

# ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION



INFORMATION

SUPPORT

AWARENESS

ADVOCACY

## What's the Diagnosis, Doc?

By Mandy Sheldrake

My story starts the same way as many other vestibular patients' stories: I woke up one spring morning in 2005 and even before opening my eyes I knew something was wrong. My head felt heavy, I was nauseous, and my bedroom was spinning.

I tried to ignore it. But that first day with a vestibular disorder taught me that they cannot be ignored. I lasted five minutes before I vomited, then fell into bed.

Based on a discussion of my symptoms, my doctor diagnosed me with BPPV. Unfortunately, I knew nothing about vestibular disorders at that time; if I had, I would have known that BPPV cannot be diagnosed without doing the Dix-Hallpike test. She gave me a handout with instructions for the Epley maneuver and sent me away.

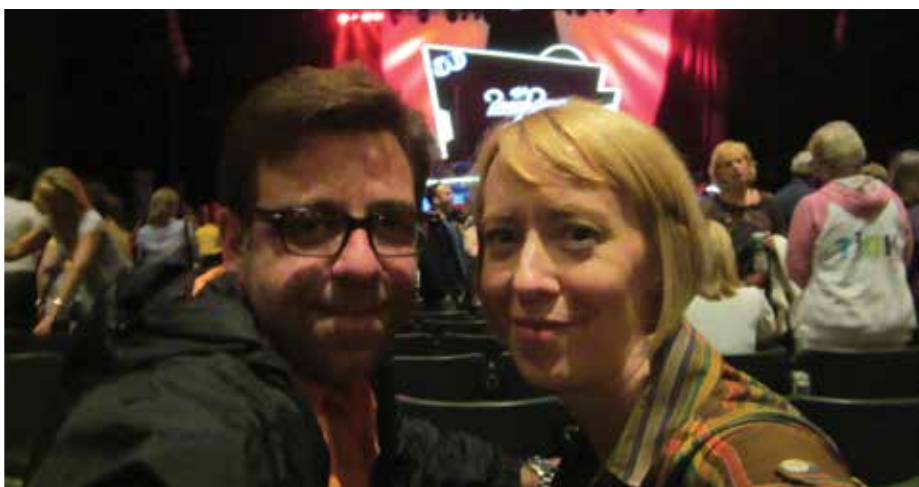
The attacks continued. The Epley didn't help, but I did it anyway, hoping that this time it would magically work.

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TOP LEFT: MANDY & HER FATHER AT A FORMULA 1 RACE  
BOTTOM LEFT: MANDY & HUSBAND TRAVELING (MANDY IS ALWAYS THE PASSENGER)  
BOTTOM RIGHT: MANDY & HUSBAND AT A CONCERT (WITH EARPLUGS, OF COURSE!)

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WHAT'S THE DIAGNOSIS, DOC?...CONTINUED FROM PAGE 1:

After a few months the attacks lessened in frequency, but strange symptoms remained. I'd always loved shopping, but I began to dread fluorescent lighting and visual stimulation. I told people that I felt like I was looking through a fishbowl, or like I was a bobble-head doll, and they laughed, thinking I was joking. I wasn't.

A year later, I was hit by the most violent episode of vertigo I'd ever experienced. I vomited several times before I managed to call a taxi to take me home from work. I lay on my bathroom floor late into the night, the slightest head movement causing intense spinning and vomiting. Finally, I went to the ER, where the doctor diagnosed me with BPPV – again.

From that point on my life was no longer the same. I continued to have episodes of vertigo and nausea, but I also developed dizziness, brain fog, unsteadiness, and difficulty focusing on moving objects – symptoms that could last for days.

I started seeing a wonderful ENT, who was the first doctor to acknowledge that I might have something other than BPPV. Over the next eight years he would refer me to neurologists, neurotologists, vestibular physiotherapists, and an ophthalmologist in an effort to figure out what was wrong. Testing showed that the vestibular function in my right ear was almost non-existent. Additional tests later showed that my left ear was affected too. But my hearing tests were normal, which ruled out Meniere's. So what did I have? No one could tell me.

My life continued, but the dark shadow of my illness loomed over everything. I worried constantly about work and having to take so many sick days. Vacations and parties became a source of stress; instead of looking forward to special events, I just worried that I would be sick – and I often was.

No doctors could explain what was happening, or why my ears were damaged. They said I would have to learn to live with it. But what was "it"?

I refused to accept that my life would be destroyed by an illness that no one could explain. I did vestibular physio and switched to a low-sodium diet. I read everything I could about vestibular disorders, including the myriad of wonderful publications on the VEDA website. I grilled my doctors with questions. I joined online support groups and talked to other sufferers, all of us searching for answers.

One illness I read about intrigued me. Vestibular migraine was a

new term, but the symptoms – positional vertigo, nausea, motion sickness – were familiar. I'd had migraine with aura throughout my childhood and adolescence. Could my problems now be attributed to vestibular migraine?

But my doctors all said "you don't have headaches, so it can't be migraine."

