

ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION



INFORMATION

SUPPORT

AWARENESS

ADVOCACY



The Anxiety of Seeking a Diagnosis

By Sherron Laurrell

May used to be my favorite month. Mild spring weather in New Jersey. Freshly planted flowers. Open windows. I always looked forward to May. That changed in 2013. May now represents the anniversary of the month I became chronically dizzy.

I awoke one morning and had trouble walking. My head felt weird. Whoa! What is this? Could it be allergies? I had managed allergy issues for years, but had never experienced dizziness. Now I felt like I was walking on a moving floor.

Five years earlier I had an honest to goodness, room spinning, I'm dying, what the heck is this, kind of vertigo. This was different. I wasn't spinning, I was terribly off balance. My first reaction was "something is really wrong!"

I have a life long history of anxiety that I have learned to manage, but it is always my go-to emotion. I was dealing with this crazy dizziness

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(TOP LEFT) SHERRON'S CAT, SPENCER, PROVIDING MUCH NEEDED COMFORT
(BOTTOM LEFT) SHERRON'S GRANDFRIENDS ADD JOY & FUN TO HER LIFE
(BOTTOM RIGHT) SHERRON'S YOGA INSTRUCTOR, LISA, HELPS KEEP HER BALANCED

On the Level is a quarterly publication of the Vestibular Disorders Association (VEDA), published in Portland, OR and distributed to national and international members. Information in this newsletter is not intended as a substitute for professional health care. 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. © All rights reserved.

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SEEKING A DIAGNOSIS CONTINUED FROM PAGE 1:

and the overwhelming anxiety that I had something dramatic like MS or a brain tumor. I was a mess!

What followed were months of seeing doctors and having tests.

My primary doctor said “vertigo” and sent me to a physical therapist, who knew little about vestibular issues. He said I had a pinched nerve. As he worked on my neck, I would get so dizzy I could hardly walk. “I think you are overly anxious” he would say. Not helpful. I already knew I was freaking out because of the dizziness and nausea. I decided to see an ENT. By this time the ringing in my ears was deafening. The ENT ordered balance and hearing tests and an MRI with and without contrast – which added to my anxiety! In the middle of all of this, my beloved 17 year old cat died.

By the end of July, I had shut down emotionally. I forced myself to leave my house for doctors’ appointments and a weekly visit with a psychologist. At the end of August the test results were in – Unilateral Vestibular Hypofunction, most likely from a virus. The ENT asked if I was willing to try Vestibular Rehabilitation Therapy. After four months of unrelenting nausea, disequilibrium, tinnitus and anxiety that ruled my every waking hour, I would have tried anything.

That’s when I met Dr. Jennifer Liss. Jen is a certified Vestibular Rehabilitation Therapist. We began working together in September 2013. The anxiety was crushing. I was sure I was one stumble away from falling. Jen understood what I was going through. She gave me hope.

I started VRT 2 times a week and at home 4 times a day. I walked 20 minutes a day, which was not easy! I forced myself to eat. I did not improve as everyone thought I would.

In January, my ENT sent me to a neuro ophthalmologist. He “guessed” I had a form of Meniere’s disease. The ENT and Jen said “not Meniere’s.” I continued with VRT. I went gluten free and the nausea subsided.

I got a new cat that I named Spencer – joy wrapped in fur!

In March, Jen sent me to a Vision Therapy Specialist. He was “not surprised VRT wasn’t working because I wasn’t wearing

my glasses.” I had not been wearing my glasses because they are trifocals. Turns out people with vestibular problems should not wear trifocals. He sent me to my eye doctor for 3 sets of glasses: near, mid and far distance. VRT with the new glasses resulted in noticeable progress until spring allergies hit. Back to nausea and dizziness!

Now we are pursuing allergy testing. I keep believing we’ll find the root cause. I keep moving forward.

