



# On the Level

Quarterly Newsletter of the Vestibular Disorders Association

## Aerial Photographer Grounded by a Vestibular Disorder

By Patricia Thompson

I had a dream job - flying, photography, great boss, fun work environment. Then my world started spinning and my dreams all came crashing down.

I was in photography school when an instructor recommended me for a position doing photography for a construction company. I really wanted to do wedding and portrait photography, but this was part-time and would allow me to work around my school schedule. At first it was just me and the owner, but as business picked up we hired others to help. There were three of us in late 2000 when the aerial photographer left to pursue another profession. I took over the airplane flights, which took me all over North Georgia. The world looks different from the air. I loved it!

In early 2009 I began to feel tired and sick after flights. My malaise continued and began to get worse, until one day I couldn't get out of bed for two days. I went to my primary care physician, who did blood work and several tests; then I was referred to an ENT.

After hearing tests, an MRI and several other exams my ENT diagnosed me with a perilymph fistula. I didn't really know what

that was but was assured it could be fixed. That was all I cared about. I was an aerial photographer - it was my life and my livelihood, and I couldn't imagine being grounded, no longer able to soar above the earth.

I scheduled the surgery as soon as possible. The doctor repaired the fistula in my round and semi-circle canals. I flew just before surgery knowing I would be grounded for 6 months, during which time I continued to do ground photography. Finally I got the O.K. to return to flight. For about a year everything was great.

Then, in late 2010, I didn't feel so good during a flight. Sometimes our flights are bumpy, speed bumps I used to call them, so I figured I had a little air sickness. Afterwards I got in my car and returned to the office, less than a quarter mile from the airport. By the time I reached the office the world was spinning. I was alone and barely got the door open before I hit the floor.

I hadn't taken time to eat lunch, so I thought that maybe I was just experiencing some low blood

Cont'd. on p.2



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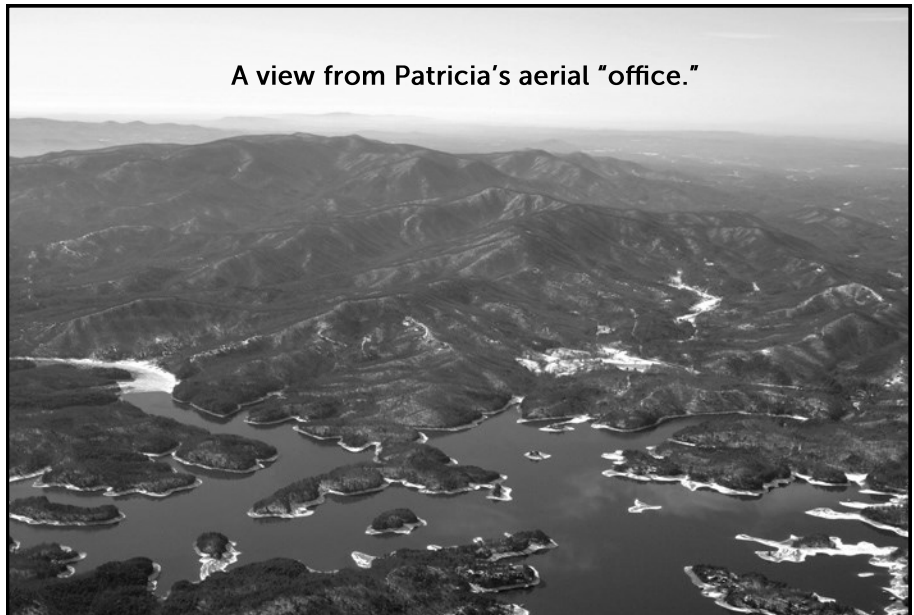
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## Aerial Photographer (cont'd. from p.1)

sugar. I tried to eat some crackers and a diet soda, but the cracker became stuck in my throat and wouldn't go down. I began choking, so I slammed my back against the door and put my fist against my diaphragm and finally dislodged the cracker. I continued to lie there, however, because I didn't know which way was up. After about an hour I felt a little better, so I grabbed a hard candy and started home.



During the next flight I took snacks and things went smoothly. However, when I got to the office I started to feel a little sick. I was unloading my images onto the computer when the room started spinning, or maybe I was spinning, I couldn't tell which. When I was finally able to get home I couldn't get out of bed for four days.

