asking them to share it with others.

TOTAL RAISED: >\$50,000

55 PEOPLE CREATED PERSONAL CAMPAIGN PAGES TO SHARE THEIR VESTIBULAR STORY AND ASK FRIENDS AND FAMILY FOR SUPPORT.

Balance Awareness Week took place amidst a spate of natural disasters - fires, floods and hurricanes. While we fell short of our fundraising goal, we know that part of the short-fall was funds being diverted to these horrible events. We honor the thoughtfulness of our donors, and hope that you will continue to support VEDA through your year-end giving.

# LIFE REBALANCED

# TOP BAW SOCIAL MEDIA POSTS

Vision plays a significant role in helping us maintain our balance. People with vestibular dysfunction may experience visual problems, such as light sensitivity and difficulty focusing on an object. Prolonged computer use and reading are often challenging, and overuse of this system can provoke vestibular symptoms, such as dizziness and fatigue.

REACH: 18,451



Join VEDA to raise awareness about the vestibular system, and problems that can result when it is damaged, by sharing our flier, "Vestibular What?"

REACH: 43,703

**Vestibular What?**  
DISCOVER LIFE REBALANCED

The vestibular system includes the parts of the inner ear and brain that process sensory information involved with balance. Vestibular disorders can be caused by disease, injury, poisoning by drugs or chemicals, autoimmune causes, traumatic brain injury, or aging. Many vestibular disorders occur from unexplained causes.

Symptoms of vestibular disorders include dizziness, vertigo (a spinning sensation), imbalance, tinnitus (ringing in the ears), fatigue, jumping vision, nausea/vomiting, hearing loss, anxiety, and cognitive difficulties.

Vestibular disorders are difficult to diagnose. It is common for a patient to consult 4 or more physicians over a period several years before receiving an accurate diagnosis. Over 35% of US adults aged 40 years and older (69 million Americans) have had a vestibular dysfunction at some point in their lives.

There is no "cure" for most vestibular disorders. They may be treated with medication, physical therapy, lifestyle changes (e.g. diet, exercise), surgery, or positional maneuvers. In most cases, patients must adapt to a host of life-altering limitations.

Vestibular disorders affect us physically and psychologically, causing anxiety, depression, social isolation, and a loss of one's sense of self. Please share to raise awareness about the invisible impacts of chronic dizziness and imbalance.

REACH: 18,228



It's hard to think clearly when your brain is spending all of its cognitive energy keeping you upright. Problems with memory, concentration, and "brain fog" are common for people with vestibular deficits.

REACH: 29,941



# Pediatric Nurse Discovers a Life Rebalanced

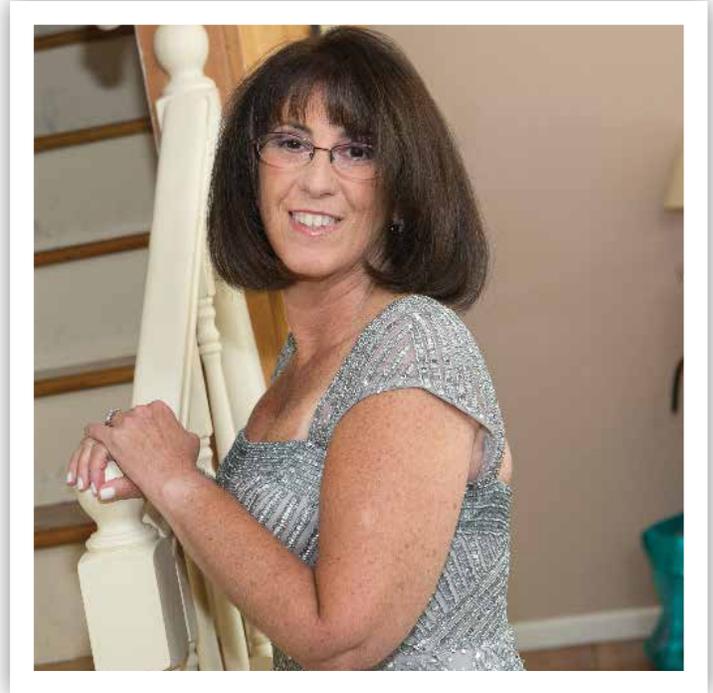
By Louise Geib, M.Ed., VEDA Board President

Vicki Appel, a pediatric nurse, went for a relaxing massage and ended up leaving in an ambulance, experiencing severe vertigo and vomiting. Little did she know that 10 years later she would be living her life with chronic and disabling vestibular dysfunction, but without a clear diagnosis.