I was 66 when this started. I’ll be 68 as you read this story. Luckily I was retired. I am much smarter now than I was at the beginning of this journey. I’ve lost 45 pounds (silver lining). I started yoga twice a week, a true blessing in my life! I meditate, and I walk 6000 steps a day (yep, got one of those step counters!).

I’ve accepted that although my friends and family want to understand, they don’t. I acknowledge that I have a chronic, incurable, non-fatal, miserable invisible illness.

I am grateful beyond words to VEDA and my Facebook support group! I am scared at night and hopeful in the morning. And most of all I am deeply sympathetic to all the others, especially the younger people, who have to deal with this while working full-time and raising families. I don’t know how you do it!



SHERRON WITH JENNIFER LISS AND THE ALL-STAR PT TEAM AT THERASPORT PHYSICAL THERAPY

Tips to Keep You Balanced

“ENTERING THE WORLD OF THE CHRONICALLY ILL WAS LIKE MOVING TO A FOREIGN COUNTRY: I NEEDED TO LEARN THE LANGUAGE, FAMILIARIZE MYSELF WITH NEW CUSTOMS, DEVELOP NEW FRIENDSHIPS, AND ADAPT MY LIFE TO A TOTALLY STRANGE SITUATION. THE BEST ADVICE I CAN OFFER TO ANYONE WITH A VESTIBULAR PROBLEM IS THIS: DON’T GIVE UP. KEEP TRYING TO FIND A PATH THAT WORKS FOR YOU. A PATH THAT CAN TURN THIS FOREIGN COUNTRY INTO YOUR NEW HOME.” – SUE HICKEY, “FINDING BALANCE”

“I’VE ACCEPTED THAT ALTHOUGH MY FRIENDS AND FAMILY WANT TO UNDERSTAND, THEY DON’T.”

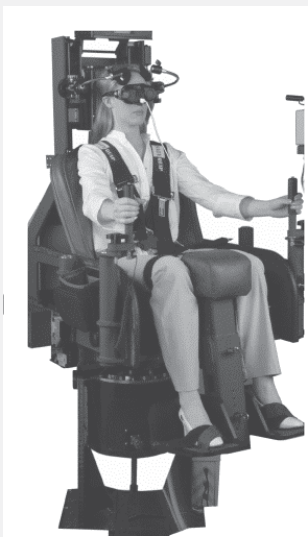
Earlier Diagnosis Can Help Avoid A Lot of Suffering But, Says Veteran Clinical Researcher Congdon, “Improved Technology Makes a Difference.”

Baylor College of Medicine’s Sharon Congdon, a clinical researcher in the Department of Otolaryngology, has been testing patients for vestibular and balance disorders for 27 years. Across those decades, and with thousands of patients passing through the clinic, she has seen any number of medical challenges, many life-changing in severity.

If there’s one common element, she says, it’s that, “so often, an earlier diagnosis could have avoided a lot of suffering. Virtually every day, we see patients who should have been in here years ago.”

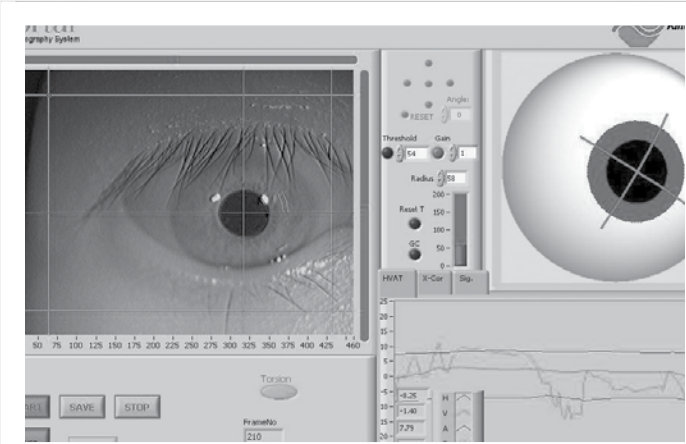
Still, Congdon says, improved diagnosis technology is making testing more precise and accurate, and that is a huge boost to improving patient outcomes.

