

ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION



INFORMATION

SUPPORT

AWARENESS

ADVOCACY



A Life Derailed

By Donna Conboy

I had a full life before vertigo, dizziness, vision loss and imbalance stole my freedom and financial security.

I have three biological children – two sons, Luke and Adam, and a daughter, Melissa. My home has always had an open door for at-risk youth, many of whom are dealing with addiction and trying to stay in school and out of gangs. I enjoyed being physically fit and loved my job. I wasn't even 50 when all of a sudden I started feeling like an old woman.

I already held degrees in Exercise and Health Science and was pursuing my Masters in Applied Gerontology. I had worked as the Fitness Coordinator at the Boys & Girls Club, lead health classes at my local senior center, and most recently was a biometrics screener, which required constant travel. My jobs allowed me to meet new people, help at-risk youth, and bring about positive change.

YOUR SUPPORT HELPS PATIENTS
LIKE DONNA FIND A WAY TO GET
THEIR LIFE BACK ON TRACK.

CONTINUED ON PAGE 2

IN THIS ISSUE

| | |
|------------------------------------|----|
| Feeling Confused & Abandoned | 5 |
| Decoding Vestibular Symptomatology | 8 |
| 2016 Annual Report | 10 |
| 2016 Milestones | 12 |
| 2016 Supporters | 13 |
| The Heart of an Ambassador | 16 |
| Dizzy Dash | 18 |
| My Dizzy Dash Story | 20 |



FAMILY IS IMPORTANT TO DONNA. BOTTOM LEFT: DONNA WITH HER "EXTRA" KIDS.
BOTTOM RIGHT: DONNA'S LARGE EXTENDED FAMILY

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A LIFE DERAILED...CONTINUED FROM PAGE 1:

Essentially, I was getting paid to "play."

Then, in 2013, while I was demonstrating a balance testing exercise, I noticed that I was falling to my right side. This was the first sign that something was very wrong with my vestibular system.

I had always been healthy, with the exception of migraines, which I'd had for the past 10 years. Then I noticed that I was having trouble driving at night and over bridges – lights were bouncing and I couldn't see. I had planned on making an appointment with my doctor, but then my father passed away and I was consumed with grief and the logistics of managing his estate.

By the time I could spare a moment to take care of my own health, I could hardly walk and was falling down the stairs. However, there were no doctors available on my health plan, so I had to pay out of pocket just to get an appointment with a primary care physician (PCP).

My PCP had no experience with vestibular disorders, so she just gave me meds and referred me to a neurologist. My MRI came out normal, so the neurologist diagnosed me with BPPV and referred me to an ENT. The ENT gave me more meds, which didn't help, then threw his hands up in the air and said he didn't know what to do. Next, he asked me if I was experiencing anxiety – of course I was! Who wouldn't, with the scary symptoms I'd been having and no one to tell me what was going on. The inference, however, was that my symptoms were all in my head. Next he ordered a VNG test, diagnosed me with vestibular hypofunction, and referred me to a physical therapist (PT).



DONNA WITH HER CHILDREN, LUKE, ADAM AND MELISSA, AND GRANDSON, LUCAS - THE LIGHT OF HER LIFE.

The PT was not specially trained in vestibular rehabilitation therapy, however. She did the Dix Hallpike maneuver to rule out BPPV and started me on visual therapy and basic balance training, but soon discharged me because she didn't know what else to do and nothing she tried made any difference. Another dead end.

Finally, I learned about Emory University, which has a balance clinic renowned for its work with vestibular patients. Unfortunately, based on my VNG results, they said they didn't think they could help me. I knew this was my only hope, so I persisted, and after two years was able to get an appointment with Dr. Jennifer Tirino in July, 2015. It took another year to get my testing completed.

Dr. Tirino had Emory do a complete battery of tests on me. I failed the posturography test miserably. My vHIT was off the scale (1 is normal; I scored 11), which indicated that I was legally blind when my head is in motion. I had zero reactivity to the caloric test (this time done with water; previous calorics had been done with air, which I now know is less accurate).

Dr. Tirino diagnosed me with complete bilateral vestibular loss, which is irreversible. She said she'd never seen a case so profound.

Of course, what I wanted to know was...what can you do about it? That's when I learned that there are no easy fixes. Basically, I'm going to have to learn to live with it, to adjust to a "new normal."

In the meantime, I lost my job because I couldn't travel, which means losing my health insurance (which wasn't helping much anyway).

In April, 2014 I applied for disability and was denied, twice. I'm now waiting for a hearing so a judge can review my case.

