VeDA Gathers the Vestibular Community Together for First Virtual Conference :: SEPT. 14-18, 2020
See page 7 for details
AMBASSADOR SPOTLIGHT
2020 Balance Awareness Week Ambassador
LAURA CALA
Dancing Her Way Back to Balance

Laura was officially diagnosed with vestibular migraine in 2019, however, she’d been suffering with symptoms since 2015.

“At the breaking point for me was in 2016. I woke up one morning and felt like I was spinning — except I was laying down. I remember going to the emergency room and saying that there was something wrong with me, and the doctors telling me, “It’s just a virus. It will pass.”

“It wasn’t a virus. It did not pass. It got worse from there.

“I felt so frustrated. I searched for answers by going to different doctors and taking many different tests. I got to this point where I thought I was actually going crazy. I explained my situation to one general practitioner and he said, ‘You have generalized anxiety disorder.’

“That really blew me away! Don’t get me wrong, I certainly had anxiety. But life for me was quite bubbly before it actually happened. I’d almost get myself to a point of panicking that an attack was going to happen before it actually happened, then I’d panic because it did happen.

“But when vestibular symptoms started to hit me, I was too scared to keep going. I was afraid I’d fall over and have to explain, I felt I would be judged for being something less than I was. With vestibular migraine, I’d almost get myself to a point of panicking that an attack was going to happen before it actually happened, then I’d panic because it did happen.

“I look back on it now and I think, ‘How on earth did I do years of that treatment plan?’

“I was working full time but I was struggling. I felt like I was always having to cancel plans, like I was always letting other people down.

“Dancing used to bring me so much light. I taught classes and competed in competitions — the dance floor was my world. My sister and I ran a dance studio together here in Australia.

“My sister and I ran a dance studio together here in Australia. I was always careful when walking, I was always so careful when walking. I held her; standing up sometimes just wasn’t even an option.

“I was finally diagnosed by a physiotherapist, Dr. Alex Ring, who specializes in balance disorders. I was referred to him by my endocrinologist, Dr. Paul

On the Cover
“Bonfire on Green Grass Field”
Photo by Gantas Vaiciulenas from Pexels.

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Glendenning, who primarily looks after me for vestibular disease. She is my main care provider and I'm very grateful for her support.

“I went home after my appointment and searched online for anything I could find about vestibular migraine — that was the day I found VeDA and started to connect with other people who had what I had. I remember sobbing my eyes out because for the first time in years I felt like someone had punched me right in the heart. I used to think I was all alone and misunderstood. Today I have found my people, people who have stuck by me, my family and my closest friends who have never made me feel less than what I am.

“I recently earned my master’s degree in business management, and now I’m doing further study in psychology. I also run two businesses: one with my sister and another with a very close friend who also suffers from migraine.

“The business I run with my sister is called Revolution of Dance. We saw an opportunity to give back to our community and started a dance competition in Western Australia. The competition grew and in 2020 we are running 15 competitions around Australia.

“The flexibility of not having to be ‘on’ all the time makes a tremendous difference. But I always have to be particularly careful when I travel, and make sure that I don’t overdo it. I still teach dance, but now only twice a week.

“The other business I run is called Clique Events Management. Its mission is to empower other women, and to promote community and friendship.”

Laura spots a teammate at the State Championships in Perth, Western Australia – the last time she competed.

I applied for my current job, which was advertised as full time, but I committed to working only four days and it has never been a problem. To be honest, my new job is more “me” anyway! Now I work with amazing team members who never make me feel less than what I am.

“When I decided to change employers, I sought out opportunities that were more suitable for me. And the partner and his family who didn’t get me or my migraine? They’re no longer around either.

“I used to think I was all alone and misunderstood. Today I have found my people, who truly understand and get who I am and what I feel.

“I encourage all Vesties to ‘Uncover the Vestibular Mystery’, the theme of this year’s awareness campaign. Ask yourself, ‘Why am I dizzy? Why do I get headaches? What are my triggers?’ VeDA is here to help you uncover the mystery of your symptoms and find solutions.”
Due to the destabilizing effect COVID-19 has had on the world, VeDA will host its first Virtual Vestibular Conference in conjunction with this year’s Balance Awareness Week activities. This online conference will bring together vestibular experts and patients from around the world for five days of informational, inspirational sessions.

