



FALL 2020

MOVING PICTURES

Visual artist documents her life with
Mal de Débarquement Syndrome **PAGE 3**

PHOTO BY KIMBERLY WARNER

The logo for the Vestibular Disorders Association (VEDA) consists of the word 'VEDA' in a bold, black, sans-serif font. A horizontal blue line is positioned behind the letters 'E' and 'D'.

A QUARTERLY NEWSLETTER
OF THE VESTIBULAR
DISORDERS ASSOCIATION

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KIMBERLY WARNER

The filmmaker, photographer, and visual artist shares her past five years living with Mal de Débarquement Syndrome, and the inspiration behind her new project about chronic illness – “Unfixed”



Mal de Débarquement Syndrome (MdDS) throws people off balance in every aspect of their lives.

In Kimberly Warner’s case, MdDS derailed her thriving career as a filmmaker and photographer. Her award-winning work was published in a variety of magazines and for a long list of commercial clients.

Then in 2015, Kimberly developed MdDS, a neurological disorder, which manifested in her as a feeling of constant rocking, bobbing, and swaying.

“The unsteadiness that I live with feels like the ground is constantly moving under my feet. Laying down or closing my eyes does not make it stop. Whatever surface I’m on turns to liquid and my equilibrium is constantly trying to correct for it. Ironically, being in passive motion [such as driving in a car] is my only source of relief,” she says on her website (liferaftmdds.com).

Kimberly has also experienced a strong gravitational pull to her right. She’s extremely sensitive to light and noises. In the lower left back of her head she’s felt a sharp pain and a loud vibrating sound.

“I call it the dumpster truck in my head,” Kimberly says.





Thankfully, the worst of her MdDS symptoms subsided to a more manageable level after about two years. Today her symptoms reappear strongly but only intermittently and usually coincide with high “wild seas” days: a constant perception of motion that feels like bobbing at sea. Only motion, such as driving, makes the bobbing feeling recede.

Now five years into her vestibular journey, Kimberly has learned to persevere and live her life with purpose amidst nearly constant discomfort. She has also found ways to use her skillful storytelling abilities and thrive in new creative ways.

HER VESTIBULAR JOURNEY

Kimberly traces her MdDS back to an accident in May, 2014, but is unsure of its actual origins. While bicycling on a city street in Portland, Oregon, she crashed into a car door that suddenly swung open in her path, flipping her over the handlebars, breaking her pelvis, and cracking her helmet against the pavement.

After two months of recuperation, she started to walk again and had just started returning to normalcy when she experienced her first blackout. Shortly thereafter, she started having dizzy spells and other strange sensations. One time while driving, she felt like her car was doing a somersault. Another time it seemed like the countertop flipped on her, as well as other weird intermittent feelings.

“I felt like I was walking on a trampoline,” she says.

When the episodes became more frequent, she sought help from a variety of doctors: naturopath, two ENTs, a neurologist ...

“There was a lot of shoulder-shrugging with doctors trying to figure out what was going on with me,” she says.

She saw a vestibular physical therapist who specialized in neck (cervicogenic) vertigo, but after a dozen sessions her symptoms worsened. The sensation of walking on a trampoline turned into

wild dizziness, insomnia, and nerve pain coursing through her chest. She fell into a deep state of grief.

“At that point I was barely hanging on,” she says. “I wasn’t able to do daily walks around the block or go to the grocery store. I was not sleeping, not living anymore. I kept feeling like I just need to figure out what’s wrong with me so I can fix myself.”

What does “Mal de Débarquement” mean?

The name of this vestibular disorder originates from a French term dating back to 1575 that translates to “sickness of disembarkment.” Mal de Débarquement Syndrome (MdDS) is an illusion of movement felt as an aftereffect of travel or other novel movements, such as sleeping on a waterbed, which continues even after the source of the motion is no longer present, and sometimes becomes chronic. There is no cure, and treatments are often not effective. For more information about MdDS, visit

vestibular.org/mdds

SAVED BY WOOL

Feeling like she’d exhausted her medical options in Portland, Kimberly moved to Boulder, Colorado, to live with her mother. She sought out specialists, including an ophthalmologist who worked with traumatic brain injuries.

“Around that time, I picked up wool, which is what saved my life, and I don’t say that lightly,” she says. “I didn’t know how to get through the day since I wasn’t engaged anymore in a creative profession. So I started poking around with wool, which took enough of the peripheral ‘noise’ down to focus on my breath and the needle poking the wool.”

For the photographer and filmmaker, “noise” was visual feedback.