"I have seen 7 doctors, had acupuncture, taken holistic herbs, and tried vestibular rehabilitation therapy. I have been told to "just live with it," and I've been yelled at by a medical professional for letting others make money off my search for answers," Vicki says.

"Vicki's story is not unusual for vestibular patients," says Cynthia Ryan, executive director of the Vestibular Disorders Association (VEDA). "During Balance Awareness Week, September 18-24, we extended our efforts to raise awareness and financial resources to further our mission - empowering patients to find hope and help along their often difficult and frustrating journey to get a diagnosis, and supporting them whether they do or not."

Vicki eventually found a neurologist who listened to her complaints and sent her for more testing to rule out other potential causes of her dizziness. The doctor helped her understand that her tests showed she has vestibular abnormalities, but that she could not be pigeonholed into one diagnosis. He was honest with her about the unknowns of her condition and her prognosis. Just being heard and respected allowed Vicki to begin to move forward in her life as a vestibular patient.



VEDA's motto is Life Rebalanced. For Vicki, living this out has meant simplifying her life by cutting down on her work, only driving locally, and using a shopping cart for stability at the grocery store. In addition, she must avoid noisy and crowded environments because there is too much stimulation, which triggers her vestibular symptoms.

"Don't get me wrong. I have my days where I want to punch a pillow, scream and cry out of frustration since I feel like I have no control over my body and it is playing a horrible trick on me. I have no say in when or where my next vestibular attack will come, but when it does happen I've learned to ride it out using time, rest, and Valium, which helps quiet my symptoms."

"I am not going to stop living my life but am working around the obstacles. I'm always hopeful that more research, new tests, therapy or medicine will come along. Until that day comes, this is my new "normal" and I own it."

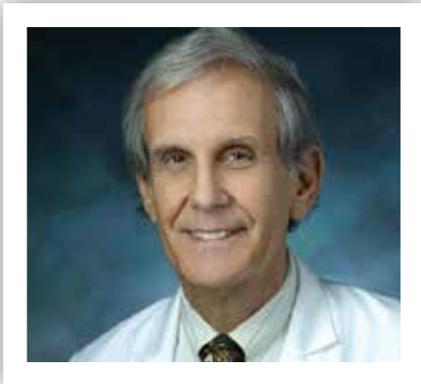
VEDA celebrates the courage and determination of Vicki and millions of people like her suffering from vestibular disorders.

**"I AM NOT GOING TO  
STOP LIVING MY LIFE BUT  
AM WORKING AROUND  
THE OBSTACLES."**

# 4TH ANNUAL CHAMPION OF VESTIBULAR MEDICINE AWARDS

We honor these champions of vestibular medicine, who have made significant contributions toward reducing diagnosis times and improving treatment effectiveness for vestibular patients.

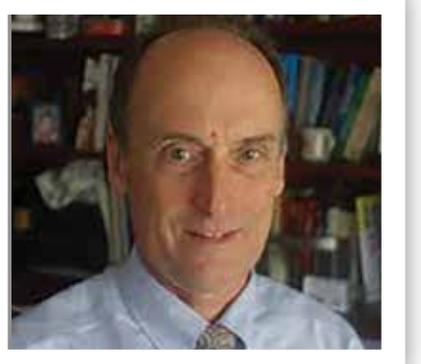
## DAVID ZEE, MD - JOHNS HOPKINS UNIVERSITY



