

ON THE LEVEL  
NEWSLETTER

FALL 2018

## BIKING TO A LIFE REBALANCED

IT'S AN UPHILL  
BATTLE



VEDA

A QUARTERLY NEWSLETTER  
OF THE VESTIBULAR  
DISORDERS ASSOCIATION

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## Biking to a Life Rebalanced

By Diane Montances

On March 31, 2017, I was quietly sitting at work when I experienced a sudden sharp pain across my entire abdomen. The nerve pain was overwhelming, and I fainted without hitting my head. When I opened my eyes, I was confused and different in a way I couldn't understand. How do you describe vertigo when you've never "seen" vertigo before? For three months I witnessed objects vibrating and tilting, as if there was an earthquake. On a bike ride, my center of gravity seemed to shift in the direction of passing cars, and I immediately stopped riding. At that moment I finally accepted that I needed help.

As a physical therapy aide, I knew my journey started with a visit to my primary care doctor and a vestibular physical therapist (PT). Initially I was diagnosed with BPPV, but my vestibular PT requested a differential diagnosis. The following weekend I did a series of field tests to understand what triggers my vertigo. As a result, we discovered loud sounds and valsava maneuvers\* were the culprit.

Throughout July I read medical journals and VeDA publications to develop the language needed to navigate the healthcare system. After seeing a neurologist and ENT specialist I was finally diagnosed with superior semicircular canal dehiscence syndrome (SSCD). The CT scan revealed severely thin bone in my left superior semicircular canal, and a transmastoid craniotomy was offered to repair it. However, migraine associated vertigo (MAV) is a typical comorbid condition, which complicated the understanding of my symptom etiology. With the dual diagnosis I was advised to trial prescriptions and vestibular rehabilitation until surgery scheduled in October.

While on medical leave, I moved back home with my parents to recover. After several weeks of rest and vestibular rehab, I decided to ride my bike against



**ABOVE:** DIANE'S MOTHER AND BROTHER SUPPORT HER DURING THE REDBULL BAY CLIMB

medical advice. It was a risky decision, but as a long distance cyclist the road is where I feel the most normal. With ear plugs, an aggressive bike position and many trial and errors I discovered an unconventional way to overcome my vertigo.

On a bike a natural centripetal force is created for a rider to maintain balance. By pedaling faster than the vertigo I discovered I can maintain balance by simply rocking into the vertigo. Every

\*A moderately forceful exhalation against a closed airway, usually done by closing one's mouth and pinching one's nose shut while pressing out as if blowing up a balloon.



other day I trained by increasing miles, climbing hills and experimenting with sprints. As I became a stronger rider, my overall balance improved, and I decided to follow-through with my bike tour. On September 30, 2017, I successfully rode 63 miles at the Levi's GranFondo while wearing earplugs. It was a beautiful ride and well worth the hard work.

Two weeks later I had the transmastoid craniotomy performed to disable my left superior semicircular canal. The craniotomy had no complications and



ABOVE: DIANE - TWO WEEKS POST-CRANIOTOMY

successfully corrected my sound-induced vertigo. However, it also created new vestibular symptoms, too. My migraines became worse after surgery, and I had to be retrained on how to sit, stand and walk from the bottom up. Habituation is a rough journey, but the only way to overcome dizziness is to train through dizziness. With vestibular rehabilitation therapy we retrained my brain to find equilibrium with only my right superior semicircular canal. On November 30, 2017, I returned to work as scheduled.

I continued vestibular rehabilitation, but I still struggled to compensate in loud and busy environments. In February 2018, I was diagnosed with persistent-postural perceptual dizziness (PPPD), and I slowly sank into depression and anxiety. The combination of prescriptions, lack of social support and daily stress forced me to admit myself into inpatient psychiatry. It was a terrifying decision, but it was certainly the best choice I made this year. Through inpatient psych and an intensive outpatient program I've learned invaluable coping skills to manage my chronic pain, dizziness and stress. I've befriended others struggling with invisible diseases, and I'm now a vocal patient advocate because of our shared experiences. I joined VeDA as an Ambassador to support patients with chronic dizziness and imbalance.

