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My vertigo journey began like so many others: an abrupt introduction waking me early one morning. I was only thirty-four and until that day I had never really experienced vertigo besides common “car sickness.” Headaches have been an inconvenient part of my life since puberty, but they almost never incapacitated me. Other than frequent headaches I was healthy and active. At the time, I had recently bought a small home for myself and my dog, “Autumn.” Meanwhile, I was working on finally completing my bachelor’s degree. I had a fantastic close circle of friends, I traveled regularly and enjoyed a happy life. Then, all that changed.

The previous year my grandmother, who I adored dearly, died after contracting pneumonia. Then the insurance office I managed closed. I had just committed to a mortgage, so I was financially stressed after having been quite stable and responsible. Six months later I received another painful phone call: my father had died unexpectedly. Until that moment I had retained my typical optimism, but his death hurt me so deeply that I slipped into months of depression. I talk of these things because in retrospect I realize the extreme stresses my body was dealing with at the time of my first terrifying vertigo episode.

As other “dizzies” might tell you, nothing has been the same since that day. When the vertigo did not stop I went to a doctor. This became my first misdiagnosis: Benign Paroxysmal Positional Vertigo (BPPV). The doctor prescribed meclizine for a few weeks and said it would go away before I finished the prescription. The meclizine did help, but the vertigo came back a few weeks later. At this point, I entered the familiar pattern of trying different doctors and specialists trying to find someone who would say to me, “Yes, I know what is going on, and there is a cure.” But that never happened.

Years passed with my symptoms increasing from the initial episodes of “just” vertigo to a plethora of somehow worse problems,
such as extreme fatigue, all-day headaches and difficulty driving, concentrating, and reading. I had to return to work because I was out of money, but I was at a much lower paying job and I hadn’t completed my degree. My symptoms were starting to control my life. I began to avoid things for fear of that awful vertigo feeling, publicly vomiting, or causing an accident. I was struggling with my work and starting to make mistakes. Sometimes I had to be driven home. Once, I was in the bathroom at work, and while blowing my nose I fell head-first into the mirror. When I drove, my concentration was so impaired that I had to regularly say to myself “green means go” at traffic lights.

About three years from my first episode I became aware that my life had completely changed because of my vertigo. I was no longer active, optimistic, outgoing, or dynamic. I had become a homebody who could barely stay awake. I began to lose my friends, my identity, my self-esteem, my joy, indeed, my life. I gained significant weight and became increasingly depressed.

I went to an ENT that year and he was the first person who understood me. He empathized with what I was going through and told me, “We can fix this. You do not have to live like this.” It was the most comforting moment I’d had in years.

My ENT sent me to vestibular rehabilitation therapy, which was challenging and made me even more tired and nauseous but did seem to help. Even though I mostly kept up with the daily exercises, the vertigo and all the other symptoms worsened. Eventually another doctor asked why I had not seen a neurologist yet. This is when I started to really get help and develop an understanding of what was happening. I was eventually diagnosed with vestibular migraine (VM) and was told to treat the migraine not the vertigo.

This diagnosis was bittersweet. I had a diagnosis and an improvement plan, but it put me in the same uncertain condition as millions of migraine sufferers. You are never really cured, you just learn to manage it the best you can. You adapt.

That’s pretty much what I do today, and what I expect the rest of my life will look like. I have tried a dozen different pharmaceuticals: prednisone, nerve blocks, Topamax, Maxalt, meclizine, Effexor, and metoprolol among them. I have tried natural therapies: chiropractic, massage, acupuncture, nutrition management, yoga, meditation, cleanses and a migraine diet. I got a second opinion confirming that I do, indeed, have VM. I have been told it’s my diet, stress and hormones, and that I

ABOVE: GENTLE YOGA IS ONE OF RACHEL’S COPING STRATEGIES
I have serious cervical spine problems. I have also been told that it’s definitely NOT hormones. This is where I am, where so many of us are - navigating the thousand possibilities, weeding out the bad ones and nurturing the ones that seem to lessen symptoms. For me, this is the fate I’ve had to eventually accept. There is no cure. I am never going to get rid of this thing. I am not going to be the old Rachel. I will always be this new version of myself who must carefully and constantly monitor my lifestyle and warning signs to keep my symptoms in check.

