



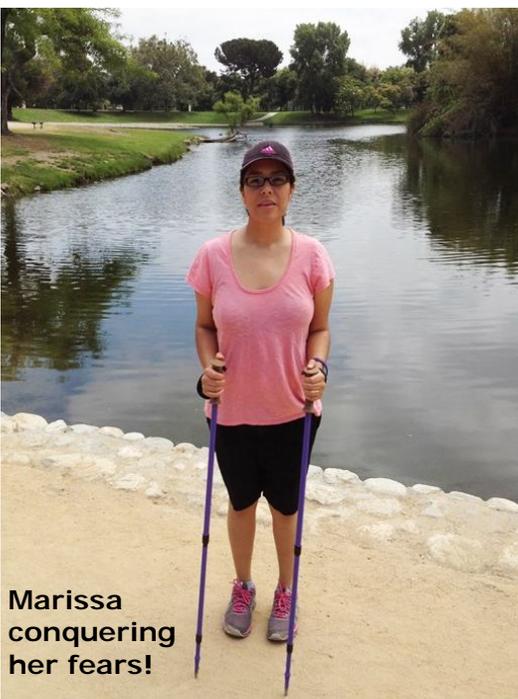
On the Level

Quarterly Newsletter of the Vestibular Disorders Association

An Alteration of Life Plans

By: Marissa Christina

I was just coming into my own and I had it all figured out. I was producing a life my parents could be proud of and everyone in my circle could respect. I was emulating what I thought was the road to success. I worked 50+ hours a week and wore beautiful power suits. My drive was work and the reward was money. I didn't spend my days thinking about nonprofits, personal health, spirituality, or inner peace because I thought I was fulfilled. Little did I know that my reality would dramatically shift.



Marissa conquering her fears!

It took an illness to shake me up. I was in my twenties when my whole world changed, and I started to become intermittently dizzy. Was this stress? Was I pregnant? Did I need new glasses? One day I woke up and the world was spinning...and the spinning never stopped. I just wanted to be myself again and I wanted the dizziness to go away. It didn't, and after a fall from the stairs at work I knew life would never be the same.

The first two years I was paralyzed by fear. I was afraid to move, leave the house or drive - the dizziness was that bad. I had difficulty walking around the block. Was it anxiety? Was I going crazy? Was this all in my head? I was forced to move home with my parents, and while I was thankful to be there I was also bitter inside. How could I get people to understand what it feels like to have your car sitting in the driveway and not be able to drive it? After two years I started falling into a depression, not getting up until 2:00pm, not showering for days, not seeing the outside of my house.

I was finally persuaded to see a counselor. I went through a few but managed to

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Thanks to everyone who participated in Balance Awareness Week!

"I began to realize that I don't have control over the symptoms of this disorder but I do have control over my mental faculties and how I respond to this condition."

- Marissa Christina

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An Alteration of Life Plans (cont. from pg. 1)

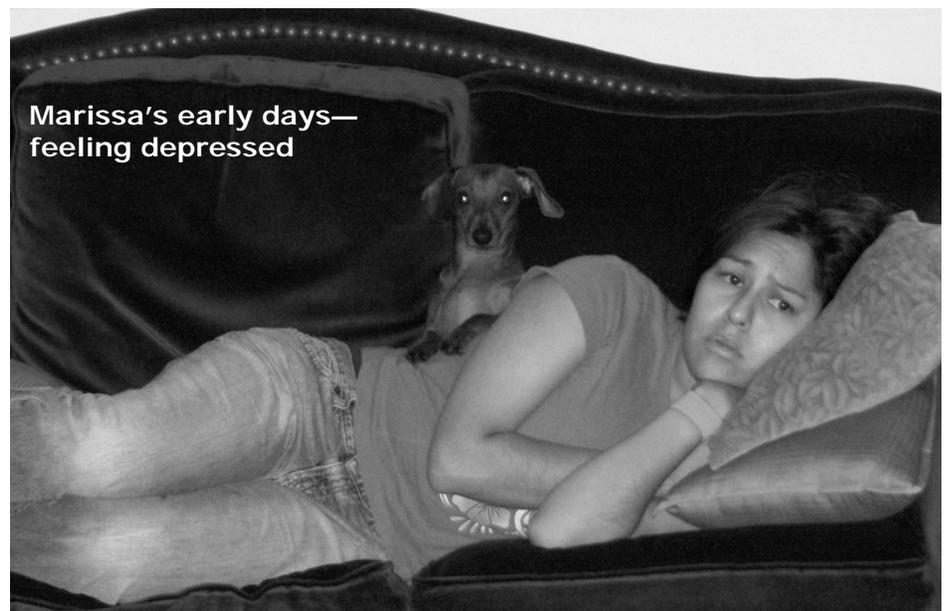
find one that could understand what I was going through. She explained to me that I was experiencing loss, that I was grieving. I asked her how long this grieving process would take, a question she couldn't answer. I continued with the sessions and started to realize that something was happening. I was pouring out my feelings and the depression just started fading away. She didn't judge me. Heck, she hardly said a word. I was working my way through this mess and I started to gain a sense of control. Then my insurance was dropped by my employer, I became uninsured, and the counseling visits stopped.