I've had to pay for all of my therapy and



DONNA LAUGHS AT THIS PICTURE, BECAUSE THESE SILLY GLASSES ARE LIKE THE ONES SHE HAD TO WEAR FOR WEEKS WHILE SHE GOT USED TO HER PRISM LENSES.

most of my vestibular medical expenses out-of-pocket, \$60,000 over the past three years. Now I'm faced with selling my house so I can use the equity to pay my monthly expenses. Basically, I'm broke.

As if anxiety over my health wasn't enough, now I'm dealing with anxiety and depression because I don't know how I'll make ends meet for me and my family.

On the upside, I've been approved for a vocational rehabilitation program that will retrain me for limited part-time work that accommodates my special needs, though it will be at least 6 months before they can place me.

My children, extended children, and best friend, Alec, have been on this journey with me. It took over a year and the results of my tests for my oldest son to believe that my symptoms were real, that I wasn't just being lazy. Now he has a child of his own, Lucas, who is the light of my life, though I hate that there are many things I can't safely do

"THIS DISEASE HAS
CHANGED ME SO
MUCH. IT'S HARD
TO HOLD ONTO
THE PERSON
INSIDE YOU."

CONTINUED ON PAGE 4



DONNA'S DAUGHTER, MELISSA, AND BEST FRIEND, ALEC, KEEP HER SPIRITS UP.

with him because of my illness.

My youngest son, Adam, is 18-years old now. He is always worrying about me. He didn't get the same opportunities other kids his age had because of my illness. I feel badly about that. He takes me hiking with my alpine sticks. He picks me up and encourages me to keep going when I fall. I can no longer look ahead while I walk so he stops and points out the things he knows I would enjoy.

My daughter, Melissa, is amazing! She has been and continues to be my rock. My extra kids have also been very supportive. I hate to think that they may lose their "safe space" if I have to sell my home.

Friends? They stopped calling because I had to cancel our plans all the time. I'm lucky, though – I have Alec. He has been my best friend and cheerleader. His unconditional, supportive attitude is a driving force that helps me adapt and overcome.

I still struggle daily with vertigo, dizziness, and imbalance. My eyes don't work together, so I do vision therapy with Dr. Joe Rouw, a vision therapist. He and his wife have taken a personal interest in my case and have been studying possible

therapies. We work on gaze stabilization and depth perception, and he is helping me try different prism lenses. I also do vestibular rehabilitation therapy exercises at home.

My muscles and joints often ache and I fatigue easily. Dr. Tirino says that for a normal person what I deal with would be like walking on a balance beam for eight hours straight. It's completely draining, and some days I don't know how I manage.

This disease has changed me so much. It's hard to hold onto the person inside you. I used to hike and travel. Now, sometimes, I don't know who I am. Just yesterday my oldest son said to me, "I don't recognize you."

The biggest frustration has been the complete lack of information, resources, and misunderstanding about vestibular disorders, not just among my friends and family, but within the medical community.

I am grateful to VEDA for being there for vestibular patients struggling with the uncertainty of their condition. I'm glad I found a community of support, and happy I can share my story.



DONNA'S "EXTRA" KIDS ARE PART OF HER THERAPY.

Feeling Confused and Abandoned

By Linda Zonana



LINDA ZONANA, ALSO AUTHOR OF
"VERTIGO! WHEN THE WORLD SPINS OUT
OF CONTROL"

During the first couple of years following my initial episode of intense vertigo I had several strong attacks, each followed by weeks of exhaustion, nausea, imbalance, disorientation, and worry about whether I would ever function normally again.

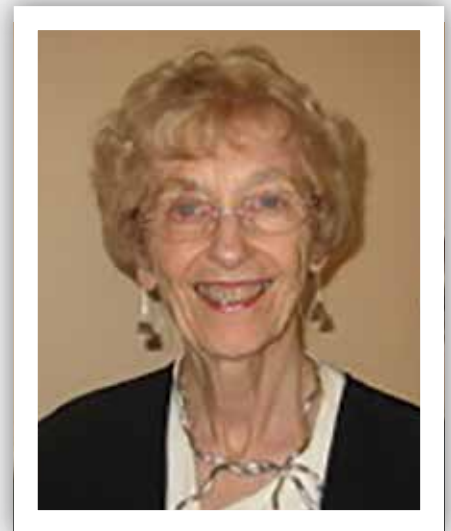
My diagnosis was

Menière's, but nothing seemed to make much difference: not medication, not dietary changes. Feeling desperate, I made an appointment with a new doctor, who specialized in the inner ear. We met and he ordered some tests. When I returned for a follow up meeting, I began telling him how deeply my symptoms affected my life. He cut in to ask, "Well, have you had another attack?" I felt tongue-tied at that. It seemed to me I was almost always having an attack, in the sense that most days I was affected to some degree. But I didn't feel able to say, "No I haven't had lying-on-the-floor vertigo this week, but I feel awful most of the time." I knew that, with Menière's, you supposedly would be exhausted after an attack and wake up the next day feeling fine. I never woke up the next day feeling fine. The fact that my case was different, and that he didn't seem to have noticed or been curious about it was very off-putting to me.