Topics will include:
• Navigating the healthcare system to get an accurate diagnosis.
• The cognitive and emotional impacts of vestibular dysfunction, and how to manage them.
• How can vestibular rehabilitation therapy improve symptoms, and how long does it take to get better?
• What is Persistent Postural Perceptual Dizziness (PPPD)? Is it physical or psychological? How is it diagnosed and treated?
• Ways to Integrate complementary and alternative healing approaches into your recovery plan.

Registered participants will have access to a virtual chat room where they can ask questions of vestibular experts and learn from others who have traveled the long and winding road to vestibular diagnosis.

NOW IN ITS 23RD YEAR, Balance Awareness Week is a weeklong awareness campaign presented by the Vestibular Disorders Association (VeDA). VeDA’s goal is to broaden the public’s understanding of balance-related vestibular disorders, such as Meniere’s disease and vestibular migraine, and symptoms ranging from dizziness and imbalance, to vertigo and tinnitus.

Balance-related disorders affect more than 69 million Americans – nearly 1 in 5 suffers from vestibular dysfunction! Yet despite the widespread occurrence of vestibular disorders, the word “vestibular” is not commonly understood. Few people know that “vestibular” refers to the inner ear and brain – the complex, mysterious human system that controls our sense of balance.

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

This year’s theme is “Uncovering the Mystery” of vestibular diagnosis. So many people go for so long trying to figure out what is going on with them. They have to become sleuths to advocate for their own healthcare.

Join VeDA this September to help us advance the funding, research, and policymaking needed to uncover the mystery of vestibular diagnosis.

How to Participate
Invite friends, family members, co-workers, and other connections to attend seminars, participate in fun Balance Awareness Week activities, and support challenges to raise awareness and funds.

Healthcare professionals across a range of balanced-related fields are also encouraged to promote Balance Awareness Week at their office, hospital, within their community, and online.

• Set a fundraising goal to support VeDA and vestibular research
• Register a Personal Campaign Page on VeDA’s website at vestibular.org/BAW2020
• Like VeDA on Facebook at facebook.com/vestibulardisorders/
• Follow VeDA on Instagram at instagram.com/vestibularveda
• Share a selfie with Fiona Flamingo on social media
• Host a virtual get-together
• Purchase a t-shirt
Stress is a part of life. However, how we handle it makes a big difference. Finding what works best for you to help you manage stress and practicing it daily is key to helping you with stress reduction.

Relaxation can reduce stress by:
- Decreasing heart rate
- Decreasing blood pressure
- Slowing respiratory rate
- Increasing blood flow to major muscle groups
- Decreasing muscle tension
- Improving concentration
- Improving self-confidence

**RELAXATION TECHNIQUES**

**Meditation:** Focusing the mind on a word or phrase and letting go of other thoughts.

**Progressive Muscle Relaxation:** Focusing on slowly tensing then relaxing each muscle group.

**Visualization:** Imagining yourself in a peaceful, relaxing place.

**TIPs TO R-E-L-A-X**

- **Relaxation takes practice.** Even if you aren’t conscious of feeling anything, the physiologic effects are still occurring. Tune into what your body is telling you.

- **Find the technique that works for you.** You may have to try several techniques before you find the best one for you.

- **Don’t force it.** Relaxation happens naturally.

- **Get comfortable.** Sit in a chair with neck and back support, or lay on a firm bed, or try a mat on the floor. Choose a position that you can maintain for at least 10 minutes.

- **Zone out.** Find a quiet environment that is distraction-free.

**MAKE STRIDES WITH WALKING POLES**

When she was 13 years old, Melissa B. sustained an injury to her inner ear during a commercial airline flight, which resulted in chronic dizziness, fatigue, unsteadiness, brain fog, nausea, and vomiting.

After two surgeries, physical therapy, and many years, Melissa learned to adapt to the dizziness and was walking full marathons with the assistance of walking poles.

“It was a slow, daily struggle to overcome the dizziness and reclaim my life,” says Melissa. “I am continually pushing my boundaries to live an active and healthy lifestyle despite dealing with constant dizziness that ebbs and flows like the tide.”

Like Melissa, many people with vestibular balance dysfunction struggle with chronic balance problems and are unable to walk unassisted. Having a tool that ensures that they can exercise safely can promote compensation and assist in their recovery.