For Balance Awareness Week I created Team VeDA cycling jerseys and bib shorts to raise vestibular awareness among cyclists in the San Francisco Bay Area. On September 8, 2018, I competed in the Red Bull Bay Climb, which was a sprint on one of San Francisco's iconic hills.

Despite finishing last it was exhilarating to compete with support from family and friends. Vertigo has transformed me into a stronger rider and has brought me

closer to my local bike community. I regularly participate in group rides and continue to live a very active lifestyle.

This October I planned to ride 100 miles at the Levi's GranFondo, but a recent bike accident has postponed my training. It's disappointing, but life is full of unexpected obstacles. With rest and training I'll be strong enough to do the full century with my flock of flamingoes next year. (Did you know a flock of flamingoes is called a "flamboyance"?)

The future used to scare me, but I've changed my mindset and live every day in the present. By regularly practicing self-compassion and gratitude I've become a better person because of my disabilities. I'm very blessed to have a large medical team and loyal friends for social support. I currently

**"THE FUTURE USED TO SCARE ME, BUT I'VE CHANGED MY MINDSET AND LIVE EVERY DAY IN THE PRESENT."**

live independently, but I'm happy my health has brought me closer to my family. And whenever I'm on my bike, I like to scan my surroundings and smile about how inconceivable that used to be.

## Supporter Spotlight

**Balance Benefactors** are donors who have given a gift of \$250 or more in the last three years.

Welcome to our new Balance Benefactors:

- John Green
- Julia Ann Bourne
- Lawrence Kreicher

Lawrence is a long time donor. He has been generously donating to VeDA since 1996. THANK YOU!

Julia Ann Bourne has been a VeDA donor for a little over a year but has already participated in the Dizzy Dash and become a Balance Benefactor.

John Green made two lists in one month: new donor and new Balance Benefactor. Welcome!

**Balance Society** donors have given \$5,000 or more to VeDA over their lifetime.

Congratulations to new Balance Society donors:

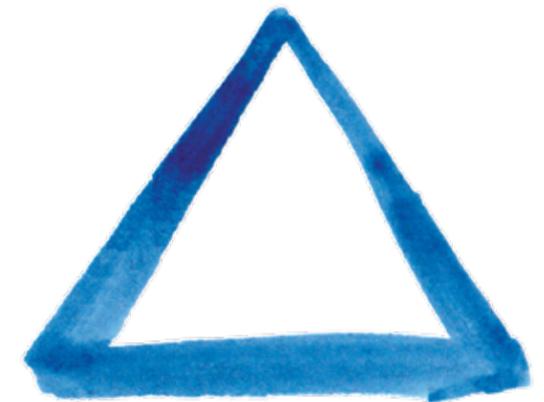
- Laura Stanford
- The Phyllis & Perry Schwartz Foundation

Laura has been supporting VeDA since 1996 and has been a Balance Benefactor for many years.

The Phyllis and Perry Schwartz Foundation has been with VeDA since 2010.

We also have a long-time donor who wishes to remain anonymous who is a Balance Benefactor and recently joined the Balance Society.

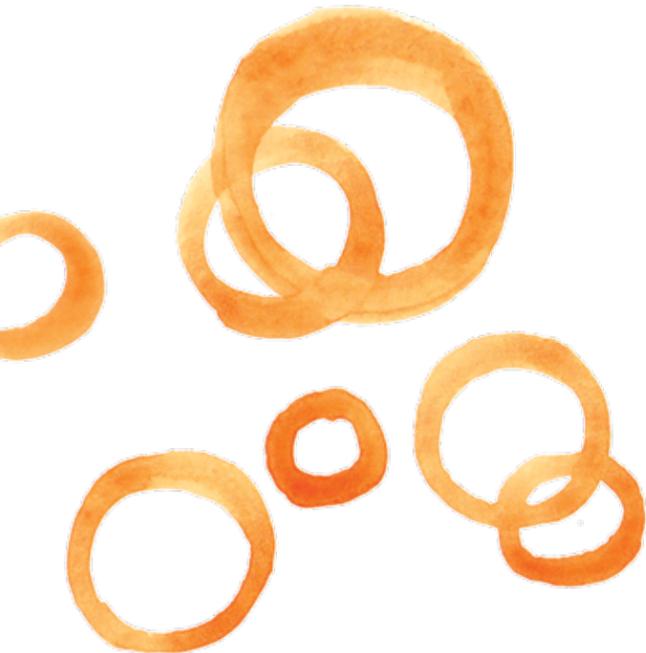
If you would like to join the Balance Society, call Michelle Eyres, Development Manager, at 800.837.8428.