Things continued to get worse. In summer, 2012 I had a bad episode. I was sick every day for months with dizziness, oscillopsia, and impaired balance. I missed a month of work. I saw a vestibular physiotherapist and did daily exercises at home. Finally the symptoms lessened, but I continued to have frequent episodes. The brain needs to compensate after a vestibular event, but my "events" were happening so frequently that I knew my brain couldn't adapt.

I struggled on, but a year later I had another setback, with daily, unending symptoms. I hit a low point during a long-anticipated vacation. I was sick the whole time, sometimes so much that I had to stay at the hotel while my husband went on without me. Sadly, the ruined holiday convinced me that my condition was worsening and that I would never be able to enjoy anything again.

In desperation, I pleaded with my doctor to try migraine prevention medicine. I started with a tiny dose and built up slowly. After a couple of months I started having more good days – able to turn my head without experiencing a lag, and able to walk without my field of vision bobbing up and down.

Two years later I'm still taking the medication, and am considering trying others to find something that might work even better. A CT scan also revealed a semi-circular canal dehiscence in my right ear, but it's not clear that the majority of my symptoms are caused by the SCDS, so for the time being I'm not a good candidate for surgery.

After ten years I still don't have a firm diagnosis, but I do have some answers. I've come to believe that I am a complicated case involving

both vestibular damage and vestibular migraine. And while the migraine preventatives haven't fixed everything, they do help. I still get lots of symptoms, and bad days during which I can't do anything, but I feel like I recover from them faster.

My advice to other patients is to educate oneself as much as possible. Vestibular illnesses are not well-understood, so you **must** be an advocate for your own care. Talking to other sufferers was a life-saver for me, both for information-sharing and support. The only good thing about my illness is that through it I've met the most amazing, strong, compassionate people – fellow patients – for whom I have so much respect.

I would not have survived without the love and support of my family. My parents are incredibly supportive, offering sympathy as well as practical help. My husband has learned more about the inner ear than he thought possible. More importantly, he's stuck by me, even when my illness ruined his plans too.

And my beloved dog has helped me far more than he could ever know. He's accustomed to several short walks a day, regardless of how I feel! Over the years we've had plenty of walks that involve me staggering down the street, dizzy and off-balance. But I credit those walks with helping me to recover my balance and compensate faster than I otherwise would have done. And on the days when I'm so sick that all I can do is lie in bed motionless, he never leaves my side.



MANDY WITH HER BELOVED DOG, MURRAY.

# Caregiver Survey Results

By Cynthia Ryan, Executive Director



The friends and family members who care for vestibular patients provide essential support. Without firsthand experience, these individuals are challenged to learn about vestibular disorders in order to lessen the impacts of their loved ones' illness. VEDA seeks to focus attention on this important part

of our vestibular community in hopes of developing programs to support their efforts.

As a first step in defining caregiver issues and needs, I sent a request for help through V-News, VEDA's email newsletter. I wanted to know:

- How has your vestibular disorder impacted your family and friends?
- What impacts or limits of yours have made their lives more challenging?
- What do you notice is upsetting, irritating, or disappointing to them?
- What do they identify as the most difficult part of dealing with your condition?

Thank you to everyone who responded and shared their struggles, as well as some wonderful ideas for adjusting to new limits. Here is a summary of many common themes and points of agreement across the responses I received.

## MOST CHALLENGING IMPACTS OF VESTIBULAR DISORDERS

There are several impacts which were often mentioned as the most challenging, limiting or disruptive both for the vestibular patient and for the family members.

### HEARING LOSS

*"It is frustrating for them when I can't hear them and I ask them to repeat themselves."*

*"Even with my hearing aids I still have difficulty understanding what is being said, so many times I just fall silent."*

Many of the responses identified hearing loss as the most difficult impact of their vestibular disorder on their family and friends. When they cannot participate in conversations they are isolated and removed from family events even when they are present. It is necessary for family members to speak in a certain ear, speak more clearly, and often repeat what they say. Even with hearing aids, it is hard to maintain the same easy, spontaneous relationships as before.

### UNPREDICTABILITY OF SYMPTOMS

*"My illness has affected my family because I never know when I am going to have an attack."*

*"Sadly, many friends have moved on because I cannot participate in activities."*

Many responders noted the difficulty of making any plans because they are never certain how they are going to feel from day to day or hour to hour. This unpredictability makes it difficult to schedule events, accept invitations, and travel. Even when vestibular patients feel fine at the start of an event, they may have to leave early. As a result, the range of social interactions with family and friends becomes limited. Spouses are unable to travel and enjoy outings, daughters are unable to have their mothers babysit for their children, and friends can no longer share favorite activities.

### LOSS OF THE PERSON THEY USED TO KNOW

*"I believe they are saddened by this disease because I used to be a vibrant, confident person and now that person is gone."*

*"I want the other me back and I don't know how to find him."*

We all enjoy certain hobbies and activities – golf, swimming, dancing or riding a bike. Most of us work, go out to eat, and attend concerts or church services. Quite often a vestibular disorder greatly reduces or eliminates the ability to enjoy these activities. This impacts the vestibular patient, and it also impacts the family members and friends who enjoyed these activities as well. On a more personal level, vestibular patients are quieter, more withdrawn, and can be more tentative or nervous. These are monumental changes, and it is no surprise that many responders listed the sadness



of their friends and family at losing the person they knew and loved as the most significant impact of their illness.