Dr. Zee is a clinician who has diagnosed and treated vestibular patients for nearly five decades, a scientist who has done groundbreaking research in how the brain reacts, compensates and recovers from vestibular disorders, and a teacher who has mentored and educated clinicians and scientists around the world. He is an internationally-recognized leader whose name is virtually synonymous with the study and bedside evaluation of eye movements. He has more than 450 publications, and was co-author of the definitive textbook on eye movement disorders in neurological disease. Recently he discovered how magnetic fields of MRI machines stimulate the inner ear and cause vertigo and nystagmus. His scholarship and teaching have exerted a major influence in neurology, neuroscience, ophthalmology and otolaryngology. He has taught "Masters" courses all over the world, and recently received a National Health

Information Award for educational videotapes for patients on dizziness.

## RICHARD CLENDANIEL, PHD - DUKE UNIVERSITY



Dr. Clendaniel is a scientist, educator, clinician, and mentor for Duke University's physical therapy doctoral program. His training and scientific practice have made him a recognized expert in the rehabilitation of individuals with vestibular disorders. He is one of the founding directors of Emory University's Vestibular Rehabilitation: A Competency Based Course (formerly known as the Herdman Vestibular Course), which is recognized as the gold standard in professional education for the evaluation and treatment of vestibular disorders. He has contributed significant observations and insights to the scholarly literature of vestibular medicine, notably, the development of guidelines for vestibular rehabilitation, and multiple important investigations into the role and behavior of the visual system in vestibular dysfunction.

## JEFFREY STAAB, MD, MS - MAYO CLINIC



Dr. Staab's research is in the area of psychosomatic and behavioral medicine. He was the lead investigator and principal proponent in a series of clinical studies examining factors associated with unexplained chronic dizziness. Dr. Staab's work in dizziness has helped to define interactions between neurologic and behavioral variables that trigger and sustain persistent dizziness. He and his colleagues described a syndrome recently termed Persistent Postural-Perceptual Dizziness, or PPPD, which afflicts many patients in the aftermath of acute vertigo or imbalance. His work has shown that this is an identifiable syndrome that is NOT a psychiatric disorder, and that it is highly associated with anxiety, vestibular migraines, and other disorders of the vestibular

system. Dr. Staab led the first studies of medications to treat PPPD, and is currently looking for a biomarker for this disorder.

# Using Rapid Eye Movements to Substitute for Loss of Vestibular Function

By Kamran Barin, PhD (VEDA Board Member) and Cynthia Ryan, MBA (VEDA Executive Director)



KAMRAN BARIN, PHD

Patients with total loss of vestibular function suffer from blurry vision during head movements. It has been assumed that these patients use other mechanisms to substitute for the loss of vestibular function. A recent study suggests that rapid movements called saccades may be one such mechanism.

tests (HIMP), the target was fixed on the wall and in other tests (SHIMP), the target moved with the head. Patients with no vestibular function cannot keep their eyes on the target during HIMP and have to make a saccade (rapid eye movement) to re-fixate on the target. The same patients usually have no problem keeping their eyes on the target during SHIMP because the target moves with the head/eyes.

The researchers noticed that some patients seem to anticipate the loss of target during rapid head movements and make a corrective saccade while the head is still moving. This will reduce or eliminate the distance of the eyes from the target and help improve visual acuity. In SHIMP, such a correction is counterproductive, and the patients who use that method must make a secondary correction to get to the target. The authors suggest that the patients who use this form of substitution seem to suffer less from blurry vision during head movements.

## BACKGROUND

In the normal Head Impulse Test (HIT), the clinician turns the patient's head abruptly and unpredictably and observes the instantaneous compensatory eye movement response as the patient tries to maintain their focus on a fixed point. During each head impulse, the eye movement response of a healthy subject will compensate for head turn and gaze will stay fixed on the target. However, the eyes of a patient without vestibular function will move with the head so that the patient has to make a corrective saccade either during or after each head impulse in order to return their gaze to the target.