A few years after that encounter, I interviewed 50 people to learn about their experiences with vertigo. The strongest common thread among those people, and one that I shared, was confusion about what was wrong, even if a diagnosis was given, along with the feeling that no protocol was helping much - often accompanied by

a feeling of being of little interest to the medical folks, and a consequent sense of abandonment. Vestibular disorders share issues in common with recurring or chronic diseases, but with an added twist. They impact your perception in profound ways. You are experiencing a major assault on the integrity of your person, yet it can seem as if it arouses little concern on the part of the doctor. Perhaps this is because these disorders are rarely fatal, or because there isn't always definitive treatment. And too, people presenting with vertigo are often a challenge to diagnose. Menière's and BPPV are the most common labels, but there is a host of other possibilities. And those diagnosed as Menière's and BPPV don't always have the expected cluster of symptoms or course of illness.

BPPV is the most readily treatable vestibular disorder, thanks to the ingenious development of the Epley Maneuver. You would think these maneuvers would be familiar in every emergency room, but apparently not. Thus, many people with BPPV struggle for ages, especially if their situation does not fit the neat description of "brief episodes of mild to intense vertigo.* Over at least 20 years of intermittent symptoms, Frieda would experience weeks of vertigo, especially while lying down, but the worst of it for her was disturbances in balance. She would be unable to stop her body from being pulled to one side, felt "as if walking through a thick viscous substance." She was unable to walk on uneven ground, and couldn't drive. No doctor offered a diagnosis until a couple of years before we talked, when a doctor noted she had nystagmus, which made



FRIEDA SUFFERS FROM BPPV

CONTINUED ON PAGE 6

her “feel validated.” He administered the Epley Maneuver, which showed no immediate benefit, but happily her symptoms resolved soon thereafter.

Yvonne is another person who lived for years with complex symptoms before getting relief via the Epley. She would experience vertigo, “feel like the earth was opening up to swallow [her],” and “see walls moving in at [her].” She thought doctors were annoyed with her, and was told her symptoms were psychological. “I felt extremely abandoned,” she said. After about 30 years of this she was finally seen by a “wonderful doctor” at a large city hospital. He administered the Epley, which she still needs from time to time. She says, “I’m no longer just my illness.” She feels more confident, no longer bewildered and ashamed.



SALLY SUFFERS FROM MENIERE’S

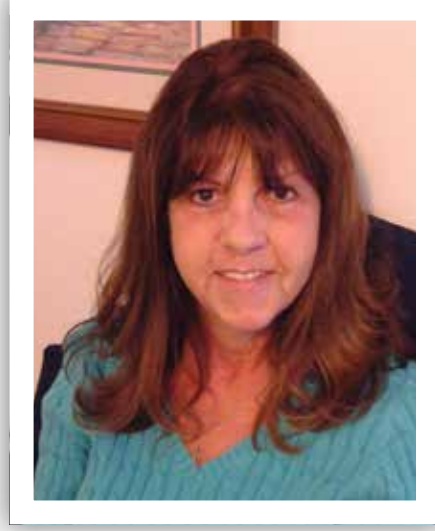
Compared to BPPV, despair and confusion are apt to be greater with Menière’s. Sally had stronger and more pervasive symptoms than mine, and like me, the dietary regimen did not help. She’d feel “a roar rush into [her] head, accompanied by “fierce vomiting” and intensifying

vertigo. Her husband took her to see an ENT, who put her on a diuretic, but it was a month before she felt okay. Over the next year she had repeated attacks but no matter what was done they kept getting worse. Another ENT was consulted, but both doctors seemed distant and didn’t explain much or seem concerned. She became depressed and says her whole personality changed. Sally decided increased hearing loss was worth the risk of gentamicin and arranged for the injections, which have enabled her to return to her old self, aided also by physical therapy.

Kim began having dizzy spells decades ago. She says that she “got out of bed and stepped onto a carnival ride” that threw her across the room. The intense attack lasted 10 minutes but she was nauseated all day. Such attacks happened occasionally during her 30s. The frequency stepped up in her 40s, but when she consulted a doctor she was told, “Lots of people get dizzy.” She said, “I felt so disregarded.” As matters grew worse, she wondered if she might have to quit her job, and worried she might have to go on disability. A year and a half before we spoke she had her most severe attack ever and met with an ENT who diagnosed her with Menière’s and recommended dietary restrictions along with a Scopolomine patch and a diuretic. She continues to have some mild symptoms, but now, after 35 years, her life is “wonderful.”