“Somehow limiting what my eyes were taking in and focusing on a singular object, I was able to calm my nervous system,” Kimberly says. “Minimizing some of my sensory stimuli always helps calm me, even if it doesn’t remove the perception of being at sea.”

For the next seven months, Kimberly needle-felted between doctor visits, holding onto the hope that she could get “fixed.” She eventually returned to Portland with a clowder of sculpted woolen cats, but without a firm diagnosis and not feeling much better, and in some ways worse. Drained financially and emotionally, she was beset by a newfound sense of hopelessness.

“One day, a family member asked me, ‘What if you have to live like this for the rest of your life?’ I didn’t like that suggestion but it planted a seed in me,” Kimberly says.



LEFT | Kimberly's team on location filming her documentary about chronic illness, "Unfixed."

REX IX | One of the woolen cats Kimberly needle-felted to quell her vestibular symptoms.



FOR MORE INFO about Kimberly, visit unfixedfilm.com, liferaftmdds.com, and kimberlywarner.com.

The idea of what would it be like to be "unfixed" compelled her to find other people also living with chronic illness. She searched online and discovered a Yahoo group devoted to MdDS.

"I could not believe how much resonance I felt with all these other people who have exactly what I have," she says. "I took literature to my doctor so she could confirm my diagnosis, so I can start being treated properly."

Recently, Kimberly connected with Sandy Brunner, a fellow Mal de Debarquement Syndrome and vestibular migraine sufferer who goes by @LifeWithoutLandLegs on Instagram. Sandy told Kimberly about VeDA and the resources available on their website, vestibular.org.

"Sandy and I connected over social media. Like me, she has issues with screens, so she asked if I'd hop on a call and we talked on the phone for a few hours. She has been so helpful," Kimberly says.

Kimberly wishes she had connected with VeDA's community earlier in her journey, and she wonders whether being better informed earlier on might have saved her from follow-up tests on brain injuries, when doctors felt certain she didn't have a vestibular disorder.

LIFE UNFIXED

"The early stages of MdDS were so excruciating," Kimberly says. "It was the first time I didn't have

an answer for something. I couldn't control it. Up until then, everything in my life was oriented to success."

Despite the challenges she faces living with MdDS, she found another creative outlet by starting work on a film she's titled "Unfixed," documenting people living with debilitating chronic illness.

"I needed to find other people living with chronic conditions, people grappling honestly and creatively with the limitations of their bodies, and I needed to know how they were doing it," she says in the film's trailer.

She began the project in September 2019 and had hoped to be finished with filming by now, but the pandemic interrupted the shooting schedule in February 2020.

Since then she's adapted from filming on location with a crew to remotely, which has opened up other creative opportunities. The people whose lives she set out to document are actually filming themselves.

"The camera allows people to show from their perspective what they are experiencing in their bodies. That's especially enlightening for people with invisible illnesses. From the outside we look totally normal," she says. "Inside it's the messy, uncomfortable journey of being alive – with no fix in sight." ■

IT'S OFFICIAL!

Balance Awareness Week 2020 was the best and biggest ever, thanks to the generous support of VeDA's ambassadors, sponsors, and attendees of VeDA's first-ever Virtual Vestibular Conference

What an AMAZING week! This year's 23rd annual Balance Awareness Week took place Sept. 13-19, 2020, and attracted a record number of entries to the **Fiona Flamingo Photo Contest**, as you can see! But more importantly, it raised awareness of vestibular disorders to a global audience, thanks to VeDA's first-ever **Virtual Vestibular Conference**.

More than 1,200 virtual attendees from the international vestibular community – from Australia, the United Kingdom, Norway, France, and elsewhere – came together for a week of informational webinars presented by vestibular healthcare specialists and people living with vestibular disorders.

The week kicked off with **Kim Bell, DPT** on "Navigating the U.S. Healthcare System" and closed with VeDA Board President **Kathleen Stross, DPT, CHC**, who discussed integrating complementary and alternative treatments into vestibular recovery.

Conference topics also included an overview of the National Health System (NHS) with **Peter Rea**, a leading neuro-otologist based in Leicester, UK. Psychologists **Eva Mihovich, Ph.D.** and **Joanna Wolfson, Ph.D.** explored the psychological impacts of vestibular disorders, and physical therapist **Tara Denham** discussed vestibular rehabilitation therapy along with **Abbie Ross, DPT**, who moderated Tuesday and Wednesday's presentations.