## METHODS

To test the idea, eight patients with severe bilateral vestibular hypofunction (BVL) were tested. All patients were given the Dizziness Handicap Inventory and questioned about oscillopsia (jumping vision) during abrupt head movements. Two paradigms of video head impulse testing of the horizontal vestibule-ocular reflex (VOR) were used: (1) the classical head impulse paradigm (focusing on an earth-fixed target, called HIMPs) and (2) the new complementary test paradigm (focusing on a head-fixed target, called SHIMPs).

## RESULTS

The patients were asked to look at a target while the clinician moved the head briskly to the right or left. In some

## CONCLUSION

The pattern of covert saccades during SHIMPs appears to be related to the reduction of oscillopsia during abrupt head movements. BVL patients who did not report oscillopsia showed this unusual saccadic (eye movement) pattern, whereas BVL patients who reported oscillopsia did not show this pattern. This inappropriate covert SHIMPs saccade may be an indicator of how some patients with vestibular loss have learned to trigger covert saccades during head movements in everyday life.

## STUDY LIMITATIONS

While interesting and worthy, this study was very small; a larger study would be needed to confirm its results and clarify some issues. For example, it is not clear how the patients acquired this corrective saccade strategy. Down the road, there may be therapies to facilitate the substitution strategy, but it is too early to say.

## REFERENCE

De Waele C, Shen Q, Magnani C, Curthoys IS. A Novel Saccadic Strategy Revealed by Suppression Head Impulse Testing of Patients with Bilateral Vestibular Loss. *Frontiers in Neurology*. 2017;8:419.

# Patient + Healthcare Provider = Super Volunteer

By Amy Downing

Hello everyone. My name is Amy. I was diagnosed with right-sided Meniere's disease 23 years ago.

I will never forget answering the phone and not being able to discriminate the person's voice on the other end. I will also never forget the endless vertigo attacks that followed. These led to a series of tests, six emergency room visits, and five physicians over four years to be properly diagnosed.

I ran five marathons with Meniere's disease, popping up to 14 mg. of Valium as I ran. Crazy, I know.

In 2006, I had a gentamycin injection in my right ear. By 2009 I was diagnosed with bilateral Meniere's disease.

In December 2014, I had a routine flu shot and ended up with Guillain Barre, a disorder in which the body's immune system attacks part of the peripheral nervous system. I had paralysis, peripheral neuropathy in both my hands and feet, lost reflexes, and a hard time walking, not to mention working. It took me 9 months to recover 85%.

In 2015 I did a free dive 25 feet deep with my children in Kona, Hawaii. Unfortunately I ended up with a left perilymphatic fistula that required surgery. It wasn't until after I developed profound hearing loss in my left ear that the ENT was able to diagnose it. I now wear bilateral hearing



AMY AND HER HUSBAND STILL FIND WAYS TO ENJOY LIFE. aids daily.

To top it all off, I was diagnosed with PPPD (Persistent Postural-Perceptual Dizziness) in June 2017 at the Mayo Clinic in Rochester, MN. I currently am being treated at the Mayo Clinic, and feel very blessed to be a part of the wonderful Mayo Clinic system.

I have been a physical therapist for the past 27 years. In 2011, I opened up my own vestibular clinic in Missoula, MT after being told by my ENT that there was no further treatment for me other than surgery or more shots in my ear. I guess that was the best thing I could have heard because it motivated me to find other solutions.

I am now a vestibular physical therapy specialist and employ four other vestibular physical therapists. With the support of my four children and wonderful husband, I am able to help others on a daily basis understand their vestibular problems and provide treatment to those in need.

I get it. I understand drop attacks, profound hearing loss, losing a part of your life only to wake up and do it all over again. I feel compassion for all those with vestibular disorders as I live with it every day with you.



AMY'S PARENTS AND CHILDREN ARE VERY SUPPORTIVE.

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

VEDA is entirely supported by donations and membership gifts. Your donation helps VEDA provide information on vestibular disorders to millions of people every year.

Thank you!