## VEDA SUPPORT GROUP NETWORK

Support groups provide an invaluable service: acceptance. VeDA provides services to help people start and manage support groups for vestibular patients. Following are the names and locations of support groups in the VeDA Support Group Network (VSGN). If you are interested in participating in one of these support groups (SG), visit [vestibular.org/support-groups](http://vestibular.org/support-groups) for contact information. VeDA also offers online support groups to people who do not have access to a local group. If you are interested in participating in an online support group, submit your information at [vestibular.org/onlineSGform](http://vestibular.org/onlineSGform).

- Banner Vestibular SG - Phoenix, AZ
- Denver Dizzy Clinic SG - Denver, CO
- Conde Center for Chiropractic Neurology Vestibular Disorders SG - Delray Beach, FL
- Cape Coral Vestibular SG - Cape Coral, FL
- FYZICAL Therapy and Balance Centers SG - Fort Myers, FL
- North Georgia Vestibular Disorders SG - Canton, GA
- Balance Chicago SG - Chicago, IL
- Vista Health Dizziness and Balance SG - Gurnee, IL
- Goodlife Physical Therapy Vestibular SG - Orland Park, IL
- Vestibular SG - Markham, IL
- Finding Balance in a Spinning World - Columbus, IN
- Des Moines Area Vestibular SG - West Des Moines, IA
- Kansas City Area SG - Overland Park, KS
- Alma Dizziness & Imbalance SG - Saint Louis, MI
- FYZICAL Therapy and Balance Centers SG - Waterford, MI
- North Jersey Vestibular Disorders SG - Wyckoff, NJ
- Dizziness and Balance SG of Buffalo & Western New York - Buffalo, NY
- Xcel Sports Medicine SG - Vandalia, OH
- Life Motion Balance Center SG - Tulsa, OK
- Portland SG - Portland, OR
- Vestibular Disorders SG - Pleasant Hill, PA
- Life is a Balance SG - Dover, PA
- Trujillo Alto Vestibular SG - Trujillo Alto, Puerto Rico
- Charleston Dizzy Group - Mount Pleasant, SC
- The Dizzy Club - Austin, TX
- Houston Area SG - Houston, TX



## Volunteer Spotlight: Kayla McCain

Three cheers for Kayla McCain, who is using her graphic design skills to create eye-catching patient education fliers based on VeDA's most popular articles.

Kayla's vestibular journey started in October 2016. She and her husband were at home watching a scary movie, which turned into a true horror-show for her.

"A sensation came over me where I felt as if I was sinking into my couch as the room started to spin," said Kayla. "My heart began to race, my face became numb and I lost all control of my balance. Like any sane person, I thought I was having a stroke or a heart attack, until I used my common sense to realize, I'm a healthy 27-year-old. It has to be something else."

A few weeks went by and Kayla began to feel like she was constantly intoxicated. She was given numerous diagnoses: sinus infection, BPPV, multiple sclerosis and superior semicircular canal dehiscence. She underwent two CT scans, an MRI, a hearing test, a vision test - the works. Finally, her ENT determined that she had been suffering from vestibular migraines.

"When you're going through something that impacts your quality of life, it's easy to give up hope," says Kayla. "It's easy to think you're going to be stuck like this forever." A strict migraine-friendly diet helped Kayla start to feel like a normal person again. She is also managing her stress and taking an assortment of vitamins and some "Kayla-friendly" medications.

Today, Kayla feels 85-90% normal on most days because she has worked hard to find the best treatments and lifestyle changes. "I refuse to let a vestibular diagnosis define

my life," she says.

Kayla loves VeDA's Balance Awareness Week flamingo mascot because "we truly take our balance for granted until it's been taken away, and here is this flamingo showing off that it can stand on one foot."