Due to some technical difficulties, Thursday's presentation on PPPD (Persistent Postural-Perceptual Dizziness) presented by **Janene Holmberg, PT, DPT** was livestreamed on Facebook instead in a feat of technical wizardry orchestrated magnificently behind-the-scenes by **Danielle Tate, DPT**, who moderated Monday, Thursday, and Friday's presentations – *a BIG thank you to Dani!*

Continued on Page 8 >>

116TH CONGRESS
2D SESSION

H. RES. 1108

Expressing support for designation of the week of September 13, 2020, through September 20, 2020, as "Balance Awareness Week".

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 14, 2020

Ms. JOHNSON of Texas submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for designation of the week of September 13, 2020, through September 20, 2020, as "Balance Awareness Week".

Whereas vestibular (inner-ear-balance) disorders are under-diagnosed and undertreated;

Whereas as many as 35 percent of adults 40 years of age and older in the United States, approximately 69,000,000 people in the United States, have experienced some form of vestibular dysfunction;

Whereas 80 percent of people 65 years of age and older have experienced dizziness;

Whereas vestibular disorder patients may consult four or more physicians and spend 50 months or more in their search for a diagnosis;

Whereas the Vestibular Disorders Association celebrates "Balance Awareness Week" to reduce the time it takes to diagnose a vestibular disorder by helping patients recognize their symptoms and encouraging them to seek help from a qualified vestibular specialist; and

On Sept. 14, 2020, the 116th Congress of the U.S. House of Representatives expressed support in House Resolution 1108 for the official designation of Balance Awareness Week.



FIONA FLAMINGO PHOTO CONTEST



This year's Fiona Flamingo Photo Contest was the most popular yet, with more than 100 entries from all over the world. Flamingos are masters of balance – something vestibular patients strive for. In celebration of Balance Awareness Week, many people decorated their home or office with flamingos and posted their photos on social media using the hashtag **#FionaFlamingo** and helped raise awareness about vestibular disorders.

"BEST FLOCK" WINNERS

ELEMENT PHYSICAL THERAPY

Missoula, Montana

FYZICAL PHYSICAL THERAPY SERVICES

Indialantic, Florida

Winners received a generous prize package from **Urban Poling**, including 10 sets of Urban and Activator poles, a copy of the "Ultimate Guide to Nordic Walking" book, and an elite accessories and resources package.

INDIVIDUAL WINNER

CLAUDIA FERNANDEZ

The photo of her dog "Pixie" won the judges' hearts and a prize – a painting generously donated by **Nicolle Cure**, the artist and vestibular patient who graciously donates her time and art to benefit VeDA's fundraising initiatives.

Thank you to everyone who sent in a photo or posted on social media!





After a live question-and-answer session with the vestibular specialists, panels of patients shared their inspiring vestibular journeys in real-time with Balance Awareness Week Ambassador **Laura Cala**, who moderated the daily discussions with amazing grace and presence from her home base in Perth, Western Australia.

"There were so many emotions, I was so overwhelmed by this amazing vestibular community," Cala said. "I am so incredibly honored to have had the opportunity to share my journey and learn from others."

Thank you to the other people who shared their vestibular journeys: **Kayla McCain, David Morrill, Andrew Hugill, Abi Aspen Glencross, Kelsey Flint, Emily Englert, Ashley Virgilio, Alex Shaddock, Nancy Shaddock, James MacGovern, Liz Burtrick Burton, Alicia Wolf, and Toby Henson.**

In all, more than 1,200 people registered for the five-day conference. Plans are already underway for another, even better conference next year.

Mark your calendar for next year's Balance Awareness Week, Sept. 12-18, 2021. ■

O.W.L. (ONE WHO LISTENS) AWARD WINNERS

Presented during Balance Awareness Week, the One Who Listens Award recognizes individuals and organizations for their contribution to the healing power of listening. People with vestibular disorders often wish for someone who will listen to them with empathy – not judgement, listen with a deep knowledge – not dismissing their concerns, and listen with understanding for the emotional impact vestibular disorders have brought to their lives. The 2020 award winners are:

Alicia Wolf, who many know better as simply "The Dizzy Cook," developed a personal treatment plan including a diet geared toward vestibular migraine patients. She shares tasty recipes and diet tips, and also posts about supplements and lifestyle changes that have helped her in her personal recovery.

"Alicia is always positive, regardless of how she may be feeling that day," said one of the many people who nominated Alicia for this award.

VeDA also thanked Alicia for her invaluable work on the organizing committee for the Virtual Vestibular Conference.