One example: the faster frequency of rotational testing combined with video-oculography (VOG), such as that offered by international diagnostic equipment manufacturer Neuro Kinetics (www.neuro-kinetics.com).



Video oculography is a method of using an eye-tracking device, equipped with digital cameras, to capture the eye responses to motion and light stimuli. By measuring those movements, audiologists, neurotologists and others medical specialists can have insight into how an individual’s vestibular system is functioning.

“The eye is the portal



to the brain,” says Dr. Alex Kiderman, NKI’s chief technology officer. “Armed with ever-more precise measurements, doctors can make more accurate and timely diagnosis and develop effective treatment programs.”

“QUALITY DIAGNOSIS
STEMS FROM
QUALITY DATA.”
-SHARON CONGDON

The company’s eye-tracking capability stems from its I-Portal® platform technology. When combined with stimulus equipment and operating and analysis software, I-Portal produces detailed, high-resolution analysis of eye movements, with real-time

reporting of results.

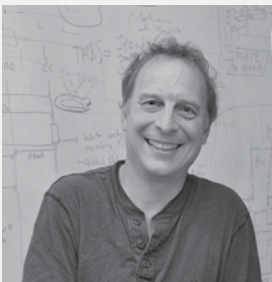
One of the company’s products is its I-Portal NOTC (Neuro-Otologic Test Center) system featuring its renowned Barany chair. Protocols that medical specialists carry out include a battery of rotation tests, pursuits, optokinetics and saccades. The NOTC generates measurements of the eye’s horizontal, vertical, torsional and pupil area responses or reflexive reactions to stimuli.

Says Baylor’s Congdon, “Quality diagnosis stems from quality data. Yes, we’d like to see patients as soon as symptoms begin to appear. But no matter when they show up here, our ability to understand what is happening is getting better all the time. That’s helping a lot of people live better lives.”

Champions of Vestibular Medicine

VEDA ANNOUNCES THE FIRST ANNUAL CHAMPION OF VESTIBULAR MEDICINE AWARDS TO INCREASE AWARENESS OF VESTIBULAR DISORDERS.

DR. DANIEL MERFELD, MASSACHUSETTS EYE & EAR INFIRMARY



Dr. Merfeld is an accomplished neuroengineer and psychophysicist. Much of his early research focused on understanding how the brain processes ambiguous sensory information, with a specific focus on how signals from the otolith organs in the inner ear are interpreted and processed by the nervous system. His research has shown that the nervous system uses rotational signals from canals in the inner ear to help us keep track of the relative orientation of gravity. His most recent research focuses on understanding how the brain processes information in the presence of noise.

DR. CAREY BALABAN, UNIVERSITY OF PITTSBURGH



The primary goal of Dr. Balaban’s research has been to develop a rational basis for understanding the neurobiology of the vestibular system so that new therapies for vestibular disorders can be designed. His research has helped explain the interplay between neurological and psychological features of co-morbid aspects of balance disorders, migraine and anxiety disorders. Recent work extends the implications of these models to analogous features of mild traumatic brain injury and post-traumatic stress disorder.