#### ANXIETY AND CONSTANT WORRY

*“My wife and my kids and grandchildren are always on alert for my next fall.”*

*“My husband cried when my neuro-otologist announced that there was nothing further he could do for me.”*

Vestibular patients can experience sudden and frightening symptoms that alarm their friends and family. If someone experiences sudden falls, everyone is on “high alert” when they accompany them. Some environments, like a large, crowded store, can trigger “attacks” and patients need to lie down on the floor or escape rapidly. When a friend or family member does not know how to help their loved one it is scary and upsetting. When your family member is sick for months with no diagnosis and no remedies, you feel sad, worried and upset.

#### LIMITS AND NEEDS

*“Accommodations are made for me as to the timing of events and places we go.”*

*“We can’t do all the things that other couples do. I feel lonely as I watch everyone else live.”*

Every response discussed new limits on their life and the difficulty of adjusting to those limits on their part and the part of family members. Quite often the new limits are a surprise and adjusting to the new

situation involves much trial and error. When your abilities change, everyone around you is forced to adjust – but they don’t know how. This can cause discomfort and stress for everyone involved.

#### OTHER IMPACTS

There were other important impacts noted by a small number of respondents. First, the financial impacts of loss of work and the cost of treatment add a definite stress to the family, compounding other issues. Several vestibular patients mentioned their inability to concentrate or to track a conversation as an alarming symptom for loved ones. Patients also noted that the long list of odd and unpredictable symptoms caused others to question whether they were really sick, since they appeared on the outside to be fine. And several vestibular patients noted the disappointment and sadness of their family when doctors were unable to diagnose or offer any help.

**“I FEEL LONELY  
AS I WATCH  
EVERYONE  
ELSE LIVE.”**

#### ADJUSTMENTS TO IMPACTS OF VESTIBULAR DISORDERS

*“I believe if you have a disease, the hardest thing is getting people to understand what you are dealing with. That’s the first step in helping your situation and in helping the people around you.”*

This insightful quote reflects both an understanding of the limits on the part of the vestibular patient as well as problem solving about adjustments that will help with family and friends. Some patients and their families are finding creative ways to adjust to the new limits of having a vestibular disorder. In



CONTINUED ON PAGE 6

many cases caregivers were specific about the kinds of adjustments they have made to make life easier for their spouse/friend, and to feel like they are participating in a solution.

#### DRIVING



Many vestibular patients no longer drive or limit their driving because repeatedly turning their head or moving their focus is a challenge. As a result, caregivers do most of the driving. When vestibular patients can clarify what they need, and caregivers understand how to adapt, their driving can more closely match the needs of the vestibular patient. For example, they drive more slowly, take turns slowly, and avoid winding roads. Parking lots are another vestibular challenge, and caregivers learn to park in the first spot in the parking lot to avoid turning and looking for spots. Parking garages are often challenging. One person even noted that she gets out of the car when it is necessary for the driver to back up. These adjustments make all outings more tolerable and symptom free.



#### DINING OUT/SOCIAL SETTINGS

There are a number of adjustments that can help in social situations. For example, if the vestibular patient is seated at a table so they can hear better, they will be able to stay at an event longer and enjoy it more. It is also preferable for a vestibular patient to sit so they are not facing a crowded room where they will see constant motion. A quiet restaurant with seating in an out of the way area is another good strategy. In addition, having an understanding (or even a signal) about when the vestibular patient needs to leave an event removes any pressure to try to stay or to avoid inconveniencing others by needing to leave. Some loud, crowded, or motion oriented events need to be avoided entirely. As one caregiver stated, "We have to plan events and outings to take my wife's vestibular condition into consideration and the fact that she tires easily."



#### SPEAKING

The main way that friends and family have adjusted to hearing loss is to speak clearly and directly. It is challenging to remember to speak only when you are in the same room, facing someone,

or to speak on their "hearing side." It is unnatural to speak in a louder or slower voice than normal. Even the most dedicated caregivers identify hearing limitations as the hardest adjustment to remember and manage.



#### TRAVEL

Many vestibular patients are challenged by riding in a car and flying and have limited ability to travel. Several people mentioned needing one to several days to recover after traveling. Friends and family need to adjust to this schedule. There are also trip lengths and locations that are more challenging and need to be avoided. For example, very hot climates might cause dehydration and vestibular episodes. The destination, types of events, and the travel schedule need to be planned to accommodate the impacts on vestibular disorders.



#### WALKING

Several important adjustments were noted to assist vestibular patients with challenges when walking. First, vestibular patients need to walk in certain locations – on the left or right - to avoid turning their head in challenging directions. Also, it is very helpful for friends and family to be on the side where vestibular patients can hear the best. Other walking challenges involve slippery or uneven surfaces, poor lighting, and walking in crowds. Friends and family learn to offer an arm when needed. One patient appreciated that: "My husband is my "blocker" as I walk through a busy environment so that I can look down as I maneuver."

