

SUMMER 2020

VeDA Gathers the Vestibular Community Together for First Virtual Conference :: SEPT. 14-18, 2020 See page 7 for details



A QUARTERLY NEWSLETTER OF THE VESTIBULAR

DISORDERS ASSOCIATION

VEDA

LIFE REBALANCED

On the Level is a quarterly publication of the Vestibular Disorders Association (VeDA). Information in this newsletter is not intended as a substitute for professional healthcare. VeDA does not recommend any particular course of treatment, clinic, or health care practitioner. The opinions expressed in these articles are those of the authors and not necessarily those of VeDA's staff, medical and scientific advisors, or board of directors. The publisher reserves the right to accept, reject, or edit any materials received for publication. No part of this publication may be reproduced without written permission. © 2020 All rights reserved.

BOARD of DIRECTORS

President :: Kathleen Stross, DPT - Pearland, TX Vice President :: Kamran Barin, PhD - Columbus, OH Treasurer :: Jordan Tucker, DPT - Troutville, VA Secretary :: Danielle Tate, DPT - Damascus, MD Holly Fisher, Ed.D. - Coppell, TX Dennis Fitzgerald, MD - Philadelphia, PA Rebecca Rubin - Sherman Oaks, CA Patricia Gerend, MS - San Francisco, CA Bridgett Wallace, PT, DPT - Austin, TX Louise Geib, M. Ed - Atlantic Beach, FL (Trustee) Bryce Salvador - Westfield, NJ (Honorary)

EXECUTIVE DIRECTOR

Cynthia Ryan, MBA - Portland, OR

MEDICAL & SCIENTIFIC ADVISORS

Chair :: P. Ashley Wackym, MD - New Brunswick, NJ Richard Clendaniel, PT, PhD - Durham, NC Joel A. Goebel, MD, FACS - St. Louis, MO Timothy C. Hain, MD - Chicago, IL Janet Helminski, PT, PhD - Chicago, IL Gary Jacobson, PhD - Nashville, TN Jeffrey Kramer, MD - Chicago, IL David Newman-Toker, MD, PhD - Baltimore, MD James Phillips, PhD - Seattle, WA Steven Rauch, MD - Boston, MA Jay Rubinstein, MD, PhD - Seattle, WA Michael Schubert, PT, PhD - Baltimore, MD Alain Semont, PhD, PT - Paris, France Neil T. Shepard, PhD - Rochester, MN Hinrich Staecker, MD, PhD - Kansas City, MO Jack J. Wazen, MD, FACS - Sarasota, FL Yuri Agrawal, MD - Baltimore, MD

WHAT'S INSIDE?

3-4-5

AMBASSADOR SPOTLIGHT 2020 Balance Awareness Week Ambassador LAURA CALA traces her journey from competitive dancer to vestibular migraine warrior.

2020 BALANCE AWARENESS WEEK

Mark your calendars for September 13-19, 2020, and get the scoop on registering for VeDA's first VIRTUAL VESTIBULAR CONFERENCE

8-9

TIPS + TOOLS

Learn new ways to relax and reduce stress. Walking poles can increase mobility.

10

RESEARCH

Dizziness in patients with cognitive impairment.

11-12-13

COPING WITH COVID-19

Heather Gonzalez recounts her battle with Bilateral Meniere's Disease, coupled with the coronavirus.

14-15

TREATMENT

Virtual vestibular rehabilitation therapy: A case study.

ON THE COVER

"Bonfire on Green Grass Field" Photo by Gantas Vaiciulenas from Pexels. AMBASSADOR SPOTLIGHT

2020 Balance Awareness Week Ambassador

LAURA CALA Dancing Her Way Back to Balance



Laura and her god-daughter Olivia. "I was always so careful when I held her; standing up sometimes just wasn't even an option."

Vestibular Warrior

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

"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 I started struggling with balance. I liked getting out. I liked doing things. I'd been teaching dance for a long time. I had my career going. Life was anything but anxious!

"What really scared me was how I felt – like I was always walking on a marshmallow. I felt I was always going to fall over. I got tired often and felt

nauseated. I stopped driving. I almost got to the point where I was just used to always feeling awful."

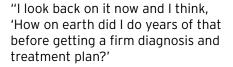
LOSING HER BALANCE

"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.

"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.



SUMMER 2020 :: VESTIBULAR.ORG

"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



About Laura

VeDA Ambassador; Board Member. Migraine Australia Ltd.