That’s why VeDA partnered with Urban Poling, a Canadian manufacturer and distributor of walking poles. Urban Poling’s mission is to help people realize that their full potential is achievable and sustainable. VeDA shares a similar mission, to support and empower vestibular patients on their journey back to balance. Together, we offer hope to vestibular patients that they can once again experience the freedom of walking.

Adding a pair of specialized walking poles to your walk can give you an added sense of security and improved confidence knowing that they are providing an extra measure of support.

Urban Poling is offering 10% off their signature Activator® Poles when purchasing them through this link >>


Urban Poling donates a portion of all sales to support vestibular education and advocacy.
Dizziness in Patients with Cognitive Impairment
By Dennis Fitzgerald, MD and Jennifer Robbins, MPT

VeDA partners with the Barany Society and Journal of Vestibular Research to bring patient-friendly summaries of the most current developments in vestibular medicine.

Researchers have found that the vestibular system is “wired” with parts of the brain that involve memory, attention, perception of space, and other major brain functions. One study found that walking on a line, counting backwards, learning, perception of space, control of posture, and memory involve both the cognitive (“thinking”) and vestibular (“balance/dizziness”) parts of the brain.

In their article, Lee et al. attempted to determine the effect of dizziness on cognitive function. Their paper asserts that cognitive decline correlates with an increased perception of dizziness. They discovered that cognitive decline could exist without dizziness, but in persons with both cognitive decline and dizziness, cognitive impairment was increased.

The study also confirmed that postural instability is an important determinant of dizziness. This is not a new thought, as patients will often use the word “dizzy” when referring to postural stability.

Other researchers examined specific vestibular syndromes that were surgically corrected. Thirteen adults and four children had improved cognitive function after surgery.

Part of the brain responsible for “thinking” has also been found to be involved with inflammation and metabolism in the brain and controls coordination of muscles and learning new muscle movements. The vestibular system appears to give sensory information to this part of the brain, contributing to “thinking”/cognition. Stimulation of this area shows promise for the treatment of unilateral vestibular hypofunction and brain atrophy.

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Dennis Fitzgerald is a board-certified otolaryngologist and assistant professor at Jefferson Health University Hospital in Pennsylvania. He has over 33 years’ experience in biology and exercise science and a master’s degree in physical therapy. He teaches physical therapy at Greenwich Hospital and practices at Integration Physical Therapy in Connecticut.

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Community of Support Interview
Heather Gonzalez has battled Bilateral Meniere’s Disease for six years. Then, in March of this year, she contracted the coronavirus. Soon after, her 18-year-old son also came down with COVID-19 symptoms. In May, her father died.

“But through all this,” she says, “I just keep trying to put one foot in front of the other.”

Six years ago, Heather Gonzalez lost her balance to Bilateral Meniere’s Disease, a vestibular disorder characterized by fluctuating hearing loss and recurrent episodes of vertigo and nausea. She has also been diagnosed with intracranial hypertension, a condition caused by high pressure within the spaces that surround the brain and spinal cord, which can intensify her Meniere’s symptoms.

This past March, Heather’s health took another serious turn when she contracted COVID-19. For more than a month she battled fever and breathlessness, which sent her to the emergency room on multiple occasions.

“I felt my body was failing me, or I was failing my body,” says Heather. Worse yet, Heather’s 18-year-old son, Logan, also came down with a bad cough and fever, landing him in the hospital, too.

And then, just when Heather and her son’s health was beginning to rebound, Heather’s father passed away.

“I just keep telling myself it’s going to be okay. I got through a scary time with me and my son, and I got through Meniere’s. Now I’m dealing with my father’s death. It’s not going to be like this forever,” says Heather.

Heather spoke with VeDA in June about her vestibular journey and her experience having the coronavirus.

VeDA: When did you suspect you had the coronavirus?

HEATHER: On March 11. My first symptom was a sore throat. The next morning, I woke up and had a fever. I thought I might have strep and asked my husband to make a doctor’s appointment. Coronavirus was just starting to be in the news then, so I thought I better get in while I still can.
hospital wouldn't allow any visitors, not even he should follow, and they said neither. The doctor gave me an inhaler and said someone would be in touch about next steps.

As they were loading my son into the ambulance, they took him to the hospital. The emergency status, so they called 911 and the paramedics arrived. My son was very pale. The doctor said he was in emergency.

On Wednesday he had a fever — eventually it was over 103.2°. We gave him an ice bath to keep his body cool.