Those with less common vestibular disorders may have an especially hard time getting an appropriate diagnosis, or in feeling support from their doctors. Lila experienced increasingly disabling and long-lasting symptoms over a period of 15 years. She was diagnosed first with stress, then Menière’s, then

bilateral vestibular loss over that time. She was reduced to using a wheelchair or crawling. She suffered with “jello brains – magnified by every body motion,” couldn’t read because of “bouncing vision,” her “eyes flew – objects slid past,” and when lying down, her vision would “break up like a kaleidoscope.” She was angry about the uselessness of the various medications she tried, and about being seen as having a psychiatric condition. Her story ended well, with a good response to Valtrax and Valium she was able to walk again and return to work.



LILA SUFFERS FROM BILATERAL VESTIBULAR LOSS

Knowing your experience is shared by others helps in dealing with vertigo, as does knowing there are variations in the way symptoms are experienced. Such awareness can help you be clearer and more assertive with the medical world, enable you to press for alternative treatment, or initiate a discussion about the details of your symptoms. If possible, it's best to search for a practitioner who listens and acknowledges what you say. If you feel

dominated by or dismissed by your doctor, it can help to bring someone along to support you.

Please note that each situation in this article had a good outcome, although often after too many years of struggle. Not all vestibular patients are so lucky.

*MAYO CLINIC WEBSITE, 5/28/15



BALANCE AWARENESS WEEK to **DEFEAT** *DIZZINESS*

SAVE THE DATE!

Join VEDA for the
20th Anniversary
of Balance Awareness Week
and share your story
about how vestibular disorders
have affected your life.



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Decoding the Symptomatology of Vestibular Disorders

By Dr. Matthew G. Crowson, MD

The signs and symptoms of vestibular disorders can be vexing. The constellation of symptoms that can affect one individual may vary vastly in degree, type, and severity in another. This complexity creates challenges for health care providers serving patients afflicted with vestibular disorders. Over time, vestibular specialists have sought to differentiate and categorize vestibular symptoms to discern between different disorders so that they can more readily identify and treat them. A recent review article by one of the contemporary leaders of vestibular medicine, Dr. David Newman-Toker, has comprehensively outlined the advances in the classification and categorization of vestibular symptoms to help providers see through the complexity, and deliver effective and appropriate treatments.

As with many medical afflictions, taking an accurate history and a review of associated symptoms is tantamount to arriving at an accurate diagnosis. Historically, vestibular providers have clung to the notion that the quality of vestibular disturbance – true vertigo, unsteadiness, disequilibrium or pre-syncope (i.e. a feeling that one is about to faint) – is key to unlocking the diagnosis. Dr. Newman-Toker asserts that there is little evidence to suggest a description of the vestibular symptom quality leads to an accurate diagnosis. Providers, let alone patients, have a difficult time differentiating between the different quality types of vestibular complaints. Room-spinning vertigo to one individual may seem more like 'listing' and floating to another.

More recently, Dr. Newman-Toker notes that providers have been honing in on the timing and triggers for vestibular symptoms as a more accurate diagnostic tool. Do the vestibular symptoms occur all the time? Or, are they

more episodic with symptom-free periods punctuated by symptom flares? For instance, brief vestibular dysfunction elicited by sudden head movements or positional changes is more aligned with positionally-dependent disorders such as benign paroxysmal positional vertigo (BPPV). Alternatively, brief vestibular dysfunction that is spontaneous and not associated with positional changes may be more aligned with disorders such as Meniere's Disease.

What happens in the cases where vestibular symptoms are from a more sinister origin? Differentiating between benign peripheral vestibular disorders and dangerous conditions

such as cerebrovascular and cardiovascular disease can be challenging. Dr. Newman-Toker summarized evidence to suggest that vestibular symptoms that have distinct reproducible triggers are more apt to be benign. When there is an issue with the heart, such as insufficient cardiac output from an arrhythmia, the symptoms are more apt to happen spontaneously. Eliciting descriptions of associated symptoms, such as shortness of breath, chest-pain, and palpitations, is also critical

for identifying dangerous sources of vestibular symptoms.

Further clues to decoding a vestibular disorder can be made from evaluating for nystagmus – idiosyncratic eye movements that can be spontaneous or contextual. For instance, nystagmus observed in a patient looking far off to one side (gaze-evoked) is likely to be benign if horizontal, symmetric and brief. However, vertical or asymmetric nystagmus with the same stimulus may indicate a pathologic cause – especially if it occurs when a patient does not need to look far off to one side for the nystagmus to

PROVIDERS HAVE
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appear. More advanced techniques such as the 'head thrust' head impulse test (HIT) can also be helpful in quickly assessing and localizing a horizontal semicircular canal hypofunction. This test is completed by an examiner guiding rapid accelerations of a patient's head while the patient attempts to maintain gaze on a fixed object. If the examiner notes the eyes must play 'catch-up' with the sudden head movements, this may indicate peripheral vestibular hypofunction. Performance of these basic maneuvers to assess for nystagmus requires little time, expense and equipment, but can be tremendously helpful in identifying peripheral or central vestibular syndromes.