Diagnosis :: Vestibular migraine

Profession ::

Accountant: co-owns two businesses, Revolution of Dance and Clique Events

Home :: Perth, Australia

Blog :: dizzydiaries.org (coming soon)



Glendenning, who primarily looks after me for the prolactinoma that sits on my pituitary gland.

"Dr. Ring turned my life around. I remember telling him about my symptoms. He performed a series of tests on me, including a vestibular assessment, and determined that I had vestibular migraine.

"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 "Life has changed, but it's changed for the better because now I do things at a pace that is better for me. My entire journey has allowed me to discover myself all over again.

"I don't work full time. I still work in an industry I love, but part time, with an employer who understands.

"My last job literally sucked the life out of me! I remember explaining to my previous boss that I wanted to change my pace and explore a four-day week. I was told it wouldn't suit the



"Your missing piece will form a part of a puzzle you just haven't solved yet."

- Laura Cala

2020 Balance Awareness Week Ambassador

Laura Cala (upper left) on a video call with fellow VeDA ambassadors Emily Englert (bottom left), Etta Sundberg (upper right) and Ashley Virgilio (lower left). "These women absolutely inspire me in every way possible," says Laura, who hosts a series of "Vestibular Warrior Talks" on Instagram Live. For more information, visit instagram.com/dizzy.diaries.

who had what I had. I remember sobbing my eyes out because for the first time in years I felt like it was okay to not be okay.

"I reached out to so many beautiful people and they were there for me, offering suggestions and sharing their stories and their journeys. Those people today are some of my closest friends and confidants.

LIFE REBALANCED

"When I look back on my journey, I think, "How did I do it?" Now I think it was one of the best things that's ever happened to me.

In addition to my diet, I've changed my wellness. I can't dance every day – I just can't do that now. Instead I enjoy yoga and meditation. I'm very holistic when it comes to oils and vegan products.

organization and that they didn't think reducing my working hours would change my recovery, even though I had doctor's notes which said otherwise. Basically, it felt like they were saying, "We don't believe you're sick!" It was then change happened! The moment I admitted to myself that I couldn't keep going, life got better.

"At the time I was with a partner who couldn't understand my migraine. His mother once said to me, "It's a bit unfair that you're always unwell." I felt like someone had punched me right in the heart. I felt shame, that it was my fault I was sick and unable to control it.

"Today my message to others is, 'Never feel guilty for being you. You are the way you are for a reason. You might not know what that reason is but it's coming. Your missing piece will form a part of a puzzle you just haven't solved yet.'

"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 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.

"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.

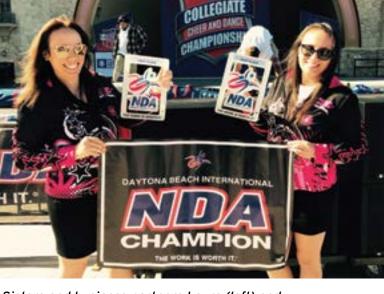
"The other business I run is called Clique Events Management. Its mission is to empower other women, and to promote community and friendship."

UNCOVERING THE MYSTERY

"I'm super excited about sharing the information VeDA has put together for this year's Balance Awareness Week and the first Virtual Vestibular Conference. My goal is to be a light and a force for others!

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





Sisters and business partners Laura (left) and Jessica (right) at a U.S. cheerleading event.

"Vestibular migraine is something you have to fight through. Many people will never understand, but I understand you. We are in this together.

"Your mindset is as important as who you surround yourself with. Along my journey, I've met so many amazing people – and I've also lost a lot of people I thought were important in my life. I am so very thankful for the amazing support of my family and my closest friends who have stuck by me.

"VeDA gave me the confidence to embrace my vestibular journey. I know now that I'm not weak, just different, and that is okay! Vestibular migraine is me, and I love me.

"I have also been so lucky to align myself with Migraine Australia, a registered charity and patient advocacy organization founded to support all Australians living with migraine.

Currently I serve as a board member.

"I used to think I was all alone and misunderstood. Today I have found my people, 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."

VESTIBULAR.ORG :: SUMMER 2020 :: VESTIBULAR.ORG



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.



VIRTUAL VESTIBULAR CONFERENCE

September 14-18, 2020

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

room where they can ask

have access to a virtual chat

questions of vestibular experts and learn from others who have

traveled the long and winding

road to 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

PRESENTING SPONSOR



Register today at vestibular.org/BAW2020

VESTIBULAR.ORG :: SUMMER 2020 **SUMMER 2020 :: VESTIBULAR.ORG** TIPS + TOOLS

RELAX + REDUCE STRESS

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.