Dr. John Carey is national expert in superior canal dehiscence syndrome, Meniere's disease, vestibular migraine, and other causes of vertigo. He is professor and chief of the division of Otolaryngology & Neurotology at the Johns Hopkins University School of Medicine, where he specializes in the health and diseases of the inner ear that affect both balance and hearing.

"Dr. Carey listens with empathy and truly understands vestibular disorders from a medical perspective, but also understands the far-reaching impact on an individual's life, especially emotionally," said one of the many people who nominated him.

Dr. Sandeep Rajagopal started the **Canberra Dizziness Clinic** in Holder, Australia, where there weren't any other specialized clinics for vestibular patients in that part of the country.

"Dr. Sandeep was the first person who could identify how all my dizziness and vertigo were interrelated, and provide a diagnosis," said one of the many people who nominated him. "He always stays up-to-date on the latest research and is keen to discuss with his patients how this might benefit them."

PAST WINNERS

2019

Dr. Meredith Adams

University of Minnesota Otolaryngology

2018

Dr. Michael Paparella

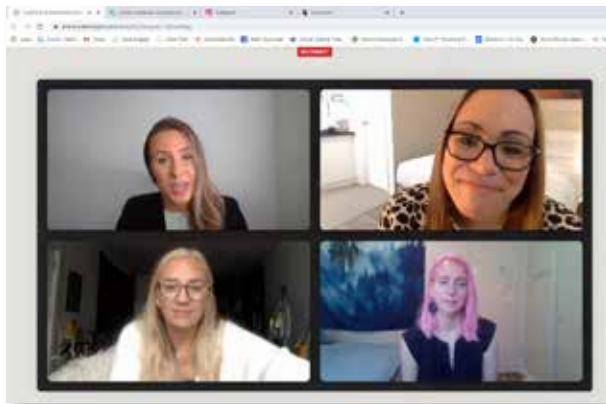
Paparella Ear, Head and Neck

Treva Paparella

Executive Director, International Hearing Foundation

Dr. Kenneth Graupner

Psychiatrist, Beaver Dam, Wisconsin



YOUR SUPPORT MATTERS!

The overarching goal of Balance Awareness Week is to raise awareness of balance-related disorders. By making “vestibular” a household word that everyone can easily understand, people who lose their balance can be more rapidly diagnosed, effectively treated, and gain the empathetic support they need from friends, family, and co-workers.

Thanks to your support, VeDA can advance the funding, research, and policy-making needed to positively impact the lives of millions of people struggling with the debilitating impacts of vestibular dysfunction.

TOP FUNDRAISERS

Sandra Roberts > \$3,500.00
Alex Shaddock > \$738.18
David Morrill > \$562.68
Ashley Virgilio > \$528.38
Rebecca Rubin > \$479.12
Anna Needle > \$235.00
Laura Cala > \$200.00
Joy Mohr > \$200.00
Dennis Fitzgerald > \$165.17
Etta Sundberg > \$150.95



TOP FUNDRAISING TEAMS

Unstoppable Dizzy Detectives > \$904.33
Ambassadors United > \$562.68
Ménière's Warriors > \$235.00

Thank you also to everyone who hosted a fundraiser on Facebook, Instagram, or other digital platform. Together, we are uncovering the mystery of the vestibular experience!

CONFERENCE RECORDINGS

If you missed VeDA's first Virtual Vestibular Conference or would like to re-watch the live presentations and patient panels, you can purchase all 6 for \$20, which goes to support vestibular patients on their journey back to balance.

For more information, visit vestibular.org/vvcreplay/

THANK YOU TO OUR SPONSORS

Thank you for helping make this year's Balance Awareness Week and the Virtual Vestibular Conference possible.

Founded in 2008 by a team of otolaryngology/head and neck surgery and several other neurotology experts, **Otonomy** works toward a singular goal: bring new treatment options to patients with hearing and balance disorders. Otonomy's work began with resolving one of the key challenges in the field: enabling drug therapies to reach their targets within the protected inner ear. Today, Otonomy leverages this expertise and technology to develop novel therapeutics addressing important unmet medical needs across the neurotology field. www.otonomy.com.



On behalf of the Dr. Jim & Linda Hainlen Discovery Fund in Otolaryngology, the **University of Minnesota–Otolaryngology/Head and Neck Surgery Department** sponsored the Virtual Vestibular Conference. UMin has more

than 100 years of history conducting research, treating patients, and educating the next generation of otolaryngologists. As part of the University of Minnesota Medical School, UMin physicians regularly collaborate with colleagues in other specialties, such as pediatrics and oncology to provide the most advanced diagnostic and treatment options, as well as groundbreaking research opportunities. med.umn.edu/ent.