Did I mention being laid off? Remember my identity that came from producing and work? Well, that got taken away from me too. I won't even get into the demoralizing process of applying for disability. I was broke, jobless, and asking for handouts. Who had I become?

My counselor was exceptional because she taught me how to manage my feelings on my own. I began to realize that I don't have control over the symptoms of this disorder but I do have control over my mental faculties and how I respond to this condition. For five years I sided with fear, anxiety and depression - I was constantly tired. I had to address this anguish, so I began mental housekeeping. I started to think outside myself, asking if others have moved through chronic illness in a positive way. The last two years I have worked on confronting myself with questions like, "Marissa, how are you going to respond to this?" and "How long are you going to beat yourself up?" as well as "How do I grow from this?"

My grandmother has been my saving grace. She opened my eyes to see a world beyond myself, reminding me of my blessings. I am fortunate to have a suppor-

Continued on p. 3



An Alteration of Life Plans (cont. from pg. 2)

tive fiancée, a family that cares, and a grandmother praying for me. I didn't have to pretend to be in control or fake it anymore. I was no longer going to continue in my familiar pattern of self-destruction.

With this increased clarity I was able to seek a new team of specialists and medical practitioners, who are now helping me work toward a better quality of life. I realize that a vestibular disorder requires a team of open-minded healthcare specialists that are willing to work with you.

The diagnoses have changed several times throughout the last seven years, BPPV, Fistula, Canalithiasis, Cupulithiasis, and currently Neuro-Vestibular disorder. I've been told the symptoms are inside my head, outside my head, and everywhere in between. I've learned that regardless of the uncertainty that comes from this vestibular disorder there are 3 things I can be certain of: 1) I trust that the symptoms are real, 2) I am surrounding myself with supportive people and medical practitioners, and 3) I know there is a community of others who share my similar experience!

"I have been told the symptoms are inside my head, outside my head, and everywhere in between."

So, here I am. This past year I started a blog, was a guest on a popular web design podcast, and volunteered, all within the four walls of my room. Yes, I am scared out of my mind, and that's OK. I realize that each day living with a vestibular disorder brings uncertainty, doubt, confusion, fear, anger, depression, and a host of other emotional and physical symptoms. I'm learning to combat these experiences by being in a heightened state of awareness, and allowing myself to filter these realities into manageable personal challenges.

Blessings to all of you who live with a vestibular disorder or care about and support someone who does. If no one believes you, trust that you have at least one person that does: me!

**You can visit Marissa's blog at:
<http://www.abledis.com>.**

Speaking from Experience: Tips to Make the Journey Easier



"Vestibular patients improve in stair steps, it's not linear. It is a long, slow and rewarding process. Healing moved at its own pace, not my pace. There were ups and downs but, overall, I kept improving. You will need to measure your own progress over longer periods – six months, a year – rather than in days or weeks."

- Sue Hickey, *Finding Balance – Healing from a Decade of Vestibular Disorders*

Research: Recovering from Semi-Circular Canal Surgery

By Dr. Michael Schubert, MD, PhD
Johns Hopkins University



Superior canal dehiscence syndrome (SCDS) is a well described disorder characterized by vertigo and oscillopsia (visual disturbance) in response to loud sounds (Tullio phenomenon) or Valsalva maneuvers (forceful exhalation with one's nose

and mouth shut).^{1,2} Patients report other symptoms including autophony (increased loudness perception of one's own voice) and chronic imbalance.^{3,4} SCDS is confirmed with high resolution computed tomography (CT).⁵ For patients with debilitating symptoms, a surgical repair is made by plugging the affected semicircular canal or resurfacing the dehiscent bone.²

Recently, Janky et al characterized impairment and recovery of balance, as well as the extent of vestibular dysfunction and subsequent compensation, following SCDS surgical repair. Thirty patients diagnosed with SCDS (mean age 46 years, range 28 – 61 years) participated in the study. The researchers measured static and dynamic measures of balance as well as measures of vestibular and auditory compensation.