<u>Find the technique that works for you.</u> You may have to try several techniques before you find the best one for you.

Don't force it. Relaxation happens naturally.

<u>Get comfortable.</u> 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.

Zz

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

Relax throughout the day. Some apps will remind you to meditate

at intervals. For instance, Insight Timer (insighttimer.com) will also show you how many other people are meditating at the same time, which can be motivating and make you feel part of a community.

<u>Meditate with a group.</u> There are many local meditation groups that can be found through Meetup.com.



Try yoga or Tai chi. Many studios offer classes for beginners and/or classes for people with balance problems, including seniors and multiple sclerosis (MS) patients.

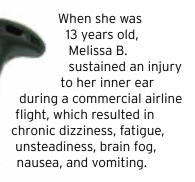
<u>Pray.</u> A growing body of research suggests prayer helps some people cope better, heal faster from illness, and experience increased health benefits and well-being.

<u>Practice mindfulness.</u> Bring your attention to experiences occurring in the present moment without judgment.



<u>Set a clock.</u> Set the timer on your phone or an alarm clock with a gentle waking sound so you can let your mind and body fully relax and not worry about the time.

MAKE STRIDES WITH WALKING POLES



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.

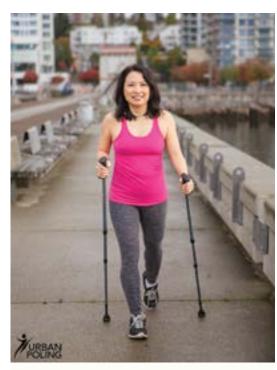
"It was a slow, daily struggle to overcome the dizziness and reclaim my life," says Melissa. "I am continually pushing my boundaries to live an active and healthy lifestyle despite dealing with constant dizziness that ebbs and flows like the tide."

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 >>

https://urbanpoling.com/urbanpoles-and-activators-vestibulardisorders-association-veda/

Urban Poling donates a portion of all sales to support vestibular education and advocacy.



SUMMER 2020 :: VESTIBULAR.ORG

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. 1,4 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.1

In their article, Lee et al¹ 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.1

Other researchers examined specific vestibular syndromes that were surgically corrected. Thirteen adults and four children had improved cognitive function after surgery.²

Part of the brain responsible for "thinking" has also

been found to be involved with inflammation and metabolism in the brain³ 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.3 Stimulation of this area shows promise for the treatment of unilateral vestibular hypofunction and brain atrophy.³

REFERENCES

¹Lee, Ho-Won, Lim, Yong-Hyun, and Kim, Sung-Hee. 'Dizziness in Patients with Cognitive Impairment'. 1 Jan. 2020:17 - 23.

²Wackym et al. Otol Neurotol. Jan;37 (1): 70-82.

³De Cicco et al. Front Neuroanato. Jan 8,2018: 1:130.

⁴Dobbels et al. Cognitive Function in Aguired Bilateral Vestibulopathy: a cross-sectional study on cognition, hearing and vestibular loss. Frontiers Neurosci;2019 April 24; 13:340

Dennis Fitzgerald is a board-certified otolaryngologist and assistant professor at Jefferson Health University Hospital in Pennsylvania. He has over 33 years' experience treating patients with vestibular dysfunction, has written numerous book chapters, and has appeared on radio and television interviews.

Jennifer Robbins is a certified vestibular rehabilitation therapist with a bachelor's degree in biology and exercise science and a master's degree in physical therapy. She teaches physical therapy at Greenwich Hospital and practices at Integration Physical Therapy in Connecticut.

YOU CAN HELP.

Your gift helps VeDA support vestibular patients, reduce diagnosis times, and improve treatment outcomes.

Donate online or return your check in the enclosed envelope.

vestibular.org/DONATE



YOUR **SUPPORT** MATTERS.

We are all affected by COVID-19. Your gift allows VeDA to continue supporting vestibular patients during these trying times, when symptoms are heightened and healthcare systems are overloaded.

COMMUNITY OF SUPPORT INTERVIEW **HEATHER GONZALEZ** Finding Balance Amidst Bilateral Meniere's Disease, COVID-19 & Grief 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

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.

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."

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.



VeDA: What happened at the clinc?

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 tingling in my chest



and I was wheezing. They swabbed me for strep and flu, but they couldn't test me 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.

Back home I got a call with the test results, which were negative for flu and strep. They said it was probably just some virus.

VeDA: When did you start thinking it was the coronavirus?