### IN CONCLUSION

As always when I reach out to our members, I am inspired by the responses I receive. The struggle with vestibular disorders is daunting and demands a great deal from patients and family. The growing understanding of vestibular impacts and the adjustments that families make to cope with the needs of their loved ones is often heroic. One caregiver made the following comment: "There is nothing I consider most difficult for me, except what I want for her: to get healthier and feel more like "before." She is a trooper, a real champion." It is these insights and this dedication that motivates me to increase VEDA's impact every day.

# A Patient Speaks About Her Family's Burden

By Sharon Yarrington

As a person who has had a vestibular disorder for many years, I must say I am glad that you are asking US how this insidious condition affects our family and friends. I, for one, am so weary of reading stories of people who smile every day, can still swing on a trapeze, run a marathon, or perform on Broadway with this disease. For every ONE of them, there are probably a thousand of US who are happy to just make it through the day without some "balance-brain-anxiety/what is happening now?" event.

When I first was diagnosed almost 10 years ago, I do not think my family and friends believed me, as most people have never heard of "vestibular" anything in their entire life. They wanted to treat me as though I was normal and kept continuing with our regular routine. I dragged along with them, getting ill in large places and stores, holding the wall in the shopping mall and pulling off the road while driving.

As the years passed, instead of traveling together or vacationing, we have reduced our family to gathering at my brother's home where I am comfortable and we can eat dinner without too many physical side effects.

I believe they are saddened by this disease because I used to be a vibrant, confident person and now that person is gone. This condition is most difficult for my husband because he is the one always at my side, taking me to the store, doctors' office, therapy...nowhere that is actually enjoyable, such as a vacation, the theatre, or a nice restaurant. He vacations by himself by visiting his brother because I am never sure of how I will be or if I have the stamina to experience an event so far from my home. Some years we have a "Christmas" and some years I cannot bend over to get the ornaments out of the box and on the tree without becoming ill.

My husband cried when my neuro-otologist announced that there was nothing further that could be done for me. Any further treatment or

surgeries could leave me worse than I currently am. We had always hoped there might be an answer. My treatment is to lie down on the floor when I am having a vertigo attack to make contact with as many nerves in my body as possible. Now, that certainly is not an act that I can perform in the airport, mall or anywhere but home. I once had to do it in the grocery store and it sent everyone into a panic.

This disease can make one look like an idiot. Sadly, many friends have moved on because I cannot participate in activities. They tell me that "we always know that you are missing when we are together." Even with my hearing aid, I still have difficulty understanding, and so many times, I just fall silent. I try not to burden my friends and family, because I know how difficult it is to watch someone you love continue to struggle with an incurable condition. I cared for my mother as she was dying from cancer. After her peaceful release from this world, I thought that a vestibular disease is just like cancer - no cure, lots of struggle and very little hope. Even though I am aware that research continues for this condition, at my age, I doubt that my family and I will ever see the day when I can join them again.

Thank you for your concern for the families and friends of those burdened by this condition.



# Save the Date!



## BALANCE AWARENESS WEEK to DEFEAT *DIZZINESS*™

September 14-20, 2015

### HOW CAN YOU GET INVOLVED?

- ◇ MAKE A DONATION TO HELP US REACH OUR GOAL OF \$80,000 AT [VESTIBULAR.ORG/BAW2015](http://VESTIBULAR.ORG/BAW2015).
- ◇ TELL YOUR STORY BY CREATING A PERSONAL CAMPAIGN PAGE AND ASK YOUR FRIENDS, FAMILY, CO-WORKERS, AND COLLEAGUES TO SUPPORT YOU.
- ◇ JOIN US IN THE BALANCE CHALLENGE! HELP RAISE AWARENESS AND HAVE FUN AT THE SAME TIME. WEAR A PINK FLAMINGO HAT AND LET YOUR CREATIVITY RUN WILD. VISIT [VESTIBULAR.ORG/BAW](http://VESTIBULAR.ORG/BAW) FOR MORE INFORMATION.
- ◇ MAKE YOUR SOCIAL MEDIA PROFILE PICTURE THE BALANCE AWARENESS WEEK LOGO.
- ◇ SHARE VEDA'S BALANCE AWARENESS WEEK SOCIAL MEDIA POSTS.
- ◇ TAKE A VIDEO OF YOURSELF TALKING ABOUT YOUR EXPERIENCE WITH A VESTIBULAR DISORDER AND POST IT ON YOUR NEWSFEED WITH #DEFEATDIZZINESS.
- ◇ HOST A "BLUE MONDAY" OR "FRIDAY JEANS DAY" – EMPLOYEES WHO DONATE TO THE CAUSE GET TO WEAR BLUE ON MONDAY OR JEANS ON FRIDAY.



### MESSAGE FROM HONORARY CHAIR – DR. KRISTEN JANKY



"I am proud to be the 2015 Balance Awareness Week Honorary Chair and lead VEDA's efforts to "Defeat Dizziness™" through this important campaign. I have been a vestibular specialist since 2005 and I am passionate about VEDA's mission to support, educate and advocate for the vestibular community. I look forward to helping VEDA raise awareness so patients, their loved ones, and the general public can better understand what vestibular disorders are, and the impact they have on people's lives."