Dr. Kim Bell, DPT specializes in root cause analysis and treatment of vertigo, dizziness and balance problems in patients of all ages. After suffering with intermittent dizziness and vertigo herself for over 25 years and going from doctor to doctor with no answers or relief, Dr. Bell realized how limited the resources are for people with these problems and developed “The Bell Method,” powered by evidence and driven by empathy. She loves to empower audiences of all ages and backgrounds with the knowledge, skills and confidence to effectively manage dizziness, vertigo, imbalance and unexplained repeated falls. For more info, visit www.betterbalanceinlife.com. ■



Implantation Criteria for Vestibular Implant Research

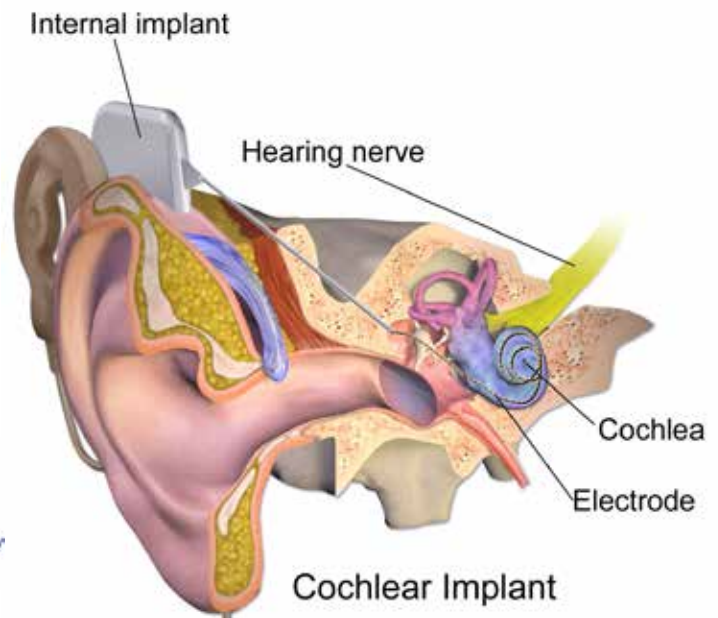
By Mona Fazzina, PT, DPT

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

The paper reviewed below proposes criteria for determining which patients with bilateral vestibulopathy (BVP) might be good candidates to participate in research studying the efficacy of vestibular implants (VI).



Bárány Society
The International Society for Neuro-otology



Bilateral vestibulopathy (BVP) is a condition characterized by significantly reduced vestibular function in both ears. Symptoms include dizziness, imbalance, and oscillopsia (a visual blurring that occurs during head movements). BVP negatively affects the patient's quality of life and increases their risk of falls. BVP can be caused by a number of secondary conditions, including ototoxicity and autoimmune disorders, or occur for unknown reasons. Current treatments include vestibular rehabilitation therapy to improve balance and visual acuity during head movements. Unfortunately, most BVP patients do not regain full function.

The vestibular implant (VI) has been proposed to facilitate restoration of vestibular function for BVP patients who meet stringent criteria. The VI is a prosthetic device that provides continuous, long-term, motion-modulated stimulation via electrodes to the three semi-circular canals in the inner ear. VI surgery is irreversible. Therefore, a comprehensive risk-benefit analysis is critical for determining which patients might benefit from this procedure, despite the potential risks.

This paper sought to provide a basis for determining criteria for VI as a foundation for future research.

VI implantation criteria are not the same as diagnostic criteria for BVP. The major difference between VI-implantation criteria and the approved diagnostic criteria for BVP is that all included vestibular tests of semicircular canal function (head impulse test, caloric test, and rotatory chair test) need to show significant impairments of vestibular function in the implantation criteria.

The provisional VI criteria recommended include (but are not limited to):

1. Chronic vestibular syndrome with unsteadiness when walking or standing, especially in darkness or on uneven ground, and movement-induced blurred vision.
2. Symptoms are greatest during head movement.
3. Bilaterally (on both sides) reduced VOR (vestibular ocular reflex – reflexive eye movements used for stabilizing your vision).
4. Symptoms are not accounted for by another disease.
5. Test results to demonstrate deficiencies in all three tests of semicircular function: the head impulse test, the caloric test and the rotatory chair test.

Illustration of cochlear implant courtesy of Blausen.com. "Medical gallery of Blausen Medical 2014". WikiJournal of Medicine 1 (2). DOI:10.15347/wjm/2014.010.