There is a happy ending though. Because I was forced to stop working, I returned to college and graduated Summa Cum Laude. I am currently completing my master’s degree and working towards becoming a grief counselor. As my symptoms improved, I was able to start a support group for us dizzies (Lehigh Valley Vestibular Support & Advocacy) and I became a VeDA Ambassador. I am very excited to help others and spread knowledge about this crippling disorder that is more common than publicly recognized.

I cannot tell you what will help you with your specific condition and symptoms, but I can advise you to understand the central role that diet, exercise, and stress play in our overall health, and certainly for migraine. More than this, I want to tell you to enjoy today. Enjoy the present moment in every way you can. So much of life is perspective, SO MUCH. Letting go of some things, accepting other things, being open to new ideas and change, connecting with others and with nature - these are the things that have meaning, that inspire awe, and that allow us to not seek some uncertain future but to be at peace and have joy today. There is always today, this moment. You, too, can adapt to living with a vestibular disorder.

ABOVE: RACHEL (PICTURED AT A CATHEDRAL IN EASTERN EUROPE) REFUSES TO LET HER VESTIBULAR MIGRAINE KEEP HER FROM TRAVELING. SHE’S LEARNED HOW TO PREPARE AND ADAPT TO CONTINUE THIS PASSION.
Virtual Reality - Real Results

By Michelle Eyres

Peripheral vestibular loss, a vestibular condition originating in the middle or inner ear, is the most common cause of severe vertigo and/or nausea. Vertigo and nausea are often accompanied by nystagmus, which is an involuntary eye movement toward the unaffected ear. These attacks cause fear, panic, and anxiety during or in-between episodes, which results in absences from work and a cost to the public at large.

Treatment with medication is only recommended in the acute stage of an attack and only for a short period of time. To reduce vertigo, many patients engage in vestibular rehabilitation therapy (VRT). VRT helps promote natural recovery of the vestibular system through exercises that help a patient’s system adapt and habituate. VRT uses visual and auditory feedback combined with exercises that involve the upper body, head and eyes. VRT is non-invasive, safe, effective, and can be used on patients in the acute or chronic stages. Unfortunately, compliance with VRT is often poor. Patients are instructed to complete the exercises for 20-40 minutes per day. The exercises can be repetitive and, let’s be honest, boring. In addition, patients don’t get feedback on whether they are doing the exercises correctly.

For the non-gamers, virtual reality (VR) refers to a virtual environment generated on a screen or into a head mounted (goggles) device. You can use sensors in your hands or under your feet to “touch” items you see in the virtual environment. Treatment using VR has been found to be effective in helping patients suffering from anxiety, schizophrenia, cognitive impairment, partial paralysis caused by stroke, and rehabilitation in pediatric patients suffering from cerebral palsy.

VR devices are not new to VRT, but before now have required the use of expensive equipment. Other studies have looked at commercially available systems such as the Nintendo Balance Board (force plate technology) or Xbox 360 Kinect (motion sensor dependent device). **VRT that is motivating and enjoyable results in better compliance by patients.** This study looked at a hybrid VR device where commercially available motion sensors, force plate technology and a display are combined with exercises and provide feedback in the VR environment. The hypothesis is that “by evoking a wider range of movements from the patient, hybrid VR systems might have a better effect on postural control and vertigo.” Therefore, this study “evaluates the effectiveness of a low-cost hybrid VR based on a vestibular rehabilitation program.”

50 patients enrolled in this study at the Medical University of Lodz, Norbert Barlicki Memorial Teaching Hospital, Lodz, Poland. Half of the patients were in a control group that used static posturography with visual
feedback; the other half of the patients used hybrid VR training. To be included in this study, patients had to have:

1. Persistent vertigo and disequilibrium with unsatisfactory spontaneous compensation at least two months post-onset; and

2. Unilateral peripheral vestibular impairment confirmed by videonystagmography (VNG).

In other words, patients with vertigo and imbalance for more than two months with no self-correction or self-healing and VNG-confirmed impairment in only one ear were admitted to the study. The hybrid VR group had 14 women and 11 men with an average age of 46 years. The control group had 13 women and 12 men with an average age of 45 years.