Their main findings included balance measures being significantly impaired immediately but not six weeks after SCDS repair. Based on the poor balance, the authors concluded that patients undergoing SCDS repair should undergo a post-operative fall risk assessment. Additionally, all patients demonstrated deficient function of the surgically repaired semicircular canal. In the majority of patients, immediately after the surgery, their eye movements at rest (spontaneous nystagmus) suggested the vestibular nerve on the same side of the surgery was functioning greater than normal, not less – as if irritated.

Immediately after surgery patients' primary

complaints were resolved; however, some patients experienced side effects – including vertigo, imbalance and/or nystagmus - for about 6 weeks following surgery. These symptoms were also eventually resolved.

Although rare, SCDS provides a unique model to study the effect of isolated lesions on inner ear function. Until this article, the effect of canal plugging in humans was not known to acutely impair balance. This study highlights the importance of subject participation in research in order to improve the lives of those with vestibular impairment.

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RECRUIT RESEARCH STUDY PARTICIPANTS

If you are conducting a clinical trial researching vestibular disorders and are looking for participants, you can post your study on the VEDA website at <http://vestibular.org/research>. For more info contact us at info@vestibular.org.

Tips for Working Out in a Busy Fitness Center

By Suzanne Johnson

Staying fit is a huge challenge! I have a vestibular problem and not only am I off balance, but I get nauseated when there is a lot of motion around me. I do best in a quiet environment with something stable to look at.

Fitness centers are not set up that way. It appears that fitness center managers think most of their members want loud, fast music, multiple televisions, and crowds to exercise with. I already have enough adrenaline from dizzy spells; I don't need more stimulation.

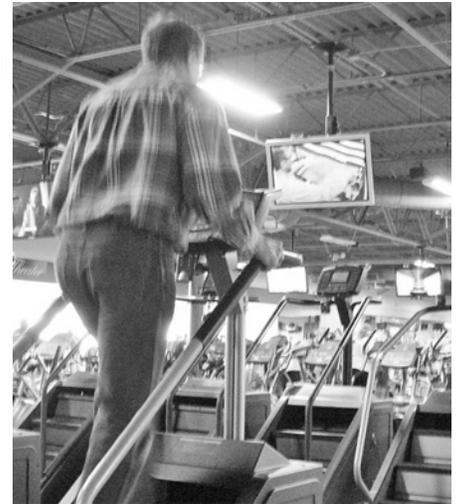
Maintaining fitness is very important to tolerating and adapting to my vestibular problem. It's also important to retaining as much function as possible as I get older. Having chronic vertigo is enough of a problem; I don't want to add cardiac, diabetic, or other health problems. I need a fitness routine I can maintain over time that includes some cardiac conditioning along with muscle strengthening, balance exercises, and stretches.

I like walking outside, but not when it is windy or there are falling hazards like ice, gravel, or leaves on the ground. I don't seem to keep up a home fitness program and I want to get out when I can. Over the last ten years that I've had a vestibular problem I've worked out at multiple fitness centers. Let me share my tips on finding a fitness center that works for you.

Ask for a Guest Pass. If you were fine exercising one day in a fitness center, don't assume that it will work out week after week. Most vestibular symptoms vary from day to day, so give the center a good try before making a long-term commitment.

Eliminate Some Areas. I avoid looking at multiple moving arms and legs in front of me (even 6 people working out in front of you means you are watching 24 arms and legs circling around). When your vestibular system is challenged, your eyes help you feel stable, but not when you are watching things that move. Thus, I avoid the back row or the center in a

row of step, bike, or treadmill machines. I avoid areas where there are TVs in front of me. And I stay away from mirrors (those 24 arms and legs in front of you become 48 arms and legs with mirror reflections).



My husband can exercise in the middle of TVs & machines; I avoid those areas.

Discover Low-Motion Areas.

Look for stretching areas or side rooms that aren't in use. Find the machines that are turned so that you face a wall or quiet area. Usually there are a few cardiovascular and strengthening machines on the sides that I can use.



Pick machines that face a wall or a low-motion spot.

Pick Equipment with Support. I like cardiovascular and strengthening equipment with stationary support for several parts of my body. When my arms, back, or hips are against the equipment, the proprioceptors in

Cont'd. on p. 6

Tips for Working Out in a Busy Fitness Center (cont. from pg. 5)



Select equipment with stable arm, leg or back support.

my joints help me feel stable. I avoid bikes or step machines where my feet and arms are moving at the same time. Instead, I pick a machine with *either* arms or legs moving, but not both.

Monitor the Noise Level. I have hyperacusis (sensitivity to noise) and tinnitus (ringing sound) with my vestibular problem. I get nauseated and exhausted quickly when I hear lots of loud, fast music. While my otologist does not want me to wear ear plugs often, he allows me to wear them if the fitness center has loud pounding music. While not many, there are a few centers that are quiet. These usually have the television or radio system on transmitters, so members can tune their audio player to receive music through their individual headsets.

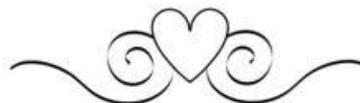
Adapt As Needed. Your goal is to develop a fitness routine that works for you. Adapt to the setting as you need to. I put a towel over the screen if a cardiovascular machine has too many moving icons in front of me. I turn toward the wall and away from other class members or I hold onto a walking stick for security when I take a yoga class. I wear a visor in a fitness center with rotating ceiling fans or bright lights.

Enjoy the Shower! Fortunately, in all fitness centers I've attended, the shower is a highlight of my visit. They all have had good handles to hold onto in the shower so I can hold on when I tilt my head back. They've had wall hair dryers, so I can lean against the wall while I dry my hair. I sometimes go to the fitness center just for their shower when I feel I need more security than my home shower provides.

Teach the Fitness Specialists. Most fitness centers have professional fitness specialists. Many want to develop a fitness center for people of different abilities. For example, many have special classes for seniors. Even though nearly 1/3 of senior citizens have some vestibular or balance challenges and many younger people do too, few specialists are aware of how to adapt the fitness center to accommodate us.

Set up a short meeting to talk with the specialist in charge of the machines and their placement. Thank them for the areas and machines that work well for you, rather than complain. Walk around the center and show them, so they can better see your perspective and what works for you. I've talked with several fitness specialists and they have all been very receptive. After talking with one specialist, he decided to put in remote and not whole-room music. In another, when the center bought new exercise bikes which had moving legs *and* arms, they kept one of the old bikes that had stable arms. This is a great opportunity to explain to people what it means to be dizzy, show them you care about being as fit as possible, and educate them about vestibular problems.

[With thanks to F. Owen. Black, M.D., who taught me that adapting is the key to living with a vestibular problem.]

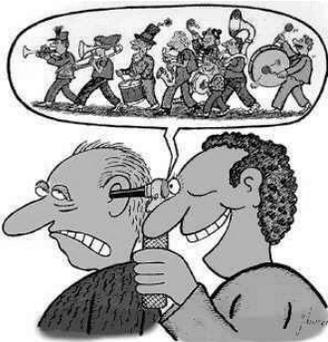


Tinnitus—The Ringing in My Ears is Driving Me Crazy!

By Bonni Kinne, PT, MSPT, MA

Throughout my career as a physical therapist I've treated thousands of patients with vestibular disorders. Many of these patients have experienced tinnitus (ringing in the ears) in addition to their vertigo. In fact, tinnitus is a very common finding associated with two types of vestibular disorders, labyrinthitis (a type of inner ear infection) and Meniere's disease.

A few years back, a patient was referred to me by an otorhinolaryngologist (an ears, nose, and throat physician) who was one of my primary referral sources. I assumed that this patient was primarily experiencing vertigo, but as I gathered her medical history it became apparent that her only complaint was tinnitus. In fact, she repeatedly complained that "the ringing in my ears is driving me crazy!" If you're experiencing similar symptoms I'm sure that you have a lot of questions and concerns. I'll do my best to educate you about this troubling condition.



Description of Tinnitus

Although it's most common to hear tinnitus described as a "ringing" sound, many individuals characterize the sound as a "buzzing", "clicking", "hissing", "roaring", and/or "whistling." This sound may be present in one ear or both and it may be periodic or unremitting. In all cases, tinnitus is an abnormal perception of sound that isn't being produced by an outside source. Tinnitus generally sounds louder when an individual is in a quiet environment. Tinnitus is not a disease, it's a symptom associated with another medical condition. Fortunately, the other medical condition is rarely a serious one.