The authors state that the VI is not a treatment technique for decreased function of the vestibular nerve or the central vestibular system.

VI surgery can adversely affect residual vestibular function irreversibly. Other potential and serious complications from VI surgery include hearing loss and facial nerve paralysis.

Success in benefitting from the VI depends in part on the patient's understanding and ability to use it, tolerate it, and participate actively and effectively in the post-implantation rehabilitation phase. A six-month waiting period following onset of symptoms is strongly recommended to determine the course and prognosis of BVP before considering VI. The entire vestibular team must agree on the operability of the patient. Psychological and psychiatric disorders complicate the process of evaluating a patient for the VI.

There are two versions of the VI. One to restore just vestibular function and another that includes a cochlear implant, which could also help restore hearing.

SUMMARY

Bilateral vestibulopathy (BVP) is a debilitating condition. Current treatment options offer only a limited chance of recovery. The vestibular implant (VI) is a promising surgical treatment, but potential complications pose a high risk to patients participating in the research process. Therefore, strict criteria for VI candidacy is essential to ensure patient safety. ■

Source: Berg R, Ramos A, van Rompaey V, et al. The vestibular implant: Opinion statement on implantation criteria for research. *Journal of Vestibular Research: Equilibrium & Orientation*. 2020;30(3):213. <https://archive-ouverte.unige.ch/unige:138787>. Accessed Aug. 24, 2020. doi: 10.3233/VES-200701.

Mona Fazzina, PT, DPT has a certificate in Vestibular Rehabilitation. She is a board-certified clinical specialist in geriatric physical therapy, and a certified exercise expert for aging adults.

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 health care systems are overloaded.



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

VEDA

JOEY REMENYI

A vestibular audiologist based in Australia's Wadawurrung Country near Melbourne, Remenyi has a background in psychology, neuroscience, acceptance commitment therapy, and cognitive behavioral therapy.

Over the last 10 years, Remenyi has created a program called "Rock Steady" for people suffering with persistent vertigo or tinnitus. Her program seeks to change the brain and body with a recovery process called "neuroplasticity."

Her first book, **Rock Steady: Healing Vertigo or Tinnitus with Neuroplasticity** is set for release this November.



"As a vestibular audiologist in Western treatment models, I thought we were letting clients down. We were testing them, getting them medication and MRI reports through doctors to get them some vestibular rehabilitation therapy or psychology support. Then they're told to go live with it -- that's as good as it gets," Remenyi says. "I really feel like we can do so much more than that."

Remenyi recently spoke about her personal vestibular journey with Cynthia Ryan, VeDA's executive director. This interview has been edited for brevity.

VeDA: What was it like the first time you started experiencing vestibular symptoms?

JOEY REMENYI: I know the exact moment when I recognized I had vestibular symptoms. At that point I was a vestibular audiologist. I knew all about vestibular disorders and had treated lots of people. One morning I woke up and was like, Whoa! I could see the room spinning. It was classic BPPV (Benign Paroxysmal Positional Vertigo).

Before that, I have a history of being very anxious, very sensitive to migraine, visual distortion, not feeling quite right, feeling that there's a party in my brain, but I would not have known any of that was vertigo. This was my pre-vestibular education in life.

Going through hormonal changes in my adolescence I had some symptoms and distortions. I gently call them "not quite right" sensations. They became much more intense and much more difficult to ignore or pretend they weren't happening in my mid-to-late 20s. That

was when I started questioning, Can I even go out to a restaurant? Can I go out for a meal with friends? Can I drive my car around? Am I safe? It's that feeling of the rug's been pulled from underneath me, my internal compass is missing, and I don't know where is up or down anymore. It's a similar feeling I have if I go underwater and I don't know where the surface is. It's like, how do I get to the top? Where is it?

The vestibular experience became a part of my daily life. I understand it so much better now in hindsight.

VeDA: You thought your feelings were just part of life and that they would go away on their own, even though they kept coming back up. As a vestibular healthcare provider, you knew intellectually, consciously what was going on, yet you still reacted with anxiety. What is it like for someone who doesn't know what's going on, especially if they're told it's just nothing?

JOEY: It's common to have this feeling of, where am I, what's going on? And, how long is this going to last? You freak out and get all this natural anxiety going on. That's a normal brain response.