The hybrid VR group received ten training sessions of 30 minutes each for two weeks. This training consisted of exercises on a force plate with an upper body motion sensor and a flat screen display. Patients were asked to perform exercises that coordinated upper body movements while still maintaining their center of gravity within a certain range. One of the tasks or games that was played was called “Meteorites.” A marker on the screen displayed the patient’s center of gravity. By shifting their center of gravity, patients targeted meteorites while avoiding satellites. The goal was to eliminate the meteorites. Each meteorite destroyed earned the patient a point. Each satellite hit lost them a point. There were many difficulty levels, and as patients progressed in difficulty the speed and number of meteorites increased.

The second game the hybrid VR group played involved moving hats to hangers and matching the colors. By raising their arms patients could move the hats. Center of gravity was projected as a green circle.

If you exited the circle the color changed to red and the hat returned to its original position so patients had to try again. Advancing levels narrowed the green circle and extended how far patients had to reach to put the hat on the hanger.

The control group received ten sessions of static posturography training with visual feedback over a two week period. Patients were required to move their center of gravity toward a point on the screen. Each session lasted 25 minutes.

Throughout the study, all participants were supervised by physical therapists. Participants were also shown at-home exercises and asked to complete these three times per day. Each group was examined before and one month after the study by posturographic assessment on a static platform. Participants also filled in the Vertigo Syndrome Scale-Short Form, which is a self-assessment addressing the frequency and severity of vertigo symptoms.

All patients completed the full program and no side effects were reported. The hybrid VR group showed a statistically significant improvement in eyes closed center of gravity measurements. The authors of the study believe this is because VR modifies visual input in the same way performing the exercises with closed eyes does. The hybrid VR group showed a statistically significant improvement in their self-assessment scores.

More research needs to be done, but this shows promise in the decreased cost of the equipment needed for VR VRT, and the greater improvement in the hybrid VR participants.

Theater Adapts To Be “Sensory-Friendly”

By Hunter Gullickson & Jim Hainlen

Going to see a live production in a theater is one of those “bucket list” items. Whether you like musicals, Shakespeare, comedies, dance, opera or symphony, there is something so special about being in a theater, in the dark, sharing the feelings a live production can evoke.

There is a growing movement afoot in the theater community to make this experience available to everyone, regardless of disability. Hunter Gullickson, Access Coordinator for the Guthrie Theater in Minneapolis, Minnesota, has been researching this topic, and it has long been his goal to have a “sensory friendly” production.

“This idea came about because of a theater patron, Jim Hainlen, who had been writing us letters about his vestibular issues,” said Hunter. Sue Kotila, Front of House Coordinator, said, “Jim was instrumental” in bringing this sensory-friendly production to life.”

Jim was invited to the theater for a conversation around how his vestibular issues make theater attendance difficult. There are large windows and the theater is located on the fourth floor. There are also glass walled elevators. Jim let them know what performance factors had the potential to set off his vestibular symptoms.

Jim informed the group that he was holding a conference for vestibular patients and was hoping that a production could be altered so conference attendees could also come to the theater. The timeline was too short for that to happen, but The Guthrie did later schedule a performance of “A Christmas Carol” and altered it for vestibular and sensory sensitive audiences.

Currently, most sensory programming is aimed at juvenile populations. Hunter’s goal was to extend the audience by expanding the diagnoses and ages who could attend. Hunter started this project by creating a working group made up of staff and
community partners. The working group included Jim, parents of kids who suffer from sensory issues, and two staff members (one with autism and another whose son has autism).

“I was very nervous about altering ‘A Christmas Carol’ because it has the most sensory input of the productions we put on,” Hunter said. “However, it ended up not being that hard.”

Hunter and the production staff gave themselves plenty of planning time and relied upon staff who have experience with sensory issues. Sue observed that “technically, it was an entire second play, with huge efforts on the part of the staff.”

The technology available to the theater industry made many of these alterations possible, and even easy. One of the adjustments was to limit sound output to below 90 decibels. Strobe light rates were slowed, and quick black outs became a fade to black. All the actors were on stage for the run through of these changes so they had real time experience for how this might alter their timing. House lights were elevated a little so it was possible to still see, and additional lights were installed in some areas where there was too much darkness.