I went back to my ENT, who found that I had fluid in my ear. He inserted tubes to drain the fluid and recommended therapy. He also told me to stop flying. I am an aerial photographer, so I listened to his advice in the hopes that it would fix my problem so I could return to work.

I went to a therapist for three months twice a week, but nothing helped. Desperate, I searched the internet for 'vestibular problems' and found VEDA's website, and there it was - perilymph fistula. I printed out the info and took it to my next therapy session. My therapist suggested I try to find someone in my area who treated this specific problem.

I visited the site again and found Dr. Steenerson on VEDA's provider directory. He did tests and recommend vestibular therapy with Dr. Gaye Cronin. I began therapy the next week, where I was evaluated with machines customized for vestibular problems, and given balance exercises. These were very different from the therapy I had received before. I improved somewhat and found that I seem to

Cont'd. on p.3

## Aerial Photographer (cont'd. from p.2)

have triggers - scrolling on the computer, windshield wipers, straight lines, flashing lights, lots of things. When I told Dr. Cronin she understood - someone finally understands! She told me that my symptoms are not just in my head, that she has other patients who tell her the same thing. She explained how the vestibular system works and why these things are so difficult.

Unfortunately, I could no longer continue as an aerial photographer. I couldn't fly, go on construction sites, process images on the computer, or even make it to work regularly. I trained a replacement and then, with tears in my eyes, left my employer. She is still a friend.

The biggest thing this experience has taught me is that I am not defined by what I do. I am Patricia. I am myself. I am a wife, a mother, a grandmother and yes a great-grandmother.

My family is supportive. Sometimes I find my daughter and son-in-law "herding me" just to keep me walking straight. When we go down stairs someone gets in front and someone in back, we laugh about it. I love them and appreciate their concern.

"Having a vestibular disorder may change your life, but it doesn't change who you are."  
- Patricia Thompson

I run into walls quite a bit at home but am extra careful when I am out or I take someone with me. I have always been very independent and it is quite an adjustment to be reliant on others. I have good days and bad days. It is something I am still learning to deal with.

If you have a vestibular problem, keep searching until you find help - someone that will listen to you, who will understand and explain what is happening to you. I thought I was going crazy until I found Dr. Steenerson and Dr. Cronin on the VEDA website. They taught me that I am not crazy. I have a disability, and I'm learning to deal with it.

Having a vestibular disorder may change your life, but it doesn't change who you are.

I am strong. I am smart. I am adaptable.

I am Patricia.



**Save the Date!**  
**Balance Awareness Week**  
September 16th-22nd, 2013  
**Help VEDA "Defeat Dizziness"**

# Professional Member Spotlight:

## Dr. Gaye Cronin, OTD, OTR



***An interview with VEDA professional member, Dr. Gaye Cronin—Director of Vestibular Rehabilitation and Balance Retraining Programs at the Atlanta Ear Clinic in Atlanta, Georgia.***

### **What does an occupational therapist do?**

OTs work with children and adults suffering from vestibular and balance disorders so that they can continue to participate in everyday activities, such as work and school.

OTs have traditionally been involved in pediatric and geriatric vestibular rehabilitation longer than PTs (physical therapists), though over time the roles have become somewhat blurred. In most vestibular rehab programs, OTs and PTs use similar techniques. PTs may work on gait and balance, while OTs work more on visual motor and eye-head coordination exercises. Functional mobility, repositioning procedures, and safety training techniques are emphasized by both disciplines.

OTs emphasize environmental safety and help a patient return to previous functional activities, such as work, school or driving. We utilize adaptive techniques such as modifying the environment to improve safety, increase mobility, adjust seating, and enhance tolerances. We assess and adjust lighting, computer monitors, stairs, and bathroom safety equipment (e.g. rails, grab bars, raised toilet seats), and re-arrange environments to improve functionality (e.g. moving necessary objects in the bedroom, bathroom or kitchen to within reach so that the person with movement provoked vertigo is able to limit repetitive bending/reaching).