HEATHER: That weekend I started noticing I was short of breath, even walking just a small amount. I was huffing, like I was exercising. By Sunday my breathing was even worse. Just talking made me winded. I also had a sore throat and my fever wouldn't break.

On Monday I woke up and called the doctor's office right away. But the doctor's office wouldn't see people in the office who had corona symptoms. So, they called in an antibiotic for me. I just wanted to feel better, so I started the antibiotics.

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 105.2! 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 status, 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 he should follow, and they said neither. The hospital wouldn't allow any visitors, not even

12

family, because it was suspected he had the coronavirus. Emotionally that really hurt. It was so hard to accept that we couldn't be there for him. That brought it to a new scary level.

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 corona 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 corona, but we were told to quarantine for two weeks.

A doctor wrote us a prescription for a corona 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 did a COVID swab. It felt like a huge accomplishment.

My swab came back positive for corona. 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 news was frustrating, so I joined a Facebook group of people who have tested positive for COVID. There are so many people who had corona and were sick for more than 30 days. It was very validating to hear stories similar to ours.

VeDA: How 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 my 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.

Read more about

Heather's vestibular journey at vestibular.org/heather

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 corona, 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 71. He had COPD (chronic obstructive pulmonary disease). We were very worried about exposing him to us while we were sick.

We were very close. We talked on the phone almost every day. About eight weeks after we had corona, my son and I were feeling well enough to visit him. We talked in the driveway. That was last time I saw him alive.

Now I'm grieving, I'm trying to take care of legal matters, along with my vestibular health and now my lungs. It's more painful than I could ever have imagined. Grief is wreaking havoc with my balance. My mind is all over the place. But through all this, I just keep trying to put one foot in front of the other.

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

HEATHER: I think back on the hard times with my vestibular disorder, especially that first year. If it wasn't for hearing from others who experienced vestibular problems the same way as I did, I don't think I would have been able to get through it.

Vestibular dysfunction makes you feel so alone. People are so unaware how things affect you. 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 corona too. It's validating and gives you a sense of hope when you hear someone else has gone through this.

13

VESTIBULAR.ORG # SUMMER 2020

Virtual Vestibular Rehabilitation Therapy

By Abbie Ross, PT, DPT, NCS

You just sat up from a night's rest. Suddenly, the room begins violently spinning. You are unable to determine which way is up or down. What could possibly be happening? Are you 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 in the vestibular dysfunction world. 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



Todd, a vestibular patient, and Dr. Abbie Ross meet on a telehealth video call.

room, where he hoped for some sort of answer to explain what was happening to him. The doctors ruled out a stroke, so he was told it was likely vertigo and released.

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 few more tests came back negative. He was prescribed Valium and sent on his way again without any answers.

"I had no other plan than to follow up with my physician, who was over 1,000 miles away. There was no explanation behind the vertigo, no tips for what to do if I experienced it again," says Todd.

Once home, Todd checked into a third hospital,

where he was diagnosed with Benign Paroxysmal Positional Vertigo (BPPV).

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, tilting 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.

"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.

Teleheath 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.

Todd's virtual vestibular rehabilitation program began at the end of April. We initially met once a week and have since moved on to biweekly appointments as his symptoms and overall function improved.

THANK YOU FOR YOUR SUPPORT!

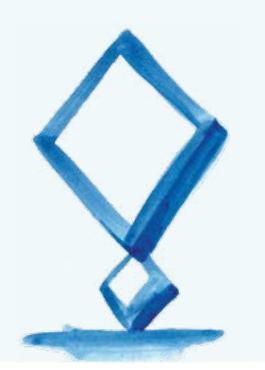
More than two million people visited VeDA's website last year looking for answers. Our Facebook posts reached 3.6 million people, and our Patient Support Coordinator provided one-on-one coaching to 900 people.

Your support makes it possible!

WELCOME TO OUR NEW BALANCE BENEFACTORS

Jean Barrell Randi & Paul Schweitzer Robert Steele Julie Yurko

To donate, visit vestibular.org/OTL



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).

VESTIBULAR.ORG # SUMMER 2020 # VESTIBULAR.ORG 15

CHANGE SERVICE REQUESTED

800.837.8428 | INFO@VESTIBULAR.ORG | VESTIBULAR.ORG 5018 NE 15TH AVE, PORTLAND, OR 97211, USA

> PAID PONTIAC, IL PERMIT NO. 592 NONPROFIT ORG U.S. POSTAGE

SAVE THE DATE



SPONSORED BY:

