ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION

VEDA

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Putting Together My Broken Parts

By Alicia H.

I can only assume that if you are reading this story, you have somehow been touched by a vestibular disorder. As I begin to share my own personal story, I want to emphasize that although we may have different symptoms, everyone's symptoms are similar in that they are strange and difficult to describe. I emphasize this point because as I was dealing with my own personal vestibular illness I was always looking for someone with my exact feelings, and searching to make sense of and to validate and confirm my symptoms and my feelings. It can be a very lonely and terrifying place when you are unable to find doctors who fully understand or medical terms that describe your exact symptoms and experiences.

My dizzy spells began in the spring of 2011. I was never someone who had gotten dizzy or light-headed before, so I cannot overstate how extremely frightened and nervous I was. Then, one evening while I was taking a walk, I became overwhelmed with dizziness or something that I couldn't quite explain at the time. I knew only that

CONTINUED ON PAGE 2

IN THIS ISSUE

TOP LEFT: ALICIA AT HER BABY SHOWER; BOTTOM LEFT: ALICIA & HUSBAND, RICK, IN PARIS; BOTTOM: ALICIA & RICK'S NEWEST FAMILY MEMBER, ELLIE

BROKEN PARTS...CONTINUED FROM PAGE 1:

it was a strange feeling in my head. As it was a Saturday, I waited until the morning and then went to a Medical Center. I had no idea how to explain or properly articulate what I was feeling. I knew only that something was wrong, something was off. And although I wasn't able to fully describe my symptoms, the doctor diagnosed me with labyrinthitis.

Prior to this, I had never thought about the inner ear, how it operated or what it controlled in the body. Thus began my journey into vestibular research. Although I began to feel better over the next couple of months, I never really mentally recovered from what I had experienced, and I remained with a heightened sense of awareness regarding my body and my senses.

My second, more intense and significant, vestibular episode occurred in December 2012. For a few weeks leading up to this second episode, I had been having some strange sensations and feelings. Then one morning it hit me hard. It was as if something inside of me "broke" - again. I was severely dizzy, and this time I was continuously dizzy for about five to six days with no relief. I was dizzy all day and all night and nothing I did or took lessened the symptoms.

Throughout this time and for over a year, I would feel off after drinking my morning cup of tea. It was difficult for me to enter a store or mall as it would make me severely dizzy. I felt odd and strange in the shower or in the dark at night. When walking, I felt like I was floating and lost my sense of stability and gravity, and I had this pulling sensation as if my head was being pulled backward or downward.

I made an appointment with an otolaryngologist, who promptly diagnosed me with Meniere's disease. I underwent hearing and diagnostic balance tests, as well as a CAT scan and an MRI. I was surprised to learn that there is no real, fool-proof medical test to definitively diagnose an inner ear problem, but that it mainly involves ruling out more serious or life-threatening illnesses or conditions. This only contributed to my overall sense of complete anxiety and paranoia about my health: not ever being 100 percent sure of what was wrong with me.

I have always been someone who worried, especially about my health, but it had and has never prevented me from doing anything or going anywhere. I considered myself a very stable person, mentally and physically. The impact of an inner ear disorder on your life and ability to feel like a secure, stable individual is extremely difficult to articulate. When you are already someone who worries or can be anxious at times, this specific type of "illness" or condition is difficult to manage.

Vestibular problems are such that they seem to coincide with feelings of anxiety, and one of the most difficult things to work through is separating your anxiety from your vestibular problems. Your entire system is off. Something vital to how you operate and exist in the world is broken or damaged or compromised. It is impossible to fully articulate how and what you feel. Besides dizziness, which is the most common symptom that everyone expresses, all the other feelings or sensations you experience are so difficult to fully grasp and explain. They are slight sometimes, and yet are so all-encompassing because they get to the very essence of who you are as a person and they impact your entire bodily system, your entire life. It is impossible to ignore, and yet impossible to ever fully explain.

For me, it is important to not only share my experiences, but to also tell you how I healed. It began with the motivation to strive for a good, solid, healthy life. I found the very process of looking for solutions helpful in dealing with my situation. One of the most important decisions I made was to seek an opinion from yet another doctor, who not only did not think I had Meniere's, but who in turn sent me to the Rusk Institute in New York City, where I was able to find a vestibular physical therapist and psychologist.