### **How do OT's work with people who have vestibular disorders?**

The patients participate in clinic and home-based exercises specifically designed to treat their individual disorder. It is a therapeutic movement approach. Exercises may include

eye-head and gaze stabilization exercises, balance retraining, self care, repositioning procedures, and safety and mobility tasks.

### **What kind of training do OTs receive?**

I have Bachelors, Masters and Doctorate degrees in Occupational Therapy and Education. Advanced training through continuing education courses is recommended. I have been teaching instructional courses to OTs, PTs, audiologists and physicians since 1988.

"The most rewarding part of being an occupational therapist is that the majority of your patients improve and, in many cases, their symptoms of vertigo and imbalance can be eliminated." - Dr. Gaye Cronin

### **What are the challenges you face when working with vestibular patients?**

Most children and adults have associated anxiety with their vestibular disorder. They may feel unsure about when their symptoms may arise, so they limit their activities and/or become less confident when performing them. They must first overcome their anxiety so they can participate in treatment. We use relaxation techniques, biofeedback, and in some cases refer patients to counseling.

### **How long does it generally take for a vestibular patient to show improvement?**

The most rewarding part of being an occupational therapist is that the majority of your patients improve and, in many cases, their symptoms of vertigo and imbalance can be eliminated.

Most patients experience an improvement in their function in 3-4 weeks, and this is exciting because many have suffered from their vestibular symptoms for years.

Symptoms of vertigo, nausea and/or imbalance may worsen during the first few weeks of therapy, but safety and management techniques are covered in therapy and most increased symptoms abate with-

Cont'd. on p.5

## Occupational Therapy (cont'd. from p.4)

in 1 hour. Many patients who are not driving or working due to dizziness/vertigo and have been able to return to these activities following vestibular rehabilitation intervention.

### **Can you tell us about a vestibular patient you have worked with?**

I have treated so many interesting cases: children who were unable to attend school due to vertigo and imbalance who, after treatment, were able to return to school; professional athletes with post concussion syndrome and vertigo whose symptoms have resolved; seniors who were falling and being injured, who have regained some stability; young mothers who could return to taking care of their children; airline pilots, medical doctors, post cancer survivors, and wounded warriors; people who had suffered from positional vertigo for 10 plus years, and with one treatment their vertigo was eliminated. The list goes on. This

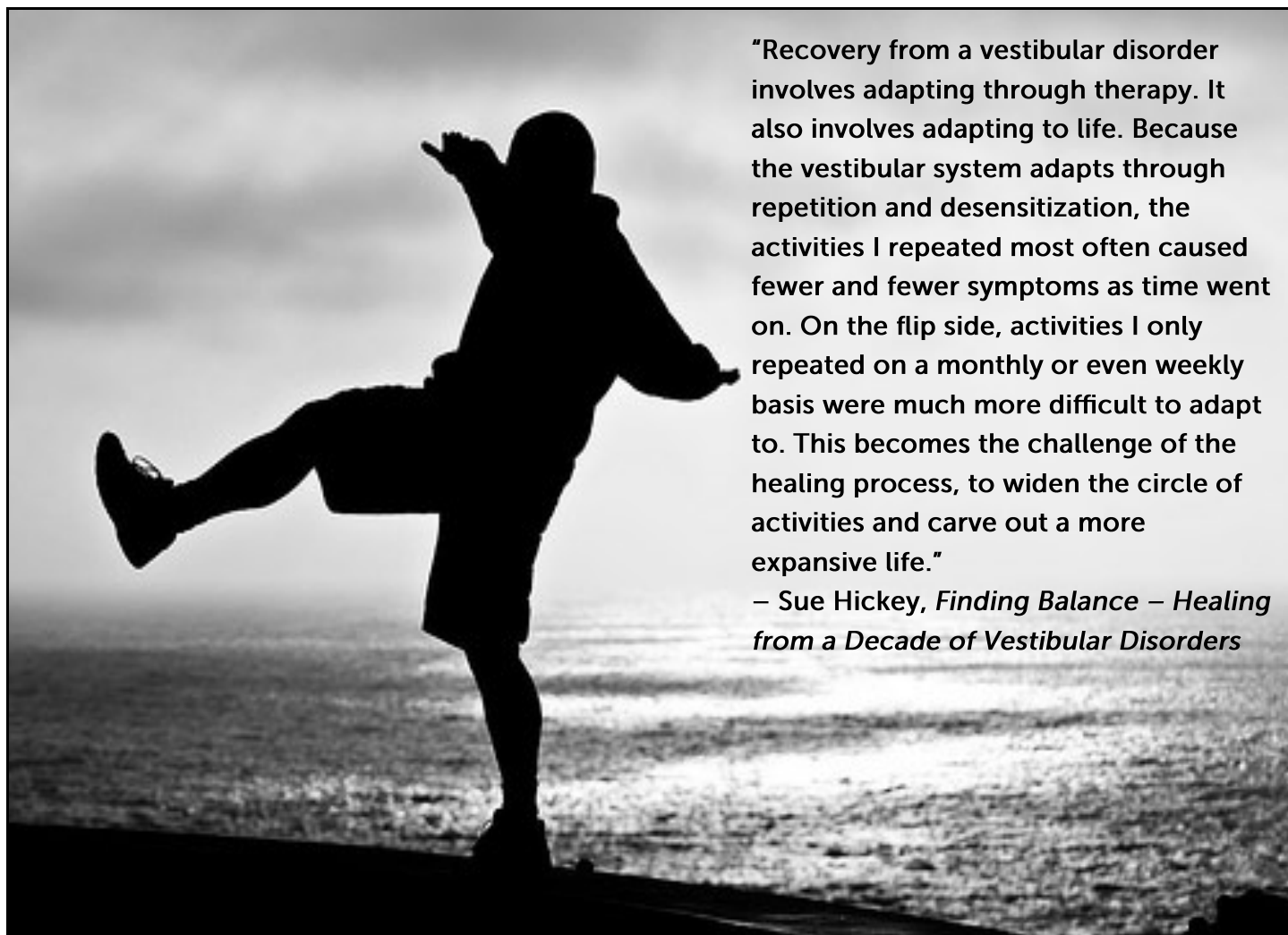
is why I find my career very rewarding.