KEY CONCLUSIONS:

- The history of the vestibular symptom, review of associated symptoms, and a general **medical history** should be in every provider's routine in evaluating patients with vestibular symptoms.
- Focus on the **timing and triggers** of the vestibular symptoms, not the quality or description of the dizziness. Are the symptoms present for seconds, minutes, hours, days, or weeks?
- Not all vestibular dysfunction stems from benign conditions. Potentially dangerous causes such as cerebrovascular disease (e.g. transient ischemic attacks, stroke), serious infections, malignancy, and cardiovascular disorders need to be ruled out. **Dangerous conditions tend to produce spontaneous vestibular disruption without an obvious trigger.**
- Several bedside maneuvers, such as assessing for spontaneous or gaze-evoked nystagmus, and **nystagmus elicited by the head impulse test** are cheap, quick, and can be informative.

While we summarized just one review on the symptoms of vestibular disorders, contemporary medical literature is rife with different methods and perspectives on this topic. A VEDA project that is currently underway is seeking to mine the literature to consolidate the collective wisdom of

these methodologies. Informed by this search, VEDA is working with a team of specialists to generate a simplified diagnostic framework for peripheral vestibular disorders to assist front-line clinicians in the initial evaluation of patients presenting with vestibular symptoms. It is our hope that a streamlined diagnostic protocol will help quickly orient clinicians to more effectively serve this patient population, and identify the appropriate referral resources to treat their conditions.

REFERENCE

Newman-Toker, D. E. (2012). *Symptoms and signs of neuro-otologic disorders. CONTINUUM Lifelong Learning in Neurology, 18(5), 1016–1040.*

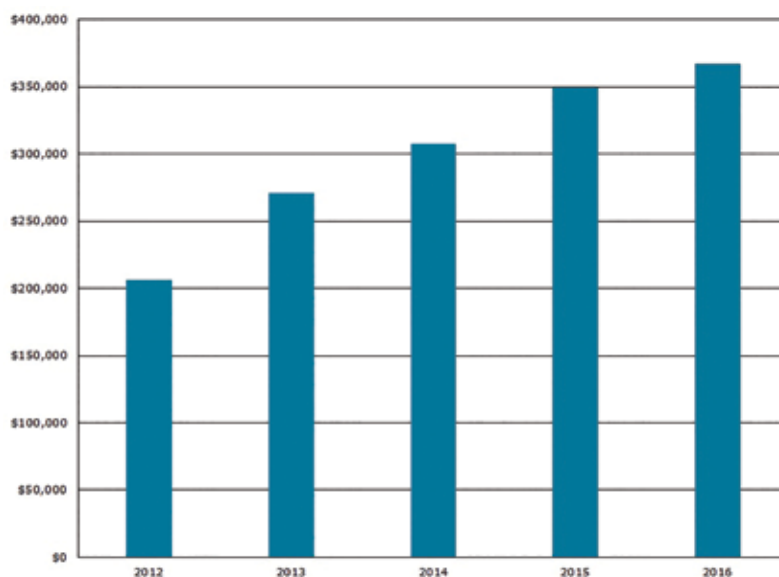
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informs vestibular research
by participating in VEDA's
Patient Registry.**