DR. CAROL FOSTER, UNIVERSITY OF COLORADO

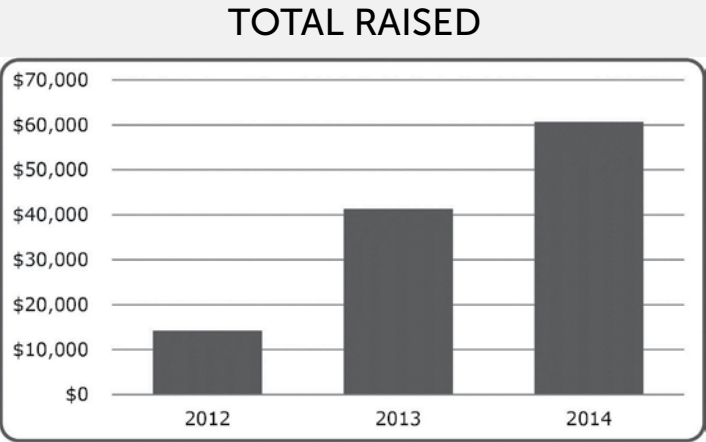


Dr. Foster specializes in the non-surgical treatment of dizziness and imbalance caused by inner ear, brain, or sensory disorders. Foster is also a vestibular patient who suffers from Meniere’s disease and BPPV. With the room spinning around her, Foster developed a maneuver to get the particles out of her horizontal canal and back where they belonged. Now called the “Foster maneuver,” this half-somersault followed by a head turn and another quick move of the head gives BPPV patients a tool they can use at home.

Balance Awareness Week 2014 Highlights

Thanks to YOU, our donors, sponsors, Ambassadors, volunteers, and people who created a personal campaign page, **we raised \$60,689** during Balance Awareness Week - that's a **47% increase** over last year! These funds will be allocated toward further expanding our outreach and advocacy efforts. Thanks to your generous support we're well on our way to reducing diagnosis times. Together we can Defeat Dizziness™!

FUNDRAISING REVENUE	
Total Raised	\$63,030
# Donations	392
Personal Campaign Page (PCP) Revenue	\$38,189
# PCP	45
Sponsorship Revenue	\$23,500
# Sponsors	7



Personal Campaign Superstars

VEDA would like to thank everyone who created a personal campaign page and asked their friends, family, coworkers and social networks to support their campaign to Defeat Dizziness™. We would especially like to acknowledge our superstar fundraisers, who contributed almost half of the personal campaign page revenue.



Kate Gaertner & Mary Ziegler
\$6,086



Gary Breitbord
\$6,025



Sandra Roberts
\$5,865



Thanks to our Sponsors!

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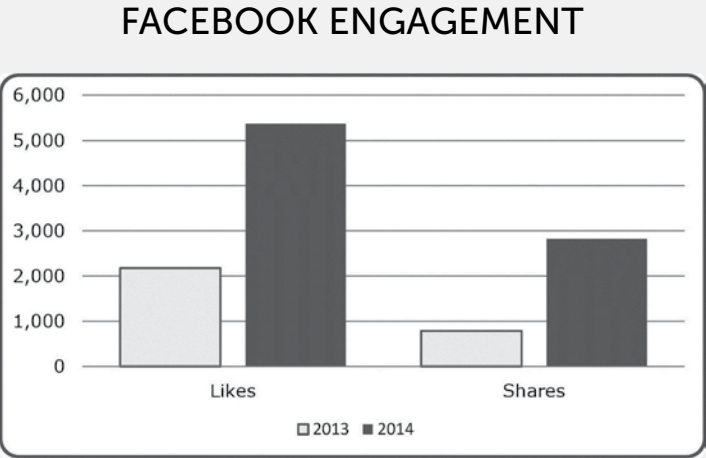
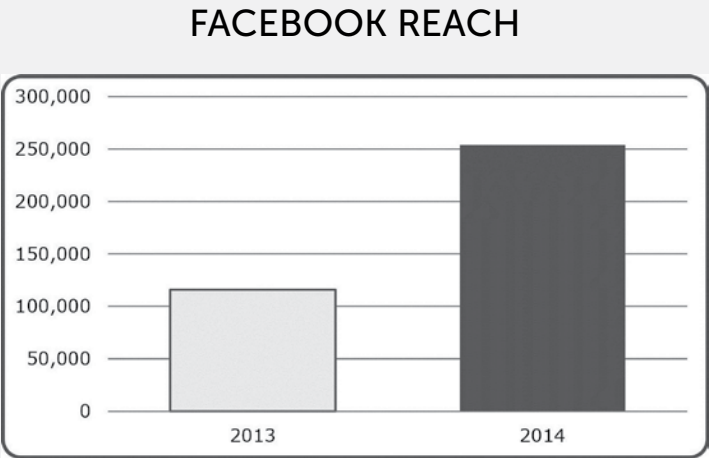