In my case, I'm highly anxious, a classic candidate for PPPD (Persistent Postural-Perceptual Dizziness). I've got all those hyper-vigilant markers: I think the world is going to fall on top of me, something bad is going to happen, but that's my baseline temperament and personality. It's the same with my "not quite right" feelings and vestibular migraine; I feel like there's a part of me that is fundamentally wrong.

As a child I had pretty intense asthma and I was

hospitalized. That really punctuated my entire childhood, all the way through to the age of 15. I have a lot of memories of blacking out, not having enough oxygen. I was allergic to the grass, the pollen, and cats.

So what this means psychologically is from a very young age I felt like my body was a failure. I had a lot of trust issues. That fed the anxiety. From a neuroplasticity point of view, that set up the structures in my brain to not trust my body, to not trust the world. This was also my experience at school with friends, and with other adults. It was like, well, you're sensitive, so get over it, deal with it. The message was, I can't trust anybody because I'm sensitive and allergic to everything and that's not okay.

So basically my coping mechanism is to be cheerful, bright, to fake it, to push through. Now I'm in my mid-30s and realizing how exhausting it was!

It makes so much sense now, my work, and why I was fascinated by the vestibular conditions. I really felt what my clients were going through. I'd meet people and they'd be describing this spinning and the stomach falling, and having a pinball machine in their brain, or feeling dissociated. I've felt all that.

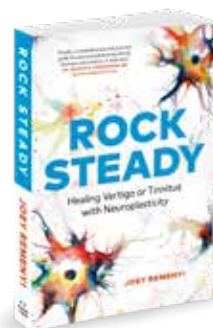
I had four very difficult years of feeling very anxious, very alone, very traumatized, depression, isolation. I went through a suicidal period of just wanting out. For me it felt like this apprenticeship of figuring out my own neuroplasticity, my own healing. It was very lonely but I'm super grateful for that four-year period because it gave me perspective, compassion, and empathy, and at the end of it I had this incredible toolkit to help me soothe, settle, and recalibrate.

VeDA: How did you change your approach to your vestibular impairment?

JOEY: I let go of being the victim. I shifted into a mindset where I have no idea how I'm going to heal but I feel willing to try and work it out and say I'm going to do it for myself.

From that place I slowly started to build my strength, build my confidence, regulate my emotions. It might have been a whole year later that I actually discovered for myself self-compassion and what it meant to hold and nurture myself and be tender to myself.

All of these stressors in life actually change the biochemistry of our body and change what we sense, feel, and hear. Our sensations are



Joey Remenyi is graciously donating electronic copies of her new book, **ROCK STEADY**, to those who donate to this year's Giving Tuesday campaign benefitting VeDA.

For more information, visit vestibular.org/givingtuesday

moving and growing with us, and that is why neuroplasticity is so effective in healing, because it is so dynamic and changeable. We can teach the brain how to filter and categorize certain error messages.

The brain chemistry is getting the fight, flight, freeze on repeat all day long, even when I'm sleeping. It's the adrenaline and the cortisol, the chemical cocktails are saying "I don't trust this, I don't trust myself, I'm not safe."

From a neuroplasticity point of view, which is our brain and our body's capacity to change and reset and rearrange itself like road networks, that can't happen in that state. If we're in fight, flight, freeze, with that adrenaline, cortisol brain cocktail, in a chronic situation, it actually changes the shape of our brain.

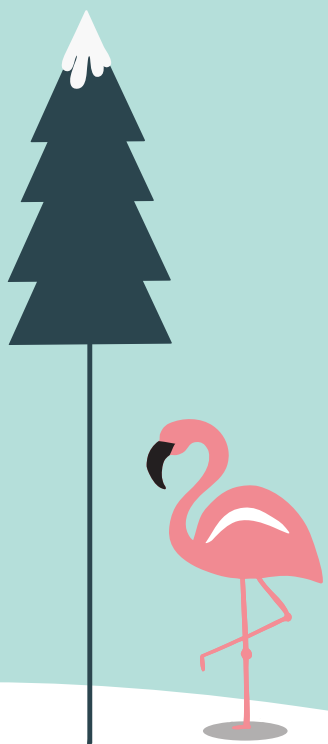
Fast-forward to my journey of self-kindness, learning about emotional self-regulation in a new, more adult way, learning how to be more tender and gentle with myself. Suddenly I shifted my brain chemistry, and those chemical cocktails were now more oxytocin and dopamine and these beautiful hormones and neurotransmitters that actually help me feel more stable, steady, settled and eventually to feel courage, confidence and inner peace. I could strategically and methodically build those chemical cocktails in myself through knowing what I was feeling and supporting that and knowing what I wanted to feel and how to get there.