Dr. Janky is the Director of the Balance and Vestibular Research Laboratory at Boys Town National Research Hospital. She received her Doctorate of Audiology from Towson University, her Ph.D. from the University of Nebraska, and completed her post-doctoral work at Johns Hopkins University.

### THANKS TO OUR SPONSORS!

#### PRESENTING



#### PLATINUM



#### SILVER



#### BRONZE



#### IN KIND & EVENT

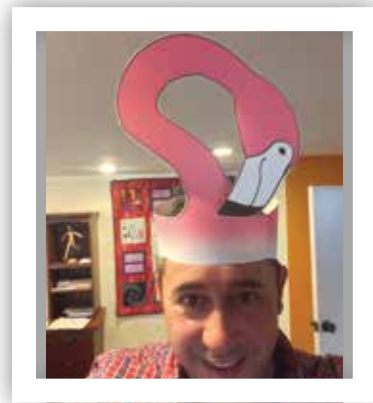


## TAKE THE BALANCE CHALLENGE!

VEDA invites you to participate in the 2015 Balance Challenge. Each year, VEDA has an activity to raise awareness about vestibular disorders. Our hope is that you find the activity fun, creative and engaging. We encourage you to get your friends, family, neighbors, community groups and schools, involved. This year's Balance Challenge theme is a PINK FLAMINGO, symbolizing balance (can you remain balanced while standing on one foot?).



VEDA has created a FLAMINGO HAT that you can easily download, print and assemble (go to [vestibular.org/baw](http://vestibular.org/baw)). You can submit a photo or video of your own Balance Challenge incorporating the flamingo theme. Listed below are just a few ways you can create your own balance challenge:



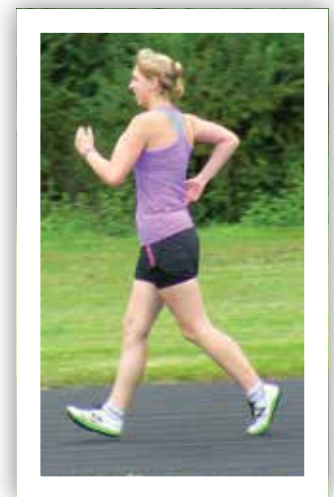
- 1) Submit a photo/video for VEDA to post on social media
- 2) Post the photo/video on your own Facebook, Twitter or Pinterest accounts
- 3) Gather as many people as possible wearing the flamingo hat and video who can stand on one leg for the longest amount of time
- 4) Organize a FLASH MOB with people wearing the flamingo hat (and pink clothing or accessories)
- 5) Place a plethora of plastic pink flamingos in your yard along with a Balance Awareness Week poster or sign
- 6) Get your local zoo involved - ask them if you can use their flamingo exhibit for a day, and set-up a booth to distribute information about vestibular disorders
- 7) Share your event with local news stations and other media

## YOU'RE INVITED TO THE FIRST ANNUAL DIZZY DASH VIRTUAL 5K

The Dizzy Dash 5k is a virtual race, so it can be done anywhere and anytime before, during or even soon after Balance Awareness Week. You can walk or run 3.1 miles all at once or over a period of time.

The purpose of the Dizzy Dash is to raise awareness about vestibular disorders. A great way to do this is to build your own customized Personal Campaign Page, which you can share with your family, friends, colleagues and neighbors. This is an opportunity for you to tell your story about how your vestibular disorder impacts your life. It also provides an opportunity for people to support your efforts financially, helping VEDA raise crucial funds for our programs and services.

For some extra fun you can wear our Balance Challenge Flamingo Hat while you walk! Don't forget to take a photo or video of yourself and submit it to [baw@vestibular.org](mailto:baw@vestibular.org) so we can share it through social media.



Please join the Dizzy Dash to increase awareness about vestibular disorders. To learn more about this event, visit [vestibular.org/baw](http://vestibular.org/baw).

# Inspiration From Across The Pond

By Sherron Laurrell, with Ian Fuller

This is a story about a man named Ian Fuller and how he has inspired me to stay positive when I was feeling defeated and overwhelmed by vestibular dizziness.

My chronic dizziness began in 2013. All of us who live with vestibular issues know it is a disturbing and life altering event. When it happened to me, I was desperate to find others who might understand what I was feeling. This is when I met Ian Fuller. I got to know him in a Facebook vestibular support group, where he always had supportive words to share, ending each post with a positive, upbeat comment, never trite, always kind. He never seemed to tire of seeing the glass half full when many of us focused on the half empty portion of our emotional and physical glasses. I started looking forward to "what Ian would say." I wondered how he could be so bloomin' positive and upbeat living with the burden of what was dragging me down! How does he do that, I wondered? So I decided to ask him.

Ian and his wife, Edi, live in the United Kingdom in a town called Ticknall in the county of Derbyshire. They have 2 grown children. Ian works as a Commercial Director for Capgemini, a French IT Company, which, thankfully, is very supportive of his vestibular issues.



IAN AND HIS WIFE, EDI, ENJOYING AN ANNIVERSARY PICNIC DURING A MOUNTAIN WALK IN THE SWISS ALPS.