"I MAY BE ANXIOUS & NERVOUS, BUT I CAN GET THROUGH THIS."

- ONE OF ALICIA'S MANTRAS

Over the next few months I combined my treatments, working on both the physical and mental aspects of my condition, and I was finally able to begin the healing process. During my vestibular physical therapy treatments, I spent much of the time asking questions and going over all of my symptoms, which I kept a running list of. My physical therapist had a replica of the inner ear and we methodically went through all my feelings and sensations and discussed what labyrinth might be damaged. By making these connections between what I was feeling and where the damage might be in my body, I started to focus on that area rather than feeling scared and nervous all the time by this mysterious and strange condition. In a very literal sense, while I was in the middle of a dizzy spell or when I was feeling off I would say to myself and others that my ear was bothering me. This helped me deal with it, and helped others understand it better, even if they didn't know exactly what I was feeling. Removing the mystery from it allowed me to gain back some control.

Another very significant aspect of my recovery was vestibular exercise. One of the scariest aspects of a vestibular problem is the utter lack of control one feels. A huge benefit of vestibular exercises is that they allow you to be in control and to pinpoint various motions that make you feel dizzy. When I would make myself dizzy by walking and turning my head side to side or turning my head while focusing on a stationary object such as a letter in the middle of a checkerboard, I would actually feel empowered and strong, as these exercises allowed me to recognize the vestibular problem.

During my treatment it was equally important for me to see a vestibular psychologist to have my feelings and anxieties validated. I learned how my feelings can become physical, how an inner ear weakness can be exacerbated by anxiety, and how, ultimately, my general anxiety can intertwine with my inner ear problem. Some of my self-soothing techniques included holding my ear when I was feeling dizzy or off and repeating certain phrases that I had learned, such as "anxiety can feel really horrible but it won't hurt me," "feelings are just feelings," and "I may feel anxious and nervous, but I can get through this situation." Although this may sound over dramatic, I would often remind myself that it is "just" my ear, and that in the end I am still alive.

Continuing Education for Vestibular Professionals

Diagnosis and treatment of dizziness can be a tricky affair, even for the most experienced and knowledgeable clinicians. As the number of people who suffer from vestibular disorders increases, the need for more awareness and training grows too. It is important for vestibular professionals to participate in continuing education trainings and conferences to stay up-to-date on the latest research and technology related to the diagnostics and treatment of vestibular disorders.

The good news is that there are many opportunities for vestibular professionals to learn from experts in their field.

DR. HERMAN KINGMA, MAASTRICT UNIVERSITY

"There have been so many new developments within the area of vestibular assessment and diagnosis in the last six years," says Prof. Dr. Herman Kingma from Maastrict University in the Netherlands. "New technologies and techniques now make it possible to evaluate and treat patients in a more objective way. Continuing education is important in helping healthcare professionals understand this paradigm shift and learn how to apply these new techniques and technologies effectively in their daily practice."

ANDERS LUND, OTOMETRICS

"We see a growing interest among clinicians to learn more about vestibular assessment using new and modern assessment tools," says Anders Lund, marketing manager at Otometrics, a company that provides computer-based audiological, otoneurologic and vestibular instrumentation and sound rooms to hearing and balance care professionals. "One type of training called "Master classes" give clinicians hands-on experience, the opportunity to ask questions about the latest techniques and technologies and refresh their knowledge of the vestibular system so they can shorten their patients' journey to diagnosis and treatment."

See VEDA's website for a list of continuing education courses for vestibular professionals: http://vestibular.org/resources-professionals/build-your-practice.

Research Corner

RELIABILITY OF THE VESTIBULAR/OCULAR MOTOR SCREENING (VOMS) TOOL

The Vestibular/Ocular Motor Screening (VOMS) is a newly developed tool that evaluates vestibular and ocular motor symptoms (headache, dizziness, nausea, fogginess) after a sport-related concussion. The purpose of this study was to examine the internal consistency of the VOMS in a large sample of healthy, non-concussed collegiate athletes. The study showed that the VOMS produces consistent results with an acceptable false-positive rate. Women and people with a history of motion sickness were at risk for scores above clinical cutoff levels. Results support a comprehensive baseline evaluation approach for concussion that includes an assessment of vestibular and oculomotor symptoms.

Am J Sports Med. 2016 Jun;44(6):1400-6. doi: 10.1177/0363546516632754. Epub 2016 Mar 15.

GENETICS OF VESTIBULAR DISORDERS

Studies are examining possible genetic components to many common vestibular disorders. Motion sickness and vestibular migraine, for example, show a familial trend. The most relevant finding during the past years is the familial clustering observed in Meniere's disease. By using whole gene sequencing and combining various tools, novel variants in certain genes (DTNA and FAM136A) have been identified in familial Meniere's disease, and this genomic strategy will facilitate the discovery of the genetic basis of familial vestibular disorders.

J Neurol. 2016 Apr;263 Suppl 1:45-53. doi: 10.1007/s00415-015-7988-9. Epub 2016 Apr 15.

VESTIBULAR MIGRAINE SUBGROUPS

The objective of this study was to evaluate patients with vestibular migraine and analyze whether different vestibular symptoms were able to discriminate different subgroups. Results showed that spontaneous rotational vertigo was more frequent in migraine with aura, whereas triggered non-rotational vertigo was more frequent in migraine without aura. This finding suggests a broad spectrum of clinical symptomatology in vestibular migraine patients. All of these patients are classified as vestibular migraine but they may represent two extremes of a disease spectrum.

Otol Neurotol. 2016 Mar;37(3):281-3. doi: 10.1097/MAO.0000000000000956.

Meniere's Disease

SEEKING PATIENTS TO ENROLL IN STUDY TO TREAT VERTIGO-INDUCING DISEASE

Otonomy, a biopharmaceutical company dedicated to innovative treatments for inner ear disorders, recently launched a research study to help evaluate the safety and effectiveness of an investigational drug for Meniere's disease, and is enrolling patients in a 16-week research study at multiple clinical sites across the U.S.

According to the American Hearing Research Foundation, Meniere's disease affects roughly 0.2% of the population, which is more than 600,000 people in the U.S. Meniere's disease is a disorder of the inner ear, which can ultimately affect an individual's balance and hearing in a progressive manner. Patients with Meniere's disease suffer from vertigo attacks (a feeling that the patient's surroundings are moving), dizziness, nausea, hearing loss, and ringing in the ears. Currently, there is no known cure for Meniere's disease.

One of the locations being used for the 16-week research study is Piedmont Ear, Nose & Throat, the premier otolaryngology group in the Triad, specifically located in Winston-Salem, North Carolina. Leading the site's efforts is Dr. Kenneth Maxwell, an ENT-neurologist with over 20 years' experience as a physician.

DR. KENNETH MAXWELL

Dr. Kenneth Maxwell explained that in the past, one way they treated patients with Meniere's disease was with a diuretic and a sodium restricted diet.

"We think there is an imbalance of sodium in the inner ear fluid," he said. "In a research study, it was estimated that one in three Meniere's patients are not controlled well, so the medications that we are putting people on, if they are not controlled well, are drugs like Valium and Prednisone, which both have side effects."

Maxwell explained that about 20 years ago, they began putting Prednisone into the ear.

"It's a good treatment, but because it is a liquid it doesn't stay in the ear for very long, so it doesn't really have a long-lasting effect," he shared. "Otonomy wanted to improve upon this particular method and looked further into how they could prolong the effects, with focus on a gelatin-like treatment. Theoretically, you could put the steroid in the gelatin-based substance, in hopes of potentially prolonging the effect in the inner ear."

Additionally, Maxwell shared that Piedmont Ear Nose & Throat has participated in several other Otonomy-related clinical trials over the years. "There were phase one and two trials, which were completed and published. However, this particular trial is still ongoing, but we are hoping for positive results," he said.

Maxwell mentioned that patients participating in the study are asked to keep track of their symptoms daily, which allows Otonomy to collect and analyze more accurate information on symptom changes from beginning to end.

"We see the patients in the office as frequently as every month. It's a fairly easy study to conduct," he said. "This is the third study in the United States that has been carried out by the Otonomy team that utilizes the same experimental medication used during previous trials."

Otonomy is currently seeking patients between the ages of 18 and 85, who have been diagnosed with unilateral (one ear only) Meniere's disease and have documented hearing loss to participate in the research study.

There are approximately 65 Otonomy study sites throughout the country. Study participants will receive study-related exams, lab tests, and investigational medication at no charge. For more information about this study and to see if you may qualify, call 888-205-5801 or visit www.OtonomyResearch.com.