“Many of the changes were better for everyone and the design team ended up liking some of the changes so much they left them in for the rest of the production’s run,” reported Hunter.

Thought was also given to potential issues before, during and after the show. Occupational therapists (OT) were consulted and given a tour of the building and gave feedback on any potential issues. The glass walls of the elevators were covered, and the elevator speed and smoothness of starting and stopping was evaluated. A virtual tour of the building was posted on the Guthrie website and a detailed map of walking routes and ramps was also put on the website (and is still available). Quiet spaces were created and used by a few patrons before and during the show. Pre-show activities were available in the lobby and the rehearsal room. These activities were run by the OTs and included tactile activities, photos to preview different parts of the production, and teaching artists leading an activity about emotions patrons might have and how to express those feelings. During the play, the rehearsal room had a live stream of the show so that anyone who needed a break or could not stay in the theater could still watch the entire show. Very few patrons needed to utilize the rehearsal room. Right before the production began, there was a live welcome statement on stage that let everyone know that the “rules” were being relaxed and that this was a “judgment free zone.”

The community members who were part of the working group helped the Guthrie marketing team create materials and allowed the theater to reach some closed Facebook groups to alert their followers about this special production. After about one week, the Guthrie marketing team sent out emails and posted about this production on Guthrie social media. The theater holds 1,100 people. The ticket sales were capped at approximately 900 and Hunter reported sales of almost 875. A very good turn-out!

After the event, Hunter and his team received feedback in person, via email and through a survey the theater sent to attendees. One family who attended with a terminally ill child reported this was their last and only chance to go to a play with their child. Sue helped a father with an overwhelmed child find the rear exit. She later received an email in which the father reported that “his son would never have been able to go to a play without this special show” and he was very grateful for the opportunity.

“In the upcoming season, we will be holding four sensory and vestibular friendly productions: A Christmas Carol, Emma, 12th Night (a student matinee) and Steel Magnolias,” Hunter reported.
NOW, THE PERSPECTIVE OF JIM HAINLEN, VESTIBULAR DISORDER SUFFERER AND THEATER PATRON:

A wonderful thing happened last December. It wasn’t “fake news.” It was the kind of news you don’t hear about often enough. Something real. More real because there was so much kindness behind the effort, particularly by Sue and Hunter.

My wife and I have season tickets to the Guthrie Theater in Minneapolis, but often accessing the theater through the chaos of the lobby and watching performances with loud, sudden sounds and flashing lights has been difficult for me. As a person with Meniere’s disease, I asked myself, how can I reach the right person who could make a difference in a large institution like this? It seemed like an insurmountable task.

The answer came about unexpectedly when an usher at the Guthrie Theater was kind to me. He assisted me out of the theater during a performance and took me to the patron’s lounge where I could watch the performance on a closed circuit TV and not endure the visual stimulus of strobe lights.

The next day I sent an email to the Front of House Manager, Sue Kotila, praising the man. I received a call from Ms. Kotila thanking me for letting her know about the help I’d received. Sue seemed extraordinarily kind, so I took the opportunity to tell her about the difficulties of getting to our seats and watching plays with sound and light effects that triggered my dizziness. She listened sympathetically and promised to work with me. She opened up back stairways so I could walk up the stairs instead of taking the long, dramatic escalator or the glass sided elevator up two floors to the theater entrance. She worked with Hunter Gullickson, the Access Coordinator, to print a timing sheet that the ushers handed me to mark all of the places in the performance with the sound and light cues that would trigger a dizzy attack. She alerted the staff in the theater to my seat location and they helped me find the stairways out of the theater at the end of the performance. The Guthrie already had a sound-assist system for hearing loss and I was able to bring my Bose noise-cancelling headphones and plug them into the unit around my neck and clearly hear the words of the actors.

Sue and Hunter expanded their assistance to other people, but it seemed to the three of us - who became good friends - that this could be extended to an even larger group by designating one play as a low stimulation performance with enhanced access for all people who had difficulty with the theater.