The next morning my husband took Logan to the clinic. The nurse tried to take his vitals, but she couldn't get his blood pressure and he was very pale. The doctor said he was in emergency, so they called 911 and the paramedics took him to the hospital.

As they were loading my son into the ambulance, my husband asked if he could ride along or if there were negative for flu and strep. They said it was probably just some virus.

VeDA: When did your son start feeling sick?

HEATHER: That evening, my son, Logan, came home from work and said he didn't feel well. On Wednesday he had a fever — eventually it reached 103.2°. We gave him an ice bath to keep his body cool.

VeDA: What happened at the clinic?

HEATHER: At the clinic I was told I had to be isolated in a room because I had a fever, which is a symptom of the coronavirus. Later that afternoon I started feeling tingly in my chest and I was wheezing. They swabbed me for strep and flu, but they couldn't test for the coronavirus because they didn't have testing supplies. The doctor gave me an inhaler and said someone would be in touch about next steps.

VeDA: When were you and Logan finally tested for the coronavirus?

HEATHER: At the hospital they tested Logan for strep and flu, which came back negative. They wanted to test him for coronavirus, but they didn't have testing supplies. It was very frustrating, but they got him stable enough to come home. He wasn't considered serious, because he didn't need a respirator.

A couple days later I felt so bad, like someone was standing on my chest with a truck tire. I was very short of breath, so we called the advice nurse. She said I needed to call an ambulance. I was transported to the hospital, where I was immediately put on oxygen and given meds to open my airways. I was so scared. I was in the hospital one day. They were able to stabilize me enough to go home. I wasn't tested for coronavirus, but we were told to quarantine for two weeks.

A doctor wrote us a prescription for a coronavirus test and we found a place where we could get it done, at an outpatient respiratory clinic. They evaluated me, listened to my lungs, and I had a COVID swab. It felt like a huge accomplishment. My swab came back positive for coronavirus. My son got tested at the same place, but his test came back negative. The doctors said it was probably a false test.

VeDA: How have you and your family coped since then?

HEATHER: It's been tough. I'm on disability. My husband couldn't work. My son had just started a new job and now he couldn't work.

My son and I took the same medications, an inhaler and strong antibiotics. For a month, we both had fevers and were having a hard time breathing, coughing, no energy or appetite. On the news they kept saying the virus lasts two weeks, but our doctors said to expect four to six weeks. Watching the next was frustrating, so I joined a Facebook group of people who have tested positive for COVID. There are so many people who had coronavirus and were sick for more than 30 days. It was very validating to hear stories similar to ours.

VeDA: Has the coronavirus affected your vestibular disorder?

HEATHER: After my fever broke, I had a vestibular episode of spinning. I couldn't talk. That day I felt like I wanted to crawl under a rock. It was so hard already. I was worried about my son. I was at a breaking point. My brain was tired. I remember sitting on the couch, I crumbled and cried, I couldn't take any more. It was a very defeating moment.

Several weeks later I had another vertigo episode. I felt my body was failing me, or I was failing my body. I wasn't getting over COVID, and now the vestibular symptoms were coming back.

There were good days, intermittent bad days. My lung capacity wasn't back to normal. I was still very short of breath. The doctor said my lungs will be the last thing to heal, and I may have permanent damage. Some days I am more short of breath, like, I can't take a deep breath. Before coronavirus, I never needed an inhaler.

VeDA: What have you learned through all this?

HEATHER: Through the whole thing, I have had to advocate for us. I got online and searched. I called the Oregon Health Authority. I had to fight for us. We have insurance, but we couldn't get tested. It was a sick feeling.

Thankfully, my husband Mario never got sick. He has to be asymptomatic. He waited on us, hand and foot, but never got sick. Once the antibody test is available, he should be checked out. Corona is still so unknown. They're just guessing what to expect. The world is in the trial run phase.

Before the coronavirus interrupted their lives, the Gonzalez family enjoyed a vacation in Las Vegas (from left to right): Heather's husband, Mario; Heather; and their son, Logan.

VeDA: On top of vestibular and COVID, you're also dealing with the recent passing of your father?

HEATHER: Yes, in May, my father died. He was 77. He had chronic obstructive pulmonary disease. We were very worried about exposing him to us while we were sick.

VeDA: How has the vestibular community supported you these past few months?

VeDA: That's why I am so thankful for VeDA. VeDA was a saving grace for me when so much was unknown. I couldn't just talk to a neighbor about my vestibular problems and have them understand. It's not a common thing like cancer or other known diseases.