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Stanley Cup Winner Champions Vestibular Concussion Awareness

BRYCE SALVADOR, RETIRED HOCKEY PLAYER

After struggling with vestibular symptoms as a result of multiple concussions, Bryce Salvador, former captain of the New Jersey Devils hockey team, decided to make a difference by joining forces with VEDA to raise awareness about the vestibular concussion connection.

VEDA welcomes Bryce as the Honorary Chair of Balance Awareness Week.

"I had to figure out for myself that there was more going on than just a concussion," says Bryce. "I want to make sure that others don't have to struggle alone like I did."

Bryce is especially passionate about raising awareness about the vestibular concussion connection among youth athletes and their parents, teachers, and coaches.

When disruption of vestibular system function occurs in children it results in symptoms of vertigo or dizziness, oscillopsia (gaze instability), and delayed development or diminished balance and other motor abilities. Children with vestibular problems often struggle in school and become socially isolated, and because of the invisibility of these symptoms, they may be accused of laziness or "faking it" by their teachers and coaches, and sometimes even by their own parents.

VEDA has developed resources to educate those impacted by youth concussion so they understand that the vestibular system may be affected, and to guide them to finding a diagnosis and getting appropriate treatment. You can view VEDA's concussion resources at vestibular.org/concussion.

Lauren DiRube also suffered from vestibular damage due to multiple concussions. A former cheerleader and soccer player, Lauren is currently undergoing vestibular rehabilitation.

Stay tuned for Bryce and Lauren's vestibular concussion public service announcement, coming soon to VEDA's YouTube channel!

LAUREN DIRUBE, YOUTH CONCUSSION PATIENT

Cervicogenic Dizziness Case Study

By Dr. Jennifer Liss, with Sherron Laurrell

Tina Kizitaff got off the flight from Los Angeles to Philadelphia feeling dizzy and off balance. Initially, she wrote it off as jet lag and a lingering 4-month sinus infection. Eventually she decided to see her family doctor, who prescribed antibiotics and steroids and suggested she see an ENT to discuss the dizziness, nausea, vertigo, and "floating feeling." Unfortunately, the ENT dismissed her symptoms and told her to just "finish the antibiotics." But Tina knew something was not right, so she persevered and consulted a second ENT, who ordered balance testing. This doctor saw her struggles and referred her to a vestibular rehabilitation therapist.

Tina is a 54-year old female, an elementary school teacher, and the wife and mother of two children, aged 19 and 24. She has a history of sinus infections, light sensitivity, and a constant sensation of rocking/being on a boat since taking an ill-fated cross-country airplane trip 6 weeks before. Her symptoms increased with changes in head position, and she was dizzier if she fell asleep on her right side. She has a history of migraines but had never suffered from dizziness previously. She had no history of cervical pathology or pain.

JEN LISS PERFORMING SEATED MANUAL CERVICAL TRACTION TEST WITH NEUTRAL HEAD POSITION ON PATIENT TINA KIZITAFF.

Tina's clinical exam included a Cervical Spine Screen that showed limited rotation bilaterally (on both sides), and dizziness with neck extension (looking up). Performance of the Dix Hallpike maneuver showed mild right horizontal nystagmus (involuntary eye movements). A supine roll test was positive for BPPV, with bilateral geotropic (downward moving) nystagmus stronger on the right than the left. Smooth pursuit with the head held stationary (a type of visual tracking test where the eye or eyes track a moving object) resulted in increased dizziness with both monocular & binocular tracking. Saccades (a quick simultaneous movement of both eyes) showed slowed speed compared to age related norms, and her rocking feeling intensified with repetition. Fast VOR (vestibular ocular reflex – a reflexive eye movement initiated by stimulating the vestibular system) resulted in some increase in dizziness after 10 seconds. Most notably, Cervical Manual Traction with the head in a neutral position throughout the test reduced Tina's dizziness and rocking feeling significantly. This is an evaluative technique I learned from Jana Landel, PT, DPT, a vestibular specialist who truly believes, as I do, that when vestibular clinical test results are inconclusive, it is essential to thoroughly evaluate the upper cervical spine.

UPPER CERVICAL ROTATION MUSCLE ENERGY TECHNIQUE.