### **Why did you choose a career as an occupational therapist?**

I had a labyrinthine trauma, so I know first-hand how frightening and debilitating vertigo can be. There were very few resources when I had my problem and I was a practicing professional, so with the support of a wonderful neurotologist we developed one of the first vestibular rehabilitation programs in the country and have treated 25,000 plus patients.

### **If you could say one thing to a person who has just begun to experience a vestibular disorder, what would it be?**

Get a clear diagnosis and find a professional that has treated your particular disorder. VEDA is a great resource to find professionals.



**"Recovery from a vestibular disorder involves adapting through therapy. It also involves adapting to life. Because the vestibular system adapts through repetition and desensitization, the activities I repeated most often caused fewer and fewer symptoms as time went on. On the flip side, activities I only repeated on a monthly or even weekly basis were much more difficult to adapt to. This becomes the challenge of the healing process, to widen the circle of activities and carve out a more expansive life."**

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

# How Do I Know If I Have A Perilymph Fistula?



By Bonni Kinne, PT, MSPT, MA

Approximately six months ago, Mrs. Smith received a telephone call from her son Henry's elementary school teacher. "You'll have to come to school and pick up your son," she said. "He was hit in the head with a soccer ball during recess, and he continues to complain of dizziness."

Later that day Mrs. Smith took Henry in to be evaluated by his pediatrician, who told her to watch Henry closely for about 24 hours, and that his symptoms would likely subside overnight.

By morning Henry felt a lot better. However, his dizziness returned as he was walking to school. Mrs. Smith contacted his pediatrician, who told her to take him to the emergency room. At the hospital, a number of tests were performed and Henry was diagnosed with a concussion.

Over the next few weeks Henry felt fine when he was inactive. However, his dizziness would return every time he attempted to exert himself. Finally Henry was referred to an otorhinolaryngologist (ears, nose, and throat doctor) who announced that he might have a perilymph fistula.

## What is a perilymph fistula?

A perilymph fistula is a condition in which there is a small hole in the membrane that separates the middle ear (an air-filled cavity) from the inner ear (a fluid-filled cavity). This hole usually occurs in the region of the oval window or round window (see figure 1). In a normal ear, middle ear air pressure changes do not have an effect upon the fluid pressure in the inner ear. However, when a perilymph fistula occurs, middle ear air pressure changes can greatly affect the balance and/or hearing functions of the inner ear.