One year ago, they chose to make a performance of The Christmas Carol in December a sensory-friendly performance. This was a huge commitment because the lighting and sound cue charts had to be rewritten and the entire lobby had to be rethought. The management of the Guthrie committed to this effort, and last summer formed a committee of 20 people from the staff and community to guide the planning process.

We met several times and Hunter guided the meetings so that sensitivities of many types emerged and great thought and effort followed to make the Christmas Carol work for an entirely new audience. I cannot begin to describe the intensity of these meetings where people with children who were sensitive to sounds, lights and visual chaos talked about what it would take to make their child feel comfortable and safe during the performance. Each idea was considered, and what followed was incredible.

“AMAZING PEOPLE CAN ACHIEVE AMAZING THINGS.”
- JIM HAINLEN
The designated performance had greeters at the doors to help people access the theater without stumbling through the lobby. The actors greeted theater goers in costumes so that kids could know what to expect during the play. The house lights were kept at 1/4 during the performance so people could feel more comfortable going in and out of the theater, if necessary. The loudest stage sounds and the brightest flashes were subdued so people with sensory difficulties were not triggered.

What followed at the performance is not possible to describe. Kids and adults in wheelchairs, more wheelchairs than I had ever seen in the theater, moved through the lobby and checked out all the “fidgets” and costumes and sets. Sue and I were in the space outside the theater as the play was about to begin, and I had tears on my cheeks looking at all the people who had never been to a theater performance. The theater was at close to capacity, and the communication between actors and audience was every bit as meaningful as a “regular” play, and perhaps even a bit more intense.

Artistic institutions have been slow in thinking about people who don’t fit in the “normal” category, except for inadequate hearing assist systems that too often don’t work, or an occasional “signed” performance of a play for the visually impaired. We are a flashing-light society, and mass entertainment keeps moving to louder sounds, brighter flashes, and over-stimulation of all sorts. The management of The Guthrie Theater, and Sue and Hunter in particular, deserve the most heartfelt praise for listening to one person and seeing the possibilities of reaching out to all people.

We desperately need the arts in our lives to help us see beauty and contemplate the complexities of living, especially people who, through no fault of their own, are not 100% “normal.”

Not every attempt to work with your local arts organization will meet with this response, but now there is a model out there and leaders of arts organizations can easily contact The Guthrie Theater.

I encourage all people with vestibular disorders to be proactive in advocating for yourself and others. The process can be collaborative, refreshing, inclusive and community building. A beautiful thing!

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DONATE TO SUPPORT VEDA'S ADVOCACY PROGRAMS
Adapting With Volunteers

By Cynthia Ryan

I was standing in my office at VeDA (I’m one of those strange people who uses a standing desk because I have back problems) and out of the corner of my eye I saw a man on the sidewalk pause in front of our building and look at it curiously. We don’t get many visitors, so I was surprised when he came to the door.

“I’m looking for the Vestibular Disorders Association,” he said. “You’ve found us!” I replied.

We both had a moment where we had to adjust our expectations. You see, while our small but mighty staff helps people all over the world every day, it’s all done remotely - via phone, email, social media, and our website. We’re not really prepared for drop-in visitors.

On the other hand, this person’s impression of VeDA from our online presence was that we’re a large organization with headquarters in Portland, Oregon and chapters in other places. He didn’t exactly say, “You mean, this is IT?” but his expression mirrored those thoughts.

I have heard similar sentiments from other people as well. VeDA has been around for 30 years. We started as an all volunteer organization. Eight years ago I was the only full-time employee. Today, VeDA has four full-time and two part-time employees, but we accomplish the work of a much larger staff. How? With the help of our amazing volunteers.

VeDA has 100+ patient education articles. All were written by volunteers.

Our infographics have been designed by volunteers.

Our spring virtual event, Steps-2-Balance, was the brain-child of volunteer, Katie Mahoney.

Our Ambassador Board is Chaired by super-volunteer, David Morrill, who also facilitates an online support group and Facebook group, and serves on our Patient Support Committee.

Our volunteer Board of Directors governs the organization and outlines our vision and strategy.

I could go on. The bottom line is, VeDA could not exist without our volunteers.