Ian's vestibular problems started in 2012. He was 51 years old and had recently received a clean bill of health. Ian's passion is long distance walking. He had just completed the Isle of Man Parish Walk, an 85 mile hike that took him 24 hours! He was not prepared for what came next.

He was awakened one night with a loud hissing in his left ear. It was so intense and persistent that he decided to seek his doctor's advice. "It could be one of those things that happen as you age," he was told. However, the doctor scheduled an MRI to rule out an acoustic neuroma. A quick Google

of "acoustic neuroma" caused Ian some alarm. This could mean a brain tumor, benign, but serious. All tests were normal but the issues & left sided tinnitus continued. An ENT confirmed the GP's diagnosis: "Just one of those things." Aaarrggghh!

Ian began losing balance confidence on stairs. He was always reaching for something or someone to hold on to. His doctor recommended he stop driving, which reluctantly he did. He was finally diagnosed with Idiopathic Vestibular Asymmetry – 25% Canal Paresis to the left side.



IAN & HIS FAMILY HIKING NEAR MONT BLANC IN THE FRENCH ALPS, BEFORE HIS VESTIBULAR PROBLEMS. NOW IAN USES HIKING POLES TO HELP HIM MAINTAIN HIS BALANCE.





PURSuing HIS PASSION FOR LONG DISTANCE WALKING, IAN CAN BE SEEN IN A YELLOW CAP AT THE START OF THE "ROBIN HOOD MARATHON" IN NOTTINGHAM, UK.

His treatment plan included 6 months of vestibular rehabilitation therapy, 3-5 times a day. He was rewarded with a 90% improvement.

I asked Ian how he maintains that improvement. He says that he has his ups and downs. His focus is on not overdoing it. He limits computer usage to 45 minute spells with 15 minute breaks. 30 minute walks every lunch-time, no working long hours, and not driving in the evening when he is tired. But most importantly, he maintains a positive outlook! "This is not life threatening," says Ian. "Whenever I start to feel sorry for myself, I think of others who are worse off than I am."

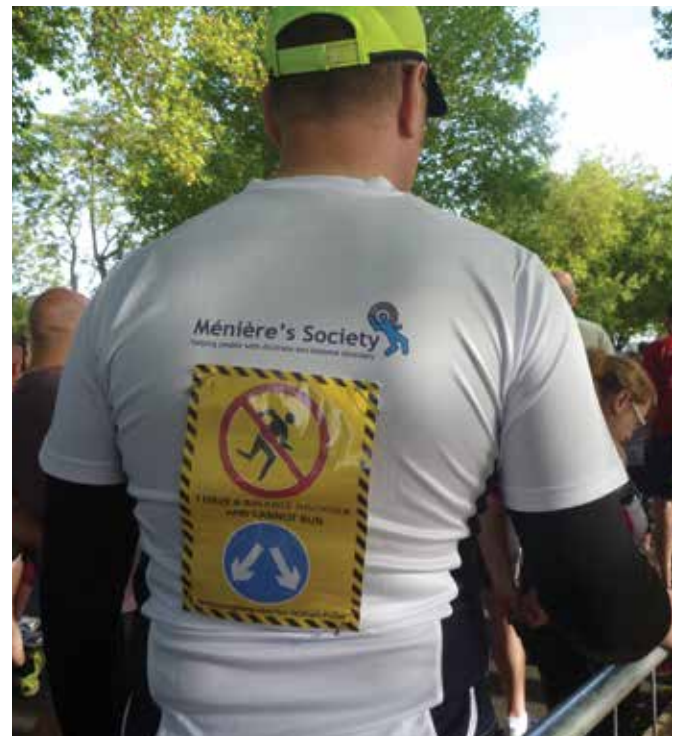
Ian and his very supportive wife are engineers by training. Understanding what is going on is important to their ability to cope and lay out how best to deal with Ian's issues. Ian joined the vestibular support group on Facebook and found comfort and fantastic support. He also mined all the excellent information on VEDA's website.

His philosophy on life is inspiring. "The world is a wonderful place to be explored and enjoyed with family & friends. I focus on helping my children, now at University, prepare to enjoy their lives."

When Ian agreed to collaborate with me on this article, I asked him what he thought would help others who have to live with a chronic vestibular illness. In his kind, gentle voice he shared: "Accept

that many things are going to be different, no longer as they were. Don't tie yourself in knots trying to have what you can't. Mourn for what you can no longer have. Grieve the losses, it will help. Learn to pace yourself to your new limits so you don't run out of steam too soon. Continue to be your awesome self for as long as possible each day! Accept that some days are going to be bad days. When you need to pamper yourself and recuperate to become awesome again, do it!"

**THANK YOU, IAN,  
FOR BEING AN INSPIRATION TO SO  
MANY VESTIBULAR PATIENTS!  
YOU ARE AWESOME!**



A SNAP SHOT OF THE INFORMATIONAL SIGN IAN WEARS ON THE BACK OF HIS SHIRT WHEN HE IS COMPETING, TO LET THOSE BEHIND HIM KNOW WHY HE IS WALKING AND NOT RUNNING.