"Balance Awareness Week showed me that I was not alone," says Kayla. Today, Kayla is thrilled to be an ambassador for VeDA and able to share with others why it's important to gather as a community and spread the word about vestibular disorders.

You can follow Kayla on her blog at <https://www.truekaylaisms.com>.



# BALANCE AWARENESS WEEK 2018

## FIONA FLAMING PHOTO CONTEST WINNERS

"Funniest"



"Flamingo on Location"



"Best Flock"



"Best Group"



"Best Rehab"



## SOCIAL MEDIA POSTS YOU SHARED

Vestibular what? Most people don't know what "vestibular" means, or how a disorder of the inner ear can impact your ability to balance, as well as vision and brain function.

REACH: 112,896

**VESTIBULAR WHAT?**  
DISCOVER LIFE REBALANCED

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

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

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

Places with busy visual stimuli can trigger vestibular symptoms. That's why it's hard for people with inner ear and brain disorders to go to supermarkets, malls, restaurants, airports, and other public places.

REACH: 35,805

**DID YOU KNOW?**

Grocery stores, restaurants, movie theaters and large crowds can be difficult environments for someone with a vestibular disorder.

**VEDA**  
VESTIBULAR.ORG

Who knew an inner ear disorder could impact the brain?

REACH: 33,686

**DID YOU KNOW?**

Inner ear disorders overload your brain, making it hard to think, speak or read.

**VEDA**  
VESTIBULAR.ORG

Wow! Vestibular disorders are more common than you think. But because they're invisible, patients don't look "sick." Help us make "vestibular" a household word by sharing!

REACH: 31,958

**DID YOU KNOW?**

Vestibular disorders affect more Americans than type II diabetes, asthma, fibromyalgia and celiac disease combined.

**VEDA**  
VESTIBULAR.ORG

TOTAL REACH OF ALL BAW FACEBOOK POSTS: 670,000



# BALANCE AWARENESS WEEK

SEPT 16-22, 2018

## TOTAL RAISED: \$47,800

### TOP FUNDRAISERS

- Ellis Kern - \$6,608
- Sandra Roberts - \$3,796
- Kathleen Stross - \$3,039
- Janit Greenwood - \$2,504



### EVENTS



#### LECTURES

Vestibular therapist and support group leader, Nathalie Grondin from Lee Health, held four lectures and free balance screenings during BAW. Topics included Balance for Life, Dancing for Balance, Walking for Balance and Tai Chi.



#### HOUSE PARTY

Lara Bishop hosted a flamingo-themed house party, complete with cake, balloons and pin the leg on the flamingo. She educated friends and family by decorating the house with post-it notes listing vestibular symptoms such as brain fog.



#### PATIENT SPEAKS TO DOCTORS

Meniere's patient, Sharon Huppert, spoke to the research team at Otonomy about the impacts of living with this frustrating, and debilitating but invisible disorder. Otonomy is developing a treatment for Meniere's and values patient input.



21 people held a birthday fundraiser on Facebook in honor of Balance Awareness Week

Total Raised: \$4,355

### BALANCE CHALLENGE



VeDA board member, Kathleen Stross, challenged friends to donate \$1 to her peer-to-peer fundraising campaign to take a video of themselves spinning around in a circle 10 times and tagging 3 friends.

### THANKS TO OUR SPONSORS!



## Champions of Vestibular Medicine

Champions of Vestibular Medicine are medical professionals who have had significant impact on increasing awareness of vestibular disorders. Thanks to their leadership we're seeing new diagnostic tools and treatment protocols that help reduce diagnosis times and increase treatment effectiveness.

### TIMOTHY HAIN, MD - CHICAGO DIZZINESS & HEARING CLINIC



Dr. Hain, a neurotologist, is the Director of the Chicago Dizziness and Hearing Clinic, and a professor emeritus at Northwestern University. In addition to his clinical and research work in the field of vestibular disorders, Dr. Hain's website, <https://www.dizziness-and-balance.com>, has educated thousands of patients and healthcare providers. One of his greatest contributions to the field of vestibular medicine is this resource, which takes Dr. Hain's vast expertise and personal experience and shares it freely. Dr. Hain has been selected to be included in the Best Doctors in America on numerous occasions, most recently in 2018 by US News and World Report, and is also featured yearly in best doctors in Chicago by *Chicago Magazine*.