On a rare occasion, a perilymph fistula may be the result of a superior canal dehiscence - a thin-

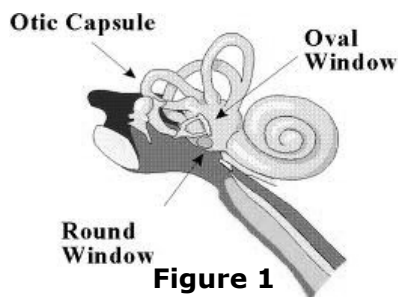
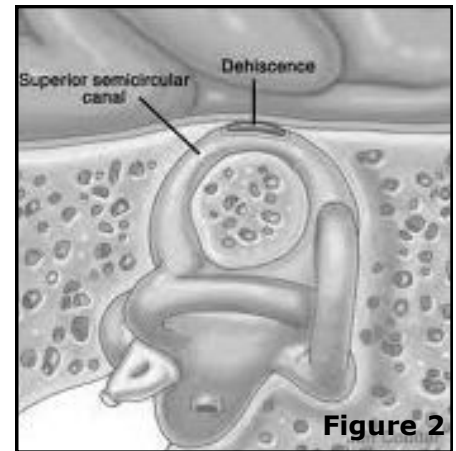


Figure 1

ning of the bone that separates the inner ear from the brain cavity (see figure 2). In this case, pressure changes in the brain cavity can affect the fluid pressure in the inner ear.

Although the incidence of this condition is equally distributed between males and females, there's some thought that children are more likely to sustain a perilymph fistula. Overall, though, it is one of the least common types of vestibular disorders.



## What causes a perilymph fistula?

The most common cause of a perilymph fistula is head trauma, especially when there has been a direct impact in the region of the ear. Oval window fistulas are also caused by surgical procedures involving the stapes (the middle ear bone that attaches in the region of the oval window), loud noises, and pressure injuries known as barotraumas, which result from a rapid atmospheric pressure change (such as that which occurs while scuba diving or while descending in an airplane), or from a rapid intracranial pressure change (such as that which occurs while coughing, lifting, sneezing, or straining). Round window fistulas may be the result of chronic ear infections or congenital defects.

## What symptoms are associated with a perilymph fistula?

Because the inner ear houses the balance apparatus, individuals with a perilymph fistula may experience vertigo (a spinning sensation) and/or balance problems. They may also experience tinnitus (ringing in the ears) and/or hearing loss. Tullio's phenomenon (a condition in which loud noises cause dizziness) is also a common occurrence. All of these symptoms tend to feel worse during periods of activity and better during periods of rest. Although some individuals only report

Cont'd. on p.7

## Perilymph Fistula (cont'd. from p. 6)

mild symptoms, a perilymph fistula can be a very disabling condition.

### How is a perilymph fistula diagnosed?

An MRI and/or a CT scan are often performed to rule out the unlikely presence of a tumor. In many cases, these diagnostic tests can also detect a superior canal dehiscence. However, they aren't able to reveal an oval window or a round window fistula. For these types of perilymph fistulas a definitive diagnosis is more difficult to establish.

The most common diagnostic tests administered include audiometry (a hearing test), dynamic posturography (a balance test), the fistula test, the Valsalva test, electronystagmography (ENG), electrocochleography (ECOG), and the vestibular evoked myogenic potential (VEMP) test.

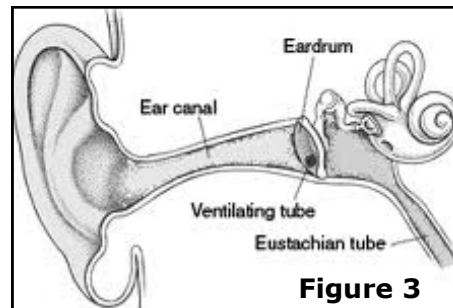
During the fistula test, the individual's eyes are observed as his ear canal is pressurized. During the Valsalva test, the individual's eyes are observed as he attempts to blow air out of his closed nostrils. If abnormal eye movements (nystagmus) are produced during either of these two tests, it's a good indication that the individual has a perilymph fistula. Sometimes multiple tests are performed, as each test provides additional information that may lead to a proper diagnosis.