**TO LEARN MORE, VISIT:
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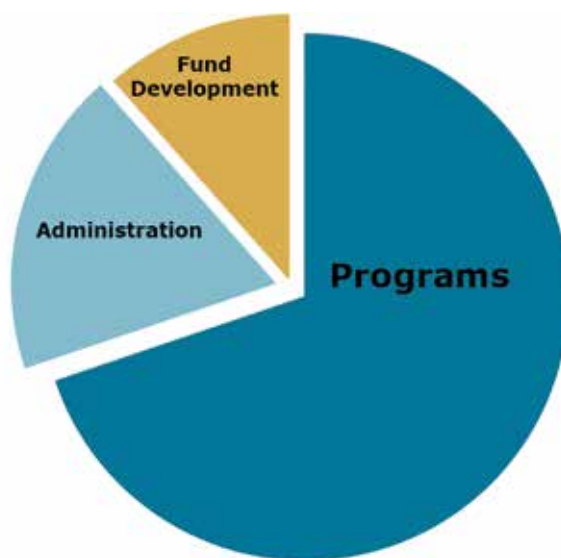
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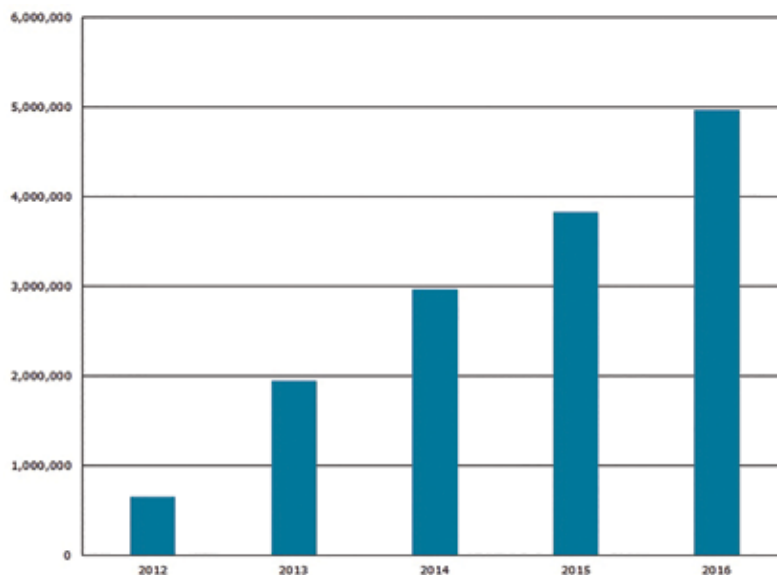
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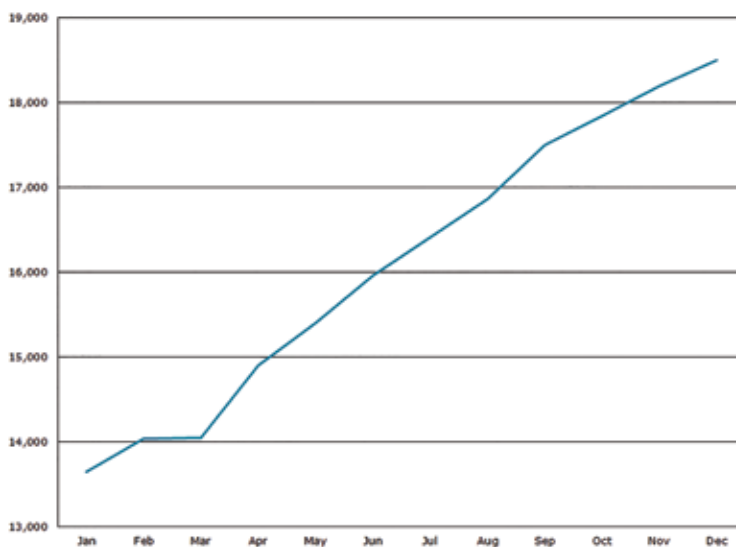
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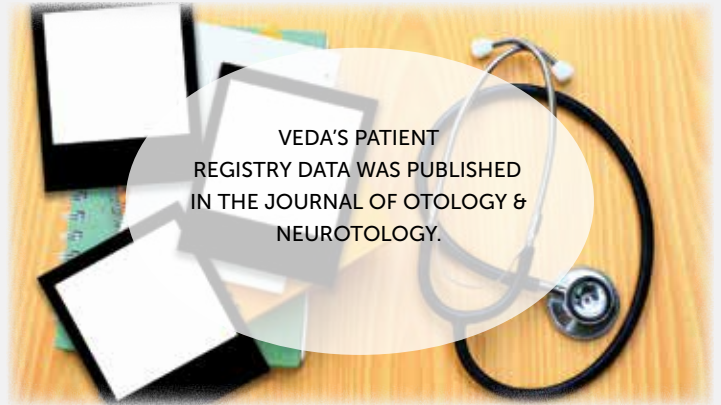
2016 Milestones

NEW PATIENT TOOLKIT



DEVELOPED A WEBSITE TOOL THAT GUIDES NEW PATIENTS THROUGH THE STEPS OF DIAGNOSIS, TREATMENT AND RECOVERY.

JOURNAL PUBLICATION



VEDA'S PATIENT REGISTRY DATA WAS PUBLISHED IN THE JOURNAL OF OTOLGY & NEUROTOLOGY.