SILVER SPONSORS:



Spreading the Word to Raise Awareness

The goal of Balance Awareness Week is to increase awareness about the impacts of living with a vestibular disorder, especially among people who may not know what “vestibular” means. We do this in many ways, including through social media, mainstream media (e.g. articles in local, regional and national newspapers, magazines, etc.), eblasts, events and posters. We rely on people like you to help us spread the word in your local communities and through your social networks, and we're very excited to report that thanks to YOU and everyone who participated in Balance Awareness Week our outreach efforts were hugely successful!



EBLASTS

	2013	2014
SENT TO	28,397	42,968
OPENED	8,758	13,734

NATIONAL PRESS RELEASE

MEDIA OUTLETS	337
AUDIENCE	71,000,000

MEMBER MEDIA

VEDA sponsors, members and supporters also shared their Balance Awareness Week events with local, regional and national media. Examples include:



» Neurokinetics, a vestibular equipment manufacturer, distributed a press release on VEDA's behalf.



» VEDA Ambassador, Mary Ziegler, placed ads in her local newspapers.



» Fox 4 in Kansas City featured vestibular therapist, Susan Tucker, and her new support group on the evening news.

AMBASSADORS

VEDA Ambassadors participated in Balance Awareness Week through their own personal campaigns to Defeat Dizziness™.

» David Morrill, chair of the VEDA Ambassador board, and Kelly Helsel created videos about what it's like to have a vestibular disorder and shared them on YouTube and Facebook.

» Marissa Christina designed and created "Dizzy not Drunk" t-shirts to promote balance awareness and donated all of her proceeds (\$1,988) to VEDA.

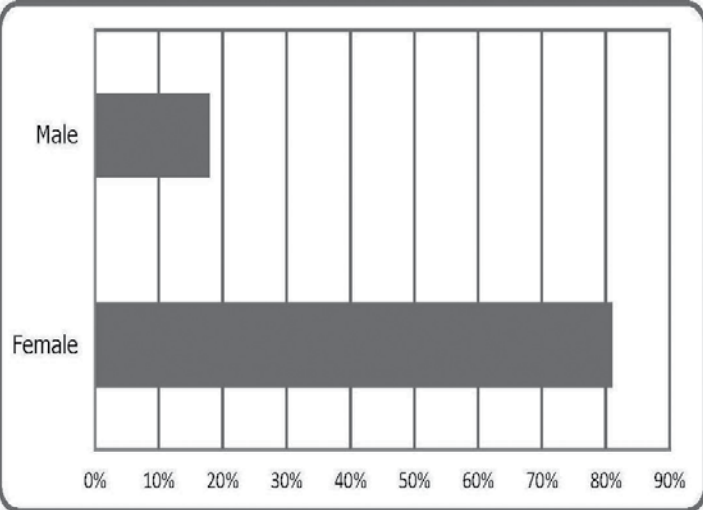
» Ambassadors distributed Balance Awareness Week posters and "Feeling Dizzy?" infographics within their local communities.