I developed Tina's treatment intervention based on the diagnosis of BPPV with a likely cervicogenic component. After her evaluation, I performed the modified Gufoni maneuver, which abolished all symptoms of true spinning with position changes. However, the rocking feeling and motion sensitivity remained. Although Tina had no neck pain and was not previously aware of a significant range of motion deficit, she was willing to try a combined intervention program including manual cervical techniques targeting the upper cervical spine and cervical proprioceptive retraining. Because saccadic and smooth pursuit eye movements exacerbated Tina's symptoms, I re-evaluated these at the end of each session for symptom provocation. After five or six visits, Tina was significantly better and had no symptoms of vertigo or rocking with any ocular movements, and reported minimal if any motion sensitivity with activities of daily living.

Early in her vestibular rehabilitation therapy (VRT) Tina wasn't sure she believed in its effectiveness. Then she attended a two-hour graduation ceremony where her neck muscles tightened up and she got very dizzy. She was treated with manual cervical techniques and performed self-stretches and active exercises at home daily, and voila, the dizziness subsided. She now describes herself as a "believer!" I suspect Tina's issues were the result of chronic, long term undiagnosed cervical Range of Motion (ROM) loss, a long-term sinus infection, and a change of pressure in the cabin during her recent flight. Her prognosis is good if she maintains full cervical motion through a consistent home program.

CERVICAL PROPRIOCEPTIVE TRAINING WITH LASER TARGET.

3 CONSECUTIVE TRIALS (RED DOT HITS) WITHIN THE YELLOW/GREEN CIRCLES, INDICATES SUCCESSFUL PERFORMANCE OF TASK.

Tina's 19-year old daughter, Katelyn, is now in VRT for post-concussion syndrome that has debilitated her for months. Stay tuned for a case study on her rehabilitation journey!

Editor's Note: Jennifer Liss is certified in vestibular rehabilitation and MDT certified for treatment of the spine by the McKenzie Institute. She is an adjunct professor of Kinesiology at Rowan University in Glassboro, NJ. Therasport Physical Therapy offices are located in New Jersey, where Jennifer has practiced for 18 years. She can be reached at jliss@therasport.org. Sherron Laurrell is a vestibular patient who has been successfully treated by Dr. Liss. They now collaborate on case studies to educate and help others.

Environmental Influences on Vestibular Disorders

By Matthew G. Crowson, MD

Have you ever wondered if vestibular disorders and their symptoms are influenced by the environment? Recent work has demonstrated that the symptoms of common vestibular disorders may be linked with certain environmental factors.

ATMOSPHERIC PRESSURE

Changes in atmospheric pressure may affect patients with Mènière's Disease.[1]

In a recent study, investigators from Germany asked their patients with Mènière's Disease to keep a daily vertigo diary to document symptom flares. To test a hypothesis that changes in the weather solicit symptom flares, the study's investigators logged local hourly air pressure, as well as absolute and dew point temperatures over the time period the patients recorded symptoms in their vertigo diaries.

Interestingly, they found that the mean change in air pressure differed one day prior to onset of their patients' reported Mènière's Disease symptom flare.

Specifically, the authors noted an increase in symptoms after an increase in air pressure, but not after a decrease in air pressure. This result was independent of the temperature and dew point measurements.

As there is little evidence published to date to suggest how an increase in air pressure might trigger Mènière's Disease symptoms, the proposed mechanism of atmospheric pressure change causing increased symptom flares in Mènière's Disease patients' warrants further exploration. The authors correctly point out that atmospheric pressure increases may affect other physiologic processes that result in a symptom flare, so it is possible there is an alternate, but related explanation for the phenomenon observed in this study.

The German study is not the first time the idea of air pressure has been implicated in Mènière's Disease. Externally applied positive pressure therapy has been developed and commercialized for the treatment of Mènière's Disease. Positive pressure therapy works through a device not dissimilar to an aquarium pump, which emits small pulses of pressure through the ear canal and a ventilation tube placed in the tympanic membrane. The belief is that these small pulses of pressure may alter fluid dynamics within the inner ear, resulting in decreased symptoms. The efficacy of this technology has been questioned, however. A recent Cochrane Review of positive pressure therapy in Mènière's Disease found no evidence that it does not produce significant symptom improvement.[2]

ALLERGIES

Another major environmental research theme in Mènière's Disease has explored potential connections with allergic conditions. A report from the renowned House Ear Institute in Los Angeles compared the prevalence of allergic conditions in their patient population with Mènière's Disease to those without Mènière's Disease.[3] In patients with Mènière's Disease, nearly 60% reported possible airborne allergies, 40% suspected food allergies, and 37% had had positive allergy tests. When

the prevalence of these allergic conditions was compared to patients without Mènière's Disease, allergic conditions were significantly more prevalent in patients with Mènière's Disease.