NEW ARTICLES

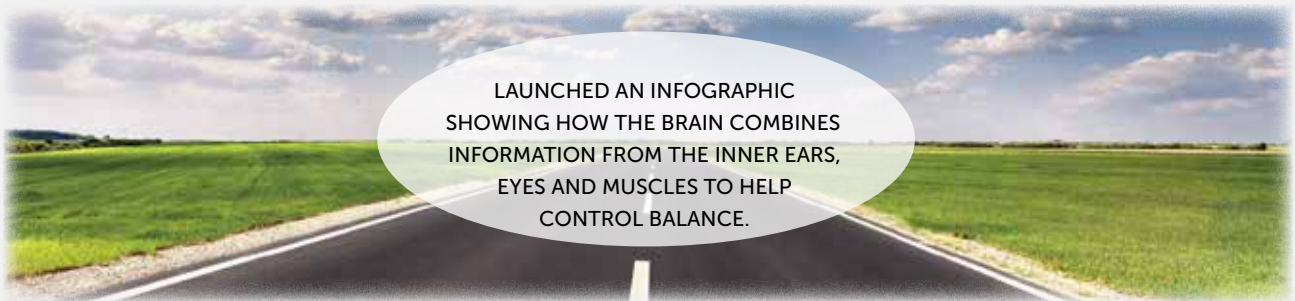


PUBLISHED 3 ARTICLES ON HOW TO APPLY FOR SHORT/ LONG-TERM DISABILITY AND SOCIAL SECURITY, WITH TIPS FOR VESTIBULAR PATIENTS.



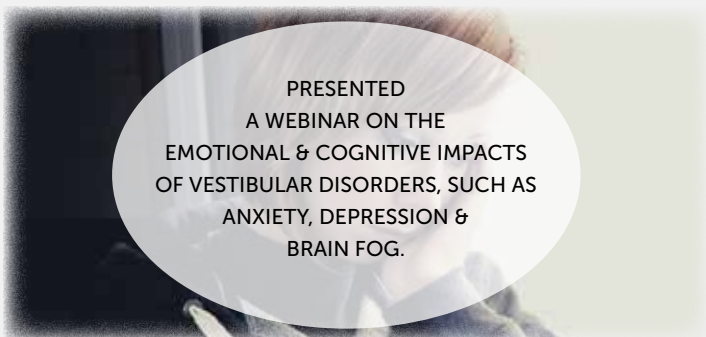
PUBLISHED AN ARTICLE ON HOW ENVIRONMENTAL FACTORS LIKE BAROMETRIC PRESSURE CAN INFLUENCE YOUR VESTIBULAR SYMPTOMS.

"ROAD TO BALANCE" INFOGRAPHIC



LAUNCHED AN INFOGRAPHIC SHOWING HOW THE BRAIN COMBINES INFORMATION FROM THE INNER EARS, EYES AND MUSCLES TO HELP CONTROL BALANCE.

WEBINARS



PRESENTED A WEBINAR ON THE EMOTIONAL & COGNITIVE IMPACTS OF VESTIBULAR DISORDERS, SUCH AS ANXIETY, DEPRESSION & BRAIN FOG.



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The Heart of an Ambassador

By Cynthia Ryan, Executive Director

David Morrill is the chair of VEDA's Ambassador Board, and an amazing individual. I am constantly in awe of David's kindness, patience, persistence, enthusiasm and dedication to many causes.

I was reminded of David's doggedness after a recent incident where David slipped on the ice and fell. Rushed to the emergency room, David's first thought was to ask his wife to call VEDA so we knew he wouldn't be able to make it to a committee meeting the next day. He is always thinking of others above himself.

I was introduced to David by Dr. David Newman-Toker, a neurologist with Johns Hopkins University, who David had contacted because of his research. Dr. Newman-Toker studies diagnostic error in the emergency room, specifically vestibular disorders and stroke. David suffers from permanent vestibular damage due to a missed stroke, an event that changed his life forever.

In August 2013, David experienced a sudden onset of vertigo. He got up from the dinner table and felt like the room was spinning. He was nauseated and had trouble walking, so his family took him to the emergency room.



DAVID AND HIS WIFE OF 36 1/2 YEARS, CHERYL

David was diagnosed with "vertigo" (not a diagnosis at all, but a symptom). The ER doctor prescribed Meclizine, sent him home and told him his condition should improve within a few days. But instead, it got worse, so he went back to the emergency room about 48 hours later by ambulance. The ER doctors ordered an MRI, which revealed a large blood clot on his brain stem. More than two days after his symptoms began David was diagnosed with a stroke.

At the time, David was working as a Food Service Specialist. When, after six weeks, David was still not well enough to return to work, he lost his job and his medical insurance. David also volunteered as an emergency medical technician (EMT). The fire department he volunteered for did a fundraiser to help David and his family.

At first David was angry and frustrated; he didn't know where to put his energy. Then he found purpose in volunteering.

"David puts his heart into everything he does," says Cheryl, his wife of 36 1/2 years.

Cheryl is a Disney fan. Just before his stroke David was going to take her to Disney World for her



DAVID TOOK HIS WIFE AND FAMILY TO DISNEY WORLD, EVEN THOUGH HE COULD BARELY WALK.