Prevalence of Tinnitus

Tinnitus is a very common disorder that af-

fects millions of Americans. It's been estimated that up to 33 % of all adults will experience tinnitus at some point in their lives. In fact, tinnitus currently interferes with the normal daily activities of approximately one million Americans and up to 15 percent of all adults seek medical attention as a direct result of its presence. Tinnitus is more common in females than in males, in Caucasians than in any other ethnic group, and in individuals over the age of 65.

Cause of Tinnitus

Although the cause of tinnitus is often unknown, there are many possible reasons for its existence. The most common cause is presbycusis (hearing loss that is created by degenerative changes, especially in older adults). Most of the causes of tinnitus are benign conditions. However, a sudden onset of a pulsating tinnitus in one ear may indicate something more serious. Therefore, it's always a good idea to consult a physician if you're the least bit concerned about your symptoms.

Diagnosis of Tinnitus

If you seek medical attention for your tinnitus, your physician will initially attempt to discover the underlying cause of your condition. The most popular test is an audiologic assessment (a hearing test). As previously mentioned, hearing loss is the most common cause of tinnitus. Other diagnostic tests that may be included in your overall examination are x-rays, an MRI, an MRA, a CT scan, and/or laboratory tests. All of these procedures are considered non-invasive.

Treatment of Tinnitus

If your physician is able to determine the cause of your tinnitus, your treatment will be managed by focusing on the underlying condition. Because the underlying cause is often unknown, the treatment of tinnitus may consist of "masking" the ringing sound so that it's less bothersome. The simple use of a hearing aid may be enough to effectively improve your hearing and decrease your tinnitus. There is

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Tinnitus (continued from pg. 7)

also a device called a tinnitus masker. This device looks similar to a hearing aid, and it produces a competing sound that covers up the unpleasant sensation of your tinnitus.



Tinnitus Masker

In some cases, a tinnitus masker is combined with a hearing aid to produce one device. Because tinnitus generally sounds louder when an individual is in a quiet environment it can negatively affect one's ability to sleep. In this case, many people find that the use of a sound machine or a fan can help them fall asleep at night. Like the tinnitus masker just described, sound machines and fans are used to cover up the unpleasant sensation of your tinnitus.

If these methods don't work there are several alternative types of therapy. Although most of these alternative therapies haven't been scientifically proven as effective methods in the treatment of tinnitus, many individuals with tinnitus have found them to be beneficial. These alternative treatments include acupuncture, biofeedback, hypnosis, meditation, and yoga as well as behavioral therapy, cognitive therapy, habituation therapy, relaxation therapy, and tinnitus retraining therapy.

A pharmacological approach may also be warranted. Medications that have demonstrated some effectiveness in managing tinnitus include anti-anxiety drugs, anti-depression drugs, ginkgo biloba, melatonin, and certain types of nutritional supplements. Other simple remedies include decreasing your intake of alcohol, caffeine, nicotine, and salt as well as increasing the amount of time that you exercise and sleep.

Prevention of Tinnitus

Like most medical conditions, it's better to prevent the onset of tinnitus than to treat it once it's present. Because hearing loss is the most common cause of tinnitus, the best pre-

ventative measure is to avoid being exposed to extremely loud noises. If this situation is unavoidable, be sure to wear protective ear muffs. Ototoxic medications if taken in large amounts can also damage one's hearing so be aware of this danger as well. Common types of ototoxic medications include certain antibiotics, cancer drugs, and diuretics. Even consuming a high dose of aspirin can result in a temporary episode of tinnitus.

Resources

- <http://www.ata.org/>
- <http://www.mayoclinic.com/health/tinnitus/DS00365/>
- <http://www.medicinenet.com/tinnitus/article.htm>
- <http://www.nidcd.nih.gov/health/hearing/pages/tinnitus.aspx>
- http://www.emedicinehealth.com/tinnitus/article_em.htm
- <http://www.webmd.com/a-to-z-guides/ringing-in-the-ears-tinnitus-topic-overview>

Bonni Kinne is an assistant professor in the department of physical therapy at Grand Valley State University, where she conducts research in vestibular rehabilitation. Bonni also works in a clinic where she specializes in the treatment of patients with vestibular disorders. Bonni received her bachelor's degree in biomedical sciences and master's degrees in exercise science and physical therapy.