The job of supporting and empowering vestibular patients across the globe and raising public awareness about vestibular disorders is HUGE. We are a nonprofit organization that exists because of your generous donations, and through the donation of time and talent of many people dedicated to making vestibular visible.

And here’s the great thing - there are many volunteer opportunities, and you can do it from your own home! If you are interested in volunteering with VeDA, learn more at vestibular.org/volunteer.
Have you been diagnosed with Meniere’s disease?

If so, you may be eligible for a clinical research trial.
This trial is being conducted to see if the Investigational Product helps with vertigo episodes in patients with Meniere’s disease.

To join the trial, you must meet these criteria*:
- Be from 18 to 75 years of age
- Have been diagnosed with Meniere’s disease in one ear
- Have had spinning (vertigo) episodes for 2 months before joining the trial
- Have no history of middle or inner ear surgery

Qualified participants will receive at no cost:
- Investigational Product or placebo (has no active ingredients) given by a one-time injection to the ear
- Trial-related exams and follow-up
- Education about condition

For more information, please contact: https://clinicaltrials.gov/ct2/show/NCT03664674

OTONOMY Phase 3 Clinical Trial for Meniere’s Disease
YOU CAN HELP.

DONATE

Last year, over 2 million people visited VeDA’s website looking for answers. Our Facebook posts reached 3.6 million people, and our Patient Support Coordinator provided one-on-one coaching to 900 people.

YOUR SUPPORT MATTERS

Donations have been lower than normal this year. Without your help, VeDA may have to make some difficult choices.

To donate, visit vestibular.org/OTL.

MEET HOLLY, A VESTIBULAR PATIENT AND PRESIDENT OF VEDA’S BOARD OF DIRECTORS.
IMAGINE LIVING LIFE WITHOUT BALANCE.

Close your eyes and stand on one foot. It’s hard right? Now imagine having that same disoriented feeling on two feet, and with your eyes open.

Balance is something most of us take for granted. It’s automatically hardwired into our bodies at birth, evolving and adapting as we grow and age.

While basic balance is innate, some of us are able to perfect or even master our balance through exercise and practice. We don’t often think about our balance—until of course, we lose it.

While most people may not be familiar with the word “vestibular”—relating to your inner ear, brain, and sense of balance—many of us have likely experienced the awkward or sometimes scary feeling when we momentarily lose our balance. Maybe it’s taking a wrong step or getting motion sickness aboard a jostling boat. Or that nauseating head-spinning sensation after one too many alcoholic beverages. Eventually our balance comes back and life moves on.

This is not the case for the over 69 million Americans who suffer from the invisible and frequently debilitating symptoms of chronic imbalance associated with a vestibular disorder.

Whether it comes on gradually over time or suddenly, bouts of dizziness, vertigo, and nausea can make many of life’s more routine tasks virtually intolerable. Just try getting a good night’s sleep with a high-pitched ringing in your ear. Or try to focus on something as everything around you appears to be spinning.

For those living with a vestibular condition, everyday life becomes a progressively more challenging obstacle course to navigate.

This is why VeDA pioneered Balance Awareness Week in 1997: to be an opportunity each year to come together and shine a light on these invisible disorders. If we’re all more aware, then we can better understand and be empathetic to those who need our support the most—our family, friends, co-workers, and neighbors.

While many vestibular disorders are incurable, faster and more accurate diagnosis, along with effective coping strategies, can greatly improve quality of life.

Join us this September 15-21 for Balance Awareness Week, and together we can pave the way toward restoring a life rebalanced.

“MAKE MELODIES” BY NICOLLE CURE
Make Vestibular Visible

By participating in Balance Awareness Week (BAW), you can increase awareness about vestibular disorders to support patients in their journey back to balance through your gifts.

**HOW YOU CAN HELP**

1. Share VeDA’s social media posts.
2. Post about your vestibular journey on your social media pages and tag VeDA.
3. Take a picture with Fiona Flamingo, post it on social media and tag VeDA.
4. Purchase a Balance Awareness Week t-shirt or other merchandise.
5. Host a local event (ask us about handouts and infographics you can use).
6. Ask friends and family to make a donation in your honor to support VeDA’s patient education programs and advocacy efforts.

Get started by downloading VeDA’s BAW Toolkits at vestibular.org/BAW.