You Spoke...We Listened

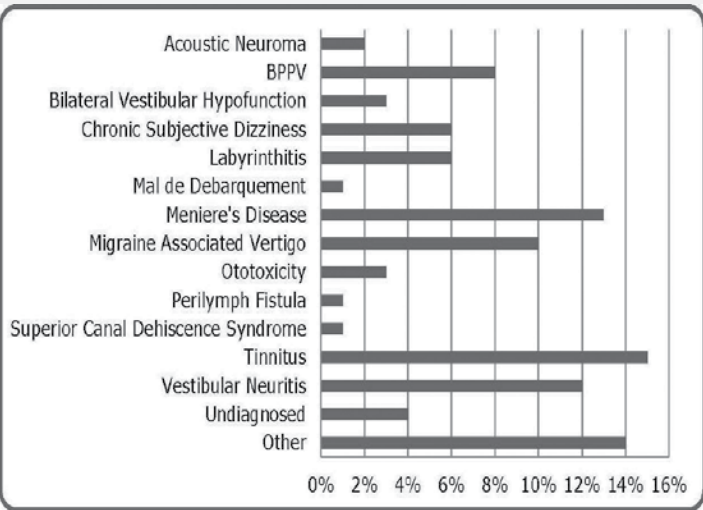
In a recent survey, VEDA asked you how we have made a difference in your recovery and what programs you think are most important. Your input will be used to improve our programs and services. Here's what you said...

WHO YOU ARE

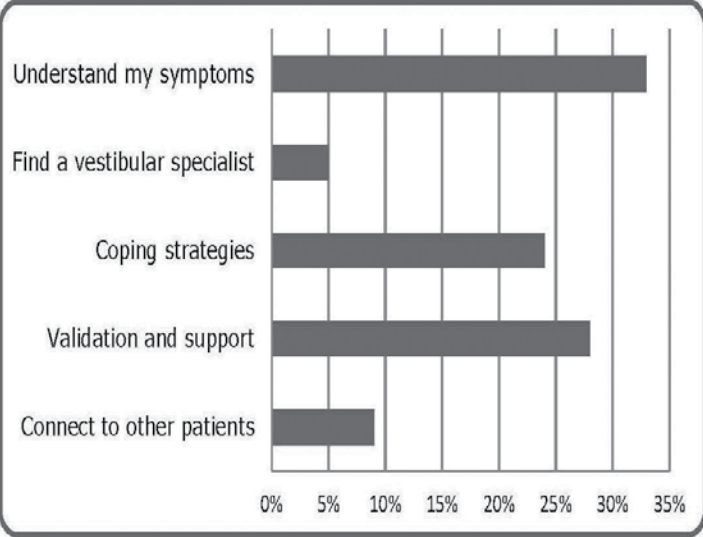
GENDER



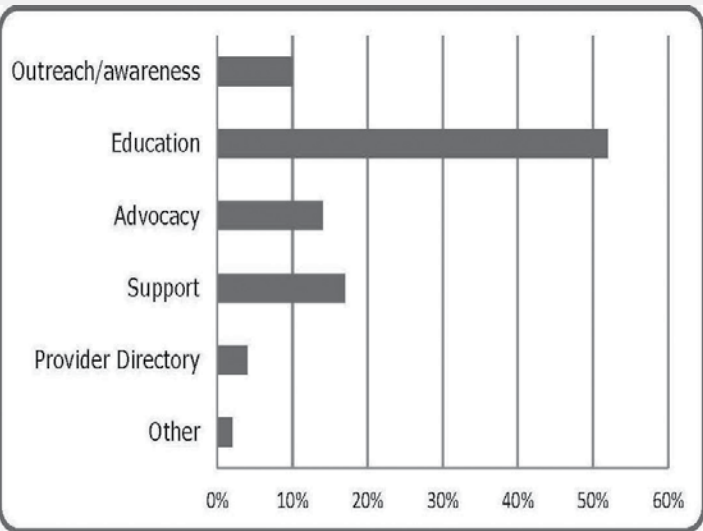
DIAGNOSIS



HOW HAS VEDA HELPED YOU?



WHAT DO YOU THINK IS VEDA'S MOST IMPORTANT PROGRAM OR RESOURCE?



WHAT WE LEARNED: EDUCATING AND VALIDATING PATIENTS IS REALLY IMPORTANT TO YOU!