I kept telling my husband, people need to know they're not alone in this. It's not just vestibular disorders, but now coronavirus too. It's validating and gives you a sense of hope when you hear someone else has gone through this.
Once home, Todd checked into a third hospital, what to do if I experienced it again,” says Todd. It was no explanation behind the vertigo, no tips for physician, who was over 1,000 miles away. There were no answers.

Prescribed Valium and sent on his way again. A few more tests came back negative. He was told it was dying? This is something you have never experienced before.

Meet Todd. The story above is his. Unfortunately, his story, or a similar version, occurs frequently. It is a story that often leaves the patient searching for answers on their own via Dr. Google.

In Todd's case, when his episode occurred he was on vacation far from home and his usual healthcare team. He went to an emergency room, where he hoped for some sort of answer. He was told it was Positional Vertigo (BPPV).

The vertigo struck Todd a second time, as it tends to do. He managed to get back to the emergency room, a new one this time. A new provider was there. Unfortunately, there were no answers. Todd started vestibular rehabilitation at a clinic close by, but he was starting to lose much of his independence. He relied on family or friends to drive him to and from appointments and relied on a walker, eventually a cane, to help him walk. Taking care of himself, getting to and from work, grocery shopping, filling his head back to shave or wash his hair, and rolling over to sleep were suddenly all challenging tasks at the young age of 56.

Through rehab, the room spinning eventually dissipated with several maneuvers, but Todd still was not feeling like his normal self. It appeared the clinic close by helped as much as they knew how, so he sought vestibular rehabilitation from a clinic a bit further away.

Once again he relied on family or friends to assist in the one-hour commute. He was provided a home exercise program to combat his symptoms of “fogginess,” “bobbly head,” and “imbalance.”

Finally, Todd felt he might be on the right track... until COVID-19 struck and the clinic closed its doors. Overnight, Todd's hope for recovery in vestibular rehabilitation therapy vanished.

“All the treatments we had done before that just disappeared,” Todd says. “It was like a big hole was opened wide.”

In the vestibular dysfunction world. It is a story that often leaves the patient searching for answers on their own via Dr. Google.

“After going through so much it was like, ‘Oh no, not again,’” Todd says. “It was kind of an abandoned feeling.”

ENTER TELEHEALTH

Todd was recommended to me by a former patient. He and I scheduled a brief phone call to learn a bit about each other. Next, we scheduled our first live video call. Telehealth was a new concept for Todd and many others at the start of COVID-19. While he admitted that he preferred to see a provider in person, it took only a session or two to feel comfortable.

"Now, I look forward to it," Todd says.

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“How does a vestibular therapy appointment work through video? Basically, it is the same as in person with a few technological exceptions.

First, Todd logs into his email, which is where he finds his secure video link. Then, he clicks the link and his video opens in an application that he already downloaded to his phone.

Once on the video, we both ensure that we can see and hear each other, then we get down to business. We review his week and any changes in his symptoms, how his home program is going, and what he is still having difficulty with.

Despite being in separate locations, I teach him exercises and activities through verbal or demonstrative instruction. We constantly reassess throughout the session and determine how to adjust his home therapy program.

Since starting virtual therapy, Todd has begun to feel more normal. At a time when Todd’s access to care disappeared due to the pandemic, telehealth restored his hope and confidence.

While virtual vestibular rehabilitation therapy is not for everyone, it can play a vital role for some, like Todd, in their quest for answers, an experienced provider, and recovery.

If you are unable to drive yourself to an appointment, unable to make it back home after symptoms flare up following an appointment, do not have a vestibular specialist close enough to even consider commuting to, are too symptomatic to tolerate a commute even as a passenger, or lost access to your provider due to the pandemic, virtual vestibular rehabilitation therapy can restore your confidence, independence, and hope as you face and conquer the challenges of your vestibular dysfunction.

Dr. Abbie Ross is a physical therapist specializing in the evaluation and treatment of patients with vestibular and balance dysfunction. She is a board-certified neurologic clinical specialist, which includes the rehabilitation management of neurological disorders such as vestibular disorders, Parkinson's Disease, stroke, Multiple Sclerosis, Traumatic Brain Injury, and more.

In addition, she is a member of the American Physical Therapy Association (APTA) and vestibular rehabilitation special interest group. She is both a professional member and committee member of the Vestibular Disorders Association (VeDA).
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