DAVID ATTENDS HEALTH FAIRS TO EDUCATE OTHERS ABOUT VESTIBULAR DISORDERS.

birthday, but the trip was canceled because David couldn't travel. Three years later, David brought Cheryl and their whole family to the magical world of make believe. David still struggles with his balance, so he had to use a wheelchair during the visit, but insisted on taking a picture of himself standing to motivate others to do something they didn't think they would be able to do.

David was the founding member of VEDA's Ambassador Board, which would never have taken off without his leadership. He participates in VEDA's Patient Education and Support Group Committees, leads a vestibular support group in Maine, and has recently started leading an online support group. He is also the facilitator of a Facebook group that lends support to vestibular patients all over the world.

David was one of the key members



of the "Dream Team," a group of patients who are petitioning the World Health Organization for increased awareness around vestibular disorders. He is also a volunteer for the American Heart Association, and was recently recognized at one of their galas. David and his family have hosted information tables at several health fairs, most recently an event called, "What Women Want," where he had a booth to promote specific ways women can advocate for their own healthcare.

I would like to thank David for being such a caring and compassionate person, always willing to lend a hand, selfless and hard-working, in a word, amazing! David, you are an inspiration to us all.

Your friend,

Cynthia



DAVID TRAINED FOR MANY MONTHS TO PARTICIPATE IN THE 2016 DIZZY DASH.

DIZZY DASH

In an instant your life changed. Dizziness, vertigo, imbalance, fatigue, anxiety – these became your “new normal.” You began a quest to find out what was going on with your body. Eventually, you found the right doctor who told you that you have a vestibular disorder. Next comes a host of lifestyle changes. Little things become a huge effort, and you wonder if you’ll ever get your “old” life back.

Three years ago Katie Mahoney conceived the idea of the Dizzy Dash. Katie had lost much of her life to vestibular neuritis. She never gave up, and began walking her dog to get moving again. Every day she pushed herself to go a little further, until eventually she was able to walk five kilometers.



FIND OUT MORE ABOUT THE DIZZY DASH AND REGISTER AT
VESTIBULAR.ORG/DIZZYDASH.

We invite you to set a goal – big or small – to accomplish something you didn’t think you could do. Share your goal on a personal campaign page, and participate in the Dizzy Dash Facebook group to let us know how you are progressing. Together we can build a community that will support you in reaching your goal.

SET A GOAL
SHARE YOUR STORY
TAKE BACK YOUR LIFE

All funds raised through the Dizzy Dash will support the growth of VEDA’s new online support group teleconferences.

GET YOUR LIMITED EDITION DIZZY DASH T-SHIRT!

Sport your official Dizzy Dash t-shirt or sweatshirt to raise awareness about vestibular disorders. Visit teespring.com/dizzy-dash-2017 today! Order soon to receive your t-shirt by May 20th.

Join with other vestibular patients who are **DOING** something to **ACHIEVE** a personal goal while **SUPPORTING** each other and **HELPING** to raise awareness about vestibular disorders (D.A.S.H.).

MAY 20, 2017

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

**VEDA is entirely supported by donations and membership gifts.
Your donation helps VEDA provide information on vestibular
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You can make a gift to support VEDA's life-changing work online at vestibular.org/otl
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My Dizzy Dash Goal

By Barbara Roggenbeck

My goal for the 3rd annual Dizzy Dash is to hike 5K on a trail around Bozeman, Montana with my friends and family. Montana is a mecca of wildlife and outdoor sports that I want to explore despite my constant battle with dizziness. It is important to me to overcome my fear of outdoor activities and start enjoying nature with my loved ones.

Before my dizziness started I was fearless, athletic, and always ready for an adventure. I still dream of the days before the dizziness started when I could do things like travel to New Zealand with my husband and enjoy an eight hour hike to Franz Josef glacier without a care in the world.

In 2011, one month after having my first baby, the dizziness started and it never stopped. I feared daylight with all the disturbing visual distortions and the constant drunken stupor that did not cease until I closed my eyes. I feared my own baby waking in the night because rocking him to sleep was torture. I feared leaving my house.

I was diagnosed with vestibular migraines after six months of questioning my sanity along with countless doctor appointments. The proper medication and avoidance of triggers helps me control my symptoms and I function like my old self most days. I made it through the remainder of a PhD program while raising my son. Four years later I was even able to defend my thesis five months pregnant with my second little guy. However, I still have bad days and I still live in fear of trying new things that could trigger symptoms because of this disease.

I want to participate in the Dizzy Dash with my fellow VEDA members to begin fighting my fear of trying new activities. Regardless of the caliber of motion you choose, whether it be to walk from the couch to the sink or the front door to the driveway, or to run a triathlon, let's help each other achieve our goals.

WHAT'S YOUR GOAL?

Support Barbara at vestibular.org/barbaraDD

BARBARA'S DIZZY DASH GOAL IS A 5K HIKE