# Catastrophe Averted - A Concussion Story

By Jennifer Liss (with Sherron Laurrell)

There are all kinds of events that have the potential for disrupting our lives. A near fatal car accident certainly fits that description. A resulting concussion interrupts life for both the sufferer and for those who love them.

That is exactly what Deana Leonard faced on a December afternoon in 2014. As she and her mother were on their way Christmas shopping, a man "late to work" blew through a red light and hit their car on the driver's side, demolishing the front end. Deana's mom was injured by the seat belt and fortunately healed without issue. Deana, however, was not so lucky.

After the collision, Deana jumped out of the car and instantly felt nauseous. Her head was hurting. Her focus was on her mom. And she was scared! The police wanted her to go to the hospital. She said "no." She was terrified, she thought, but not hurt. She just wanted to go home and go to bed.

Two days later she was "talking crazy" and not making any sense. Her husband and her twin sister began insisting that she go to the hospital but she continued to resist. Finally they didn't offer her the

choice. When they arrived at the ER the doctors asked why she had waited. They ran tests and did a CT scan and then told her, "You have concussion like symptoms. You need to follow up with a neurologist."

On December 19<sup>th</sup>, Deana saw a concussion



DR. JENNIFER LISS WITH PATIENT DEANA LEONARD ON HER "GRADUATION FROM VRT."

specialist at The Children's Hospital of Philadelphia (CHOP), who confirmed that Deana had a concussion. "Time is your friend Deana, but vestibular rehabilitation therapy will help you recover more quickly."

When Deana came to see me, she felt like her head was in constant motion. Clinically she presented with motion sensitivity, dizziness, imbalance, light sensitivity, head pressure and cervical stiffness. Her injuries were the result of the air bag deployment. During the balance exam her BESS (Balance Error Scoring System) score was a 22 (normal is 10 or less); her timed heel/toe walk (10 feet with turn) was 21 seconds (normal is less than 14 seconds without losing balance). Her MSQ (motion sensitivity quotient) showed a severe handicap at 52 percent. All other tests supported the finding of concussion. Her first appointment with me was December 31, 2014, seventeen days after her accident.

She had continual dizziness and balance issues over the holidays, but being a mom she didn't want to spoil the Christmas season for her two children, Megan, age 14 and Brett, age 9, by starting VRT. For many years before her accident, Deana had suffered from moderate to severe car sickness. Concussions can exacerbate previously existing conditions. After a thorough examination and case history I was able to say to Deana, "I have good news for you. After you complete VRT, you will feel



BASED ON THE CONDITION OF HER CAR, DEANA'S FAMILY IS THANKFUL SHE RECOVERED SO WELL.



better from the concussion and your long standing motion sickness issues may subside too!"

Deana began VRT twice a week at my office with homework she did on her own. It was a struggle at first. She continued to have severe headaches for the first few weeks. As her vestibular rehab progressed she began to feel better. When she went for her check-in with the concussion specialist at CHOP in early February she was able to report that she felt much better – fewer headaches, more balanced.



DEANA LEONARD WITH HER WONDERFUL, SUPPORTIVE CHILDREN, MEGAN & BRETT.

As a middle school guidance counselor, Deana tried not to miss too much work. In total she missed only six days. Her principal was very supportive of her situation. Her students were terrific! In her role, she had always handled accommodations of concussion cases for students but now she has a deeper appreciation of how to coach teachers who “resist” the reality that a concussion is serious business.

Her advice to others? If you are in a car accident, GO TO THE HOSPITAL! Don’t wait. Concussions are

no joke!

Deana graduated from VRT on April 30. She is doing well and is grateful that her fear that she would never be normal again has been replaced with regained balance and no car sickness!

*Jennifer Liss is “Susan Herdman certified” in Vestibular Rehabilitation. She is an Adjunct Professor of Kinesiology at Rowan University in Glassboro, NJ. TheraSport Physical Therapy offices are located in New Jersey, where she has practiced for 16 years. She can be reached at JenLiss@Therasport.org. Sherron Laurrell is a vestibular patient who has been treated by Dr.Liss. They now collaborate on case studies to educate and help others.*

## VEDA Medical Champion Award Call For Nominations

The Vestibular Disorders Association (VEDA) announces our 2<sup>nd</sup> annual Champion of Vestibular Medicine Award initiative to increase awareness of vestibular disorders.

We invite you to submit one or more nominations for this award.

Champions of Vestibular Medicine are medical professionals associated with an academic institution who have had significant impact on: 1) increasing awareness of vestibular disorders and/or 2) contributing to reduced diagnosis times and/or increased treatment effectiveness for vestibular disorders.

NOMINEES MAY BE:

- A student, intern or practicing professional;
- In any specialty (e.g. otolaryngology, neurology, physical therapy, audiology, etc.);
- Involved in clinical practice, research, academia, or all of the above.

**Submit a nomination at [https://vestibular.org/medical\\_champion](https://vestibular.org/medical_champion).**



## Volunteer Spotlight: Claire Haddad



VEDA would like to honor Claire Haddad for her extraordinary service, both to VEDA and to the entire vestibular community.