A recent review of the evidence connecting allergic conditions and Mènière's Disease said that there is credible data to suggest patients with Mènière's Disease may have an enhanced allergic response.[4] While the authors could not conclude that there is a causal association between allergies and Mènière's Disease, they argue that practicing the principles of allergy control is a safe, relatively inexpensive adjunct to typical medical management. It remains to be seen whether the efficacy of this approach produces real benefits for patients with Mènière's Disease.

MIGRAINE

Sensitivity of health conditions and symptoms to weather or climate variation has been well described in qualitative patient symptom surveys.[5] Within the many health conditions surveyed, there is evidence to link migraine disorders and perturbations in weather patterns. Qualitative analyses of patient reported migraine triggers have noted that changes in weather precede migraine attacks second to psychosocial stress.[6] Migraine sufferers in northern climates have noted that migraine symptoms seem to occur more frequently in seasons with more daylight.[7] In a group of patients studied from the United States, migraine sufferers reported high humidity, low barometric pressure, and rainy days as having the ability to trigger migraine headaches.[8] There have also been objective reports of weather and climate change on migraine headache symptoms. Periods of meteorological phenomena of warm dry winds, known as the "Chinook Winds" in Canada, have correlated with a greater probability of migraine headache symptoms.[9]

What remains to be characterized is if weather patterns affect vestibular migraine as the pathophysiologic mechanism at play in classic migraine headaches may be shared. A common pathophysiologic link would suggest the triggers of migraine headache may also trigger vestibular migraine. However, further work is needed to elucidate a role between weather, environmental factors, and vestibular migraine.

CONCLUSION

While further investigation is needed to pinpoint precise mechanisms tying environmental phenomena to Mènière's Disease, curious investigators have produced thought-provoking data to suggest possible associations. The discovery of such associations may open new frontiers for therapy in the comprehensive management of this often perplexing condition.

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"I have had unilateral meniere's disease for 10 years. I skeptically started on this product in July, 2015. My disease is at the stage that my attacks are less frequent but the pulsating tinnitus is very uncomfortable, loud and the duration may be up to 6-10 hours. I need to take benzodiazepine to cope.
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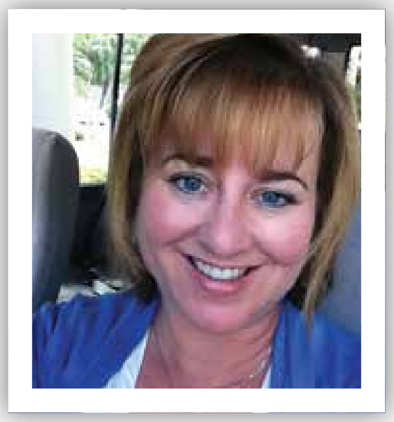
Imagine a global community where vestibular disorders are widely recognized, rapidly diagnosed, and effectively treated. That's the vision VEDA is working toward every day. You can help make this possible by being part of VEDA's Balance Society.

By joining VEDA's Balance Society you ensure that our educational resources are available to generations of future vestibular patients.



LOUISE GEIB, MS

Louise Geib found VEDA in 1994. "VEDA helped me cope with a vestibular disorder caused by a perforated membrane in my middle ear," she says. "It left me unable to walk due to the vertigo and in bed for months and months. Using the information provided by VEDA, I was able to get diagnosed by the correct specialist and undergo surgery to repair the membrane. VEDA's information about recovery continued to help me stay focused and patient throughout the process, and give me hope that I would indeed recover."

Louise would have been lost without the valuable resources and support VEDA provided her with, and she doesn't want others to suffer alone. That's why she decided to include VEDA in her estate planning.

"I want to leave a legacy of balance," says Louise. "That's why I've included VEDA in my will."

You don't have to be wealthy to leave a legacy. There are many planned giving options, some of which provide you and your family with current income.

To find out more about joining VEDA's Balance Society, contact us at legacy@vestibular.org.

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