"THE FACT THAT I WAS EQUIPPED TO BE PROACTIVE WITH MY TREATMENT WAS DUE IN PART TO THE OUTSTANDING RESOURCES MADE AVAILABLE THROUGH VEDA." - CAROL T.

YES! I WANT TO HELP PEOPLE SUFFERING FROM VESTIBULAR DISORDERS.

Your support helps VEDA provide information on vestibular disorders to thousands of people every year. Thank you!

You can make a donation to support VEDA's life-changing work online at vestibular.org/OTL_Fall2014 or send your payment to 5018 NE 15th Ave, Portland, OR 97211 with the enclosed self-addressed envelope.

Donation:

- ☐ \$25 ☐ \$50 ☐ \$100 ☐ \$150 ☐ \$200 ☐ \$250
☐ Other \$ _____
☐ Charge my credit card monthly \$ _____
☐ Please make my donation anonymous

Method of Payment:

- ☐ Check (payable to VEDA in US Dollars)
☐ Visa ☐ MasterCard ☐ American Express

Options:

- ☐ Please send me information about including VEDA in my Will or Estate Planning.
☐ My company will match my donation.
Company Name: _____

NAME _____

BILLING ADDRESS _____

CITY, STATE, ZIP _____

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Thank you for supporting the Vestibular Disorders Association! With your help we can reduce the time it takes to accurately diagnose vestibular disorders and improve treatment outcomes, helping patients live happy, productive lives.

VEDA IS ACCEPTING APPLICATIONS FOR BOARD OF DIRECTORS POSITIONS



VEDA's board of directors leads the organization by guiding its mission, vision and strategic goals. Board members are instrumental in implementing key outreach, advocacy and fund development programs.

We are seeking vestibular patients and medical professionals with experience or relationships that would assist with marketing, fundraising, media relations, legislative advocacy, medical school training and/or communication with professional medical groups.

If you would like an opportunity to be an integral part of a growing organization that is making exciting strides toward defeating dizziness, please consider joining VEDA's board of directors.

TO APPLY:

Send an email with your resume or a brief explanation of your skills and interests to veda@vestibular.org.



VESTIBULAR

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vestibular.org

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CHANGE SERVICE REQUESTED

The Vestibular Disorders Association (VEDA) is a 501(c)(3) nonprofit organization with a mission to serve people with vestibular disorders by providing access to information, offering a support network, and elevating awareness of the challenges associated with these disorders.

If you are interested in volunteering with VEDA, visit us at vestibular.org/volunteer.

Volunteer Spotlight



Sandra Roberts suffers from unilateral vestibular hypo-function, which requires ongoing physical and mental adaptation. Luckily she found Dr. Lisa Farrell, a vestibular therapist, who suggested she check out the resources on VEDA's website.

Sandra says, "VEDA has been instrumental in my recovery process. I found the terminology explanations to my condition, research studies, a support group, and great advice."

Sandra wanted to give back to the organization that helped her regain balance in her life, and help reach out to others who suffer from vestibular disorders. She's been volunteering with VEDA and participated in Balance Awareness Week, where she raised \$4,865 through her personal campaign to Defeat Dizziness™.

Sandra shares these words of wisdom to vestibular patients who may be struggling, "Learn to see that your limitations are an opportunity to enrich your life. Don't be afraid to ask for help, and reach out to support others who may feel lost and alone."

VEDA MEMBER SHARES HER STORY ON CNN.COM



Colleen McEdwards was diagnosed with a serious vestibular condition after years of being subjected to the bright lights, loud noises, and intense stress of her job as a CNN anchor.

Off balance, spinning, and losing her hearing, Colleen retired from CNN and now teaches journalism at Georgia State University. Colleen wants to raise awareness about balance disorders, so she joined VEDA's Communications Committee. Recently, she had a story about her struggles as a vestibular patient published on CNN.com.

YOU CAN VIEW COLLEEN'S FULL ARTICLE AT
VESTIBULAR.ORG/NEWS.