Claire has been a member of VEDA since 1996. She has spent a cumulative total of over 12 years serving on VEDA's board of

directors, where she has held the role of president, secretary and most recently treasurer.

Another of Claire's many contributions to the vestibular community was as a support group leader, where she helped dozens of vestibular patients overcome their debilitating symptoms and restore their quality of life with advice on dietary changes, coping techniques, and recommendations to cutting-edge medical specialists.

"What makes Claire truly special is the enthusiasm and commitment with which she approaches her volunteer efforts," says VEDA executive director,

Cynthia Ryan. "Claire gives 110%, and she does so with a smile. You can always count on Claire to offer help when needed, and to follow through on her promises."

Like many of you, Claire is a vestibular patient who went through a long and arduous journey to receive a diagnosis. VEDA helped her understand her condition, and she has more than paid it forward by helping VEDA educate other vestibular patients while raising public awareness about vestibular disorders. Claire recently resigned from the VEDA board to spend more time with her family. From the entire VEDA family, THANK YOU, Claire!



## VEDA IS ACCEPTING APPLICATIONS FOR BOARD OF DIRECTORS POSITIONS

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

**WE ARE CURRENTLY LOOKING TO FILL OUR BOARD TREASURER POSITION.**

If you have financial experience and would like to be an integral part of a growing organization that is making strides toward defeating dizziness, send an inquiry to [veda@vestibular.org](mailto:veda@vestibular.org).



# 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](http://vestibular.org/otl) 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 \_\_\_\_\_

E-MAIL \_\_\_\_\_

PHONE \_\_\_\_\_

CREDIT CARD # \_\_\_\_\_

EXP. DATE \_\_\_\_\_ CSV CODE \_\_\_\_\_

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.

## Community of Support Fall Membership Drive

*Sneak Preview!*

### VEDA'S COMMUNITY OF SUPPORT IS GROWING!

DON'T MISS OUT! RENEW YOUR MEMBERSHIP WHEN YOU RECEIVE VEDA'S COMMUNITY OF SUPPORT NOTE CARD.

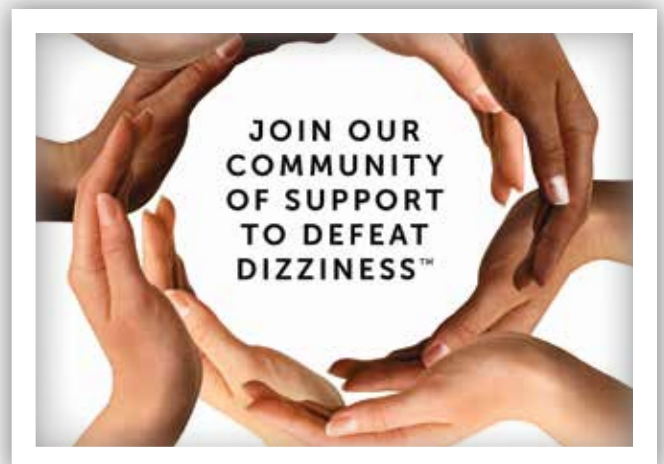
Historically, VEDA members have received a renewal letter and/or an email reminder before their scheduled expiration date. If your membership was due to expire this spring or summer, you received an invitation note card to renew your annual membership through our Community of Support in April.

If your membership expires later this year, or if you have not renewed your membership, you will receive an invitation to renew your membership in the mail in August.

This invitation REPLACES the renewal letter you formerly received. To keep your membership current, please return the Community of Support membership form that is enclosed in the card.

Don't miss out on great membership benefits, including a subscription to our quarterly newsletter, *On the Level*, access to our online member forum, V-PALS network, members only webinars, and other valuable benefits.

**Questions?** Contact us at (800) 837-8428 or [info@vestibular.org](mailto:info@vestibular.org)



# Summer Vacation Tips

By Wendy Wierzbowski, PT

Get ready for summer with some tips that can help you manage your vestibular symptoms:

## AT THE POOL

- Wear supportive shoes with rubber soles that are less likely to slip on wet floors.
- Visit the pool at a less busy time to decrease visual stimulation.
- Sun and brightness can provoke headache; remember a hat and sunglasses.
- Drink plenty of water to stay hydrated.
- Take a healthy snack.
- Goggles may be helpful for swimming so your eyes can be open and you can orient to your surroundings so you always know which way is upright.
- If swimming laps, you may want to use a mask and snorkel so you don't have to turn your head to breathe.
- Earplugs can keep water from coming into your ears, which can cause an infection and/or exacerbate vestibular symptoms.

## AT THE BEACH

- All of the above under pool list.
- Walking along the packed sand at the shoreline should be easier than in the loose sand.
- Always swim near a lifeguard. You may want to alert the lifeguard to your condition and ask them to point out where waves typically break so you can avoid them.
- If you have a moderate or higher unsteadiness, you may want to limit how deep you go into the water. Waves are unpredictable and can knock you down. Avoid rip tides.
- Pick a visual object on shore to orient yourself to your starting point (waves will move you down or up the shore).
- If looking at the waving water is bothersome, pick a stationary object to look at such as a dock or the horizon.
- Take a buddy for safety.



**VESTIBULAR**  
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