This is where I've come to a new style of therapy that says, I can inform you about your inner ear and your brain and I can give you education about how it's all moving through your emotional systems and how they're related, how the system can have error messages and how it has the potential to heal. How you are going to do that is a self-study process that you will nurture yourself through. It's not something the external expert can dictate. This fits a new style of therapy which is much more about self-inquiry and building self-trust. ■

For more information, visit Remenyi's website at Seekingbalance.com.au.

HOLIDAYS WITH COVID

Traditionally, the holiday season has presented challenges for people with vestibular disorders. Family and social engagements can cause sensory over-stimulation, resulting in fatigue and triggering symptoms. As a result, many people have avoided social situations altogether.



For more tips and tools for treating and coping with vestibular diseases and symptoms, visit VeDA online at vestibular.org/coping-support

VEDA
LIFE REBALANCED

But this year is different because of COVID-19. Many families and organizations have canceled plans for in-person gatherings to limit exposure.

Social isolation during the pandemic, however, presents its own sets of challenges. According to a report by the Kaiser Family Foundation, many people are reporting negative impacts on their mental health and wellbeing, such as difficulty sleeping or eating, increases in alcohol consumption or substance use, and worsening chronic conditions, due to worry and stress over the coronavirus.

Here are some tips that can help everyone keep on keeping on through the holidays.

PRACTICE SOCIAL WELL-BEING

Many people are opting for virtual, rather than in-person, social events, which are convenient but pose their own set of challenges. Extended screen time can be very draining and trigger vestibular symptoms.

It's important to know your triggers and avoid them, and when it is not possible to avoid them, do what you can to minimize them. Check in with your body periodically so you do not push yourself beyond your limits without realizing it.

EXERCISE

This isn't the time to shirk your walking poles or cane. Stay active but be safe, and use assistive devices as needed to prevent falls.

Consult with a physiotherapist about your personal circumstances and the kind of movement and exercise recommended for you, and take into account that your symptoms may be increased during the winter months.

EAT HEALTHY

It's normal to crave carbs during the colder months and splurge on holiday treats once in a while. But in general it's best to avoid foods and beverages that have a high salt or sugar content. A diet high in fresh fruits, vegetables, and whole grains, and low in canned, frozen, and other processed foods helps control salt and sugar intake. It's also important to stay hydrated, and keep on your medication schedule. ■

RECIPE

BY ALICIA WOLF
(AKA "THE DIZZY COOK")



PUMPKIN CHIA PUDDING is a light and easy fall breakfast or dessert. Chia seeds are wonderful for migraine sufferers because they're a good source of magnesium. >>

Studies have found that many people with migraine have low levels of magnesium in the brain and spinal fluid. This is why supplementation is important for those with migraine, even if a deficiency is not detected.

Pumpkin Chia Pudding

Makes 1 serving

1/4 cup	chia seeds
1 cup	milk of choice
1 tsp	vanilla extract
2 Tbsp	pumpkin puree
1/4 tsp	cinnamon
1-2 tsp	honey
1/8 tsp	ground ginger
Pinch	ground nutmeg
1 Tbsp	sunbutter

1. In a 12 oz. mason jar combine milk with vanilla and honey. Shake, shake, shake your booty (and the container) till fully combined. Add the chia seeds and shake some more. Place in the fridge for 1.5 hours or overnight.

2. In the morning stir in the sunbutter, along with any berries or extra seeds you'd like. Enjoy!

Visit vestibular.org/supplements/ for more information.

VEDA

VESTIBULAR.ORG

More than 2 million people visit VeDA's website every year looking for answers.

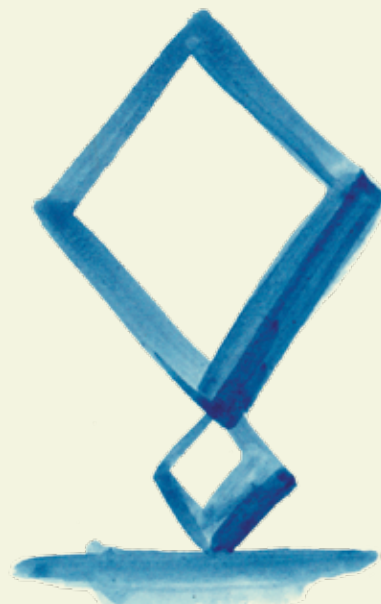
Our Facebook posts reach 3.6 million people, and our Patient Support Coordinator provides one-on-one coaching to 900 people.

Your support makes it possible!

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