From the New Yorker



"The ringing in your ears — I think I can help."

Save the Date!

American Hearing Research Foundation Symposium on Dizziness & Balance Disorders

The American Hearing Research Foundation (AHRF) is holding a FREE symposium for patients with dizziness & balance disorders, featuring physician experts in the field of vestibular medicine.

There will be workshops and Q&A sessions, as well as opportunities to connect with the doctors directly.

When: Saturday, April 6th, 2013

Where: Oakbrook, Illinois

For more info, visit the AHRF website at:

<http://american-hearing.org/ahref-news/dizziness-balance-disorders-symposium/>

Symposium Workshop Topics:

- Introduction to Dizziness & the Vestibular System
- Clinical Exam for Dizziness
- Vestibular Tests & Diagnosis
- Benign Paroxysmal Positional Vertigo
- Meniere's Disease
- Migraine Associated Vertigo
- Vestibular Physical Therapy
- Intra-Tympanic Therapy
- Future Therapies—Gene/Stem Cells/Implants

What Did You Do For Balance Awareness Week?

Greetings from your Florida member,

I just wanted to share with you what three of your VEDA members did for "Balance Awareness Week."

Because of your Link List (now "V-PALS") we were able to get in touch with one another and discuss our individual balance issues. We created a "mini support group" and after months of emails and talking on the phone we decided to finally meet. We picked a half-way point on the interstate and met at a restaurant. I drove 100 miles for the first time in years. I believe that the 4 months of vestibular rehab has helped me to accomplish that. Linda drove from her home slightly over 100 miles as well; we met Chris in the middle.

It was the most wonderful meeting for all of us. To be able to actually meet other people with similar vestibular problems made us feel "normal." We compared the type of tests we went through, the doctors involved, and how we each cope everyday. We became close friends and will be looking forward to a long friendship with future get-togethers.

We all thank VEDA for all the hard work involved in educating us and others about our vestibular disorders.

Thank you from all of us.
Regards,
Sheldon



**If you'd like to connect with other
VEDA members, join V-PALS!**

(See page 12 for details.)

Thank You!

We thank the following individuals and organizations for their generous donations and pledges to VEDA received July 1st, 2012 through September 30th, 2012.

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Please consider making a donation today!

With your support we can reduce diagnosis times, improve treatment outcomes, and enhance the quality of life for people with vestibular disorders.

Thanks!

What Will Your Legacy Be?



Jeanette Welch—a founding VEDA board member—was dedicated to supporting the mission of the Vestibular Disorders Association during her lifetime, and beyond. As a charter member of VEDA's "Balance Society," Jeanette left a legacy that will continue to help people suffering from vestibular disorders now and into the future.

When you make a planned gift to the Vestibular Disorders Association, you'll become a member of our "Balance Society" - a memorial to your commitment to improve the lives of people with vestibular disorders.

For more information about including VEDA in your Will or estate plan, contact executive director, Cynthia Ryan, at (800) 837-8428 or via e-mail at Cynthia@vestibular.org.

Yes! I want to help people suffering from vestibular disorders.

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

You can renew your membership and make an additional gift to support VEDA's life-changing work online at <https://www.vestibular.org/donate>, or send your payment with the enclosed self-addressed envelope.

Annual Membership:

- Basic \$40 (e-newsletter only) **email required*
- Professional \$110 (e-newsletter only)
- Shipping (optional) \$5 US/\$15 international (if you would like to receive your newsletter in the mail)

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 U.S. funds*)
- Visa MasterCard American Express
- Please send me information about including VEDA in my Will or estate planning.

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.



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

If you would like to receive your newsletter printed on grey matte paper, please contact us!

V-PALS: A New Way to Connect

Would you like to connect individually with others suffering from a vestibular disorder? Join "V-PALS" – VEDA's new members-only support network.

By joining V-PALS you will be put in touch with a self-selected group of people looking for others to share with and learn from.

V-PALS will receive a list of members' names with e-mail contact information. Some members are interested in connecting specifically with people within a certain age group, gender, and/or vestibular diagnosis, so V-PALS will be asked to share this information. Then it's up to you to reach out to other members to connect.



To sign up for V-PALS fill out the form below and return it to VEDA, P.O. Box 13305, Portland, OR 97213, or send us an email at info@vestibular.org.

Name: _____

E-Mail: _____

DOB (optional): _____ Gender: Male Female

Vestibular Diagnosis: _____