### CHRISTOPHER ZALEWSKI, PHD - NATIONAL INSTITUTES OF HEALTH



Dr. Zalewski received his undergraduate degree from Pennsylvania State University, his Masters in Audiology from The University of Maryland and his PhD in Audiology from Gallaudet University. Dr. Zalewski has served as a clinical research audiologist with the National Institutes on Deafness and Communication Disorders (NIDCD) at the National Institutes of Health (NIH) since 2002. His primary focus is the investigation of the auditory and vestibular phenotype of rare diseases. Dr. Zalewski has been an adjunct faculty member at the University of Maryland since 2000. His primary interest is in vestibular physiology and balance disorders with an emphasis on rotational testing, otolith assessment and the genetics of rare diseases. Dr. Zalewski also has a personal interest in the historical perspectives of medicine and in particular, vestibular science.

### SUSAN HERDMAN, PT, PHD, FAPTA - EMORY UNIVERSITY



Dr. Herdman is Professor Emeritus at Emory University, founder of Vestibular Rehabilitation: A Competency Based Course, which has become the gold standard in training healthcare professionals in vestibular rehabilitation therapy, and co-author of Vestibular Rehabilitation, the definitive textbook on the management of vestibular diseases and disorders, now in its 4th edition. Dr. Herdman's research interests include determining predictors for successful rehabilitation of people with vestibular loss and examining the development of the mechanisms involved in the recovery of gaze stability. She is recognized as one of the world's leading authorities in vestibular rehabilitation and a pioneer in training a new generation of vestibular rehabilitation therapists.

## Double Your Money

### DID YOU KNOW . . .

**BILLIONS of dollars** in corporate employee matching gifts go unused and unclaimed every year? According to Donorbox Nonprofit Blog, \$10 billion in unclaimed matching gifts are left on the table annually. Does your company have a matching gift program?

Accessing your company's matching gift program is an easy process. Check with your Human Resources Department to obtain the necessary paperwork. If you need documentation about your gift from VeDA, contact Michelle Eyres, Development Manager, at 800.837.8428 or [Michelle.Eyres@vestibular.org](mailto:Michelle.Eyres@vestibular.org).



## YOU CAN HELP.

### DONATE

Your gift helps VeDA support vestibular patients, reduce diagnosis times and improve treatment outcomes. You can donate online at [vestibular.org](http://vestibular.org) or mail your check in the enclosed envelope.

### RENEW YOUR MEMBERSHIP

If your membership is expiring soon, you will be receiving an invitation to renew. Please return the enclosed envelope to continue receiving this newsletter and other membership benefits.

To donate, visit [vestibular.org/OTL](http://vestibular.org/OTL)



MEET EILEENE, A VEDA MEMBER AND MENIERE'S PATIENT FOR OVER 30 YEARS.

## Research Corner: Motion Sickness Prevalence

By Kamran Barin, PhD

Motion sickness is a condition characterized by dizziness, physical distress and fatigue that often leads to nausea and vomiting. It occurs when there is disagreement about the perceived motion from different sensors such as visual, vestibular and those from the muscles and joints. This epidemiological study examines the prevalence of motion sickness in different vestibular disorders.

### BACKGROUND

We use information from the visual, vestibular and somatosensory systems to detect our orientation. Mismatch in the perception of motion among the sensory mechanisms leads to a condition called motion sickness. Motion sickness usually begins with a sensation of dizziness, fatigue, sweating, oversensitivity to smells and other manifestations of physical distress. It often leads to nausea and vomiting. It is not surprising that motion sickness is more prevalent in patients with vestibular disorders, but it is unclear which vestibular disorders are more susceptible to this condition. This study tries to answer that question.

### METHODS

This study enrolled 785 patients with confirmed vestibular disorders, but the results were analyzed for only 749 of them because of missing data. The patients were given a standardized questionnaire about their susceptibility to motion sickness. The results were tabulated for different types of vestibular disorders.