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

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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.**

I found VEDA after researching organizations that would offer accurate up-to-date information for my patients. I am on the Balance Awareness Week Committee for VEDA because I believe in offering help and hope to people who are struggling with vestibular disorders. My goal is to open up a balance center that offers a physician, audiologist, and physical therapists to coordinate your care. I feel it is a godsend to announce that Dr. Neil Shepard, PhD will be

consulting with patients on a part-time basis at our clinic.

You never know what your future holds. Therefore, I must say: never give up. Remember to continue to reach out to VEDA and offer your support. It does make a difference, and so do you.

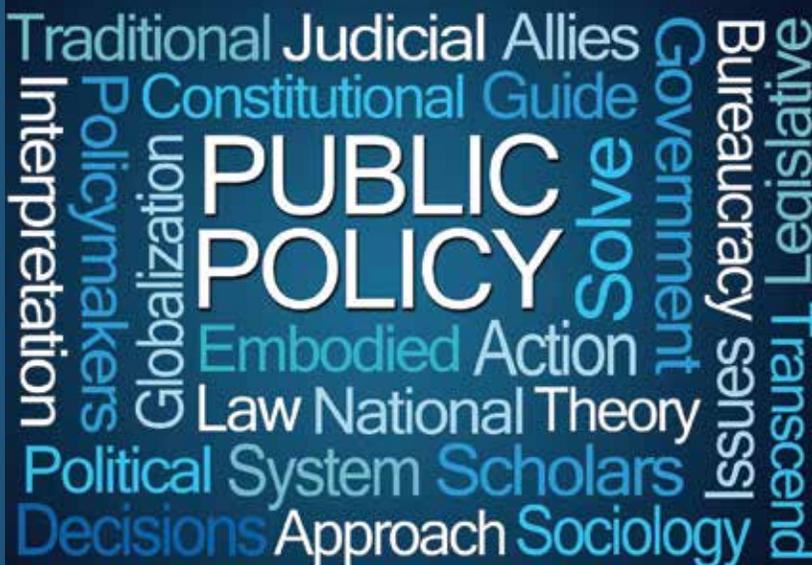
## VOLUNTEER WITH VEDA

You can support the vestibular community by volunteering your time and skills with VEDA.

VEDA is currently recruiting people to join our newly formed legislative advocacy committee.

Volunteer applications can be found at:

[vestibular.org/volunteer](http://vestibular.org/volunteer)



# Honey Paprika Glazed Sweet Potatoes

A low-sodium diet can help some vestibular patients, particularly those with Meniere's disease, vestibular migraine, and secondary endolymphatic hydrops, control their symptoms.

This low-sodium recipe is contributed by Sandy Egge, MSACN and VEDA Board Member.

2 large sweet potatoes (yams work too)  
2 tablespoons wild honey  
1.5 teaspoons smoked paprika  
1/2 teaspoon garlic powder  
1/2 teaspoon ground cumin  
A squeeze of fresh lime  
Unsalted butter  
A sprinkle of fresh chopped flat leaf parsley  
Pomegranate seeds

Wash and trim ends off of sweet potatoes. You may peel them if you prefer.

Cut sweet potatoes in half across the middle, then cut the halves into quarters or smaller.

Bring a pot of water to boil and put the cut sweet potatoes into the water. Turn heat down to medium and let sweet potatoes cook until they can just be pierced with a fork. (It's best if they are not too soft at this point.) Remove sweet potatoes from the water and let cool.

In a small bowl, combine the honey, paprika, garlic powder, cumin and fresh squeezed lime juice. Mix to blend and set aside.

Bring a skillet to medium heat and add approximately 1 tablespoon of unsalted butter. As butter melts and becomes evenly distributed around the skillet, add cooled sweet potatoes to the skillet. Cook sweet potatoes, turning so that they brown evenly and finish cooking until they are fork-tender. Add the honey glaze combination and gently stir into the sweet potatoes to coat. Turn heat up to medium-high, let honey glaze bubble and get sticky while turning sweet potatoes often (about 3-4 minutes), then remove from heat.

Put sweet potatoes in a serving bowl, garnish with chopped parsley and pomegranate seeds. Enjoy!



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