### RESULTS

In a previous study of healthy subjects the prevalence of motion sickness was 13.4%. The current study showed a significantly higher prevalence (32.3%) of motion sickness among the vestibular patients.

Patients younger than 30 years old had the highest prevalence while the patients older than 80 had the lowest. Women also showed a slightly higher prevalence compared to the men. Prevalence among patients with a current vestibular diagnosis:

- Vestibular migraine: 56.9%
- BPPV: 48%
- Orthostatic dizziness: 37.5%
- Meniere's disease: 35.1%
- Functional dizziness: 32.7%
- Unilateral vestibulopathy: 32%
- Vestibular paroxysmia: 30.8%
- Central dizziness: 25.5%
- Bilateral vestibulopathy: 12.4%

Presence of motion sensitivity with bilateral vestibulopathy is a surprise because it is assumed that the loss of vestibular function reduces sensitivity to motion. The authors suggest the reason may be incomplete loss of function. However, it is also possible that loss of visual acuity may contribute to motion sensitivity.



### CONCLUSION

This study confirms a higher prevalence of motion sickness in patients with vestibular disorders. The highest prevalence occurs in patients with recurrent attacks such as vestibular migraine, BPPV and Meniere's disease. The study brings awareness to both clinicians and patients about the co-existence of motion sickness and vestibular disorders which should be considered when treatment plans are considered.

### STUDY LIMITATIONS

The sample size is somewhat small for epidemiological studies and determining the susceptibility to motion sickness is subjective. Nonetheless, the study provides useful information about the presence of motion sickness in vestibular patients and can help with formulating better management plans.

### SOURCE

Strupp M, Brandt T, Huppert D, Grill E. Prevalence of motion sickness in various vestibular disorders: a study on 749 patients. Journal of Neurology. July 2018.

## NEW FACES AT VEDA

VeDA says good-bye to Louise Geib, who stepped down as president of our board of directors in July. Louise's experience as a non-profit marketing professional has influenced how VeDA engages our members through all of our communication channels. "VeDA helped me when I was diagnosed with vestibular migraine," says Louise. "I will continue to support VeDA as a monthly donor and volunteer."

Our new board president is Holly Fisher, who has served on VeDA's Patient Education Committee for the past five years. Holly suffers from Mal de Debarquement. "When I was first diagnosed...I had so many questions," says Holly. "The resources I found at VeDA were so important and really helped me understand my condition, learn coping techniques and find doctors that could help me."

VeDA also welcomes two new board members, Ellis Kern and Patricia Gerend. Ellis brings a lifetime of experience in the corporate world to help VeDA develop new fundraising partnerships. Patty is a retired statistical programmer and is working with VeDA's patient registry data, looking for patterns to support our advocacy efforts.

**VeDA has two openings on our Board of Directors. If you are interested, please email [veda@vestibular.org](mailto:veda@vestibular.org).**

There are also openings in the following committees: Communications, Medical Advocacy and Legislative Advocacy. If you are interested in serving on a committee, visit <https://vestibular.org/volunteer> and fill out a volunteer application.



## Pumpkin Spice Mug Cake

By Alicia Wolf, a.k.a. "The Dizzy Cook"

No Added Salt and Heal Your Headache Safe

1 serving

- 1/4 cup flour (if gluten free, substitute 2 tbsp oat flour and 2 tbsp brown rice flour)
- 1.5 tbsp of brown sugar (or sweetener of choice)
- 1/2 tsp baking powder
- 1 tbsp butter, melted
- 1/2 tsp vanilla
- 1.5 tbsp plain pumpkin puree
- 1/2 tsp cinnamon
- 1/4 tsp ginger
- 1/4 tsp nutmeg
- 1/4 cup milk of choice

Mix together all the dry ingredients in an 8oz mug or ramekin, then add pumpkin, milk, vanilla and butter. Whisk until smooth. Microwave on high for 1 minute and 20-30 seconds. Wait for it to cool, about 5 minutes, before eating.

See more migraine-friendly recipes at [thedizzycook.com](http://thedizzycook.com).