### How is a perilymph fistula treated?

In most cases, oval window and round window fistulas will heal on their own if an individual is placed on strict bed rest with his head elevated for at least one week. If strict bed rest isn't feasible, the individual should avoid situations that involve atmospheric and/or intracranial pressure changes. These precautions include situations such as driving through the mountains and riding in an elevator (atmospheric pressure changes) as well as bending over and blowing one's nose (intracranial pressure changes).

If air travel is unavoidable, nasal decongestants and ear plugs may be helpful. Some individuals who frequently travel by air have opted to have a ventilation

tube surgically implanted into their eardrum in order to keep air pressure from building up in their middle ear during a flight (see figure 3). If the individual's vertigo is extremely bothersome, medications such as Meclizine (Antivert) and/or Diazepam (Valium) may be prescribed. In addition, stool softeners may help the individual avoid forceful defecation, an activity that increases the intracranial pressure.



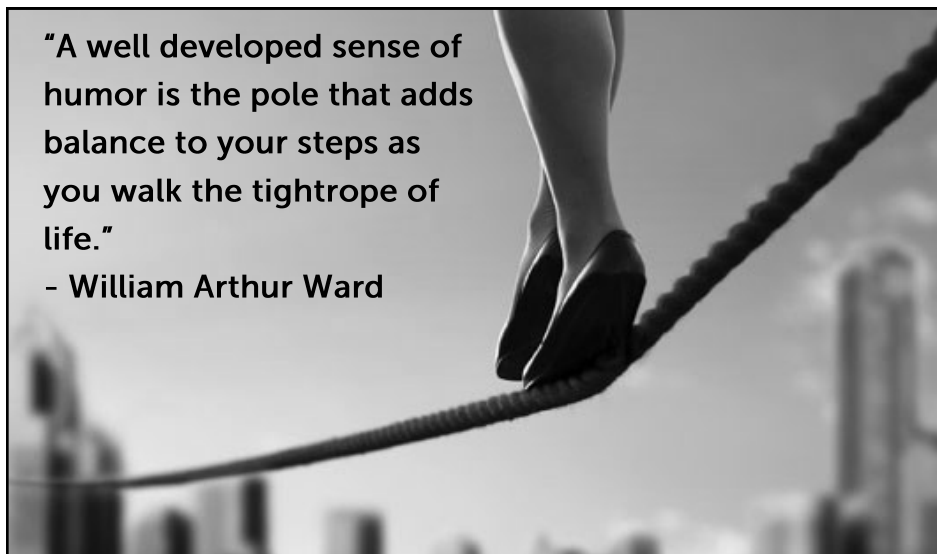
**Figure 3**

Surgical procedures are introduced if the individual's symptoms persist despite conservative management. The most common surgical procedure is called an exploratory tympanotomy. During this procedure, the surgeon accesses the middle ear and attempts to identify the perilymph fistula. If the condition is observed or if it is highly suspected, the surgeon places a tissue graft over the area of concern. Because a superior canal dehiscence usually doesn't heal on its own, surgery is more frequently indicated.

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

**"A well developed sense of humor is the pole that adds balance to your steps as you walk the tightrope of life."**

**- William Arthur Ward**



# VEDA Launches Vestibular Support Group Network

Support groups provide a safe and nurturing environment to share information and personal stories, and to connect with others who are also suffering from an inner-ear balance disorder.

VEDA often receives inquiries from vestibular patients seeking peers that they can connect with in their local area. For many years VEDA has maintained a directory of independently run support groups. When there is no support group currently operating in a patient's area we encourage them to start their own.

We recognize that this process can be intimidating, so we have developed resources over the years to help people interested in becoming



support group leaders. Recently we have expanded this effort by launching the "VEDA Support Group Network" to leverage our own resources with that of other support groups for the benefit of the vestibular community.

## What the VEDA Support Group Network Offers

### VEDA helps vestibular support groups by:

- ♦ Providing a free listing in our online support group directory
- ♦ Promoting support group meetings and events on our Facebook page
- ♦ Providing suggested meeting topics and outlines on our website
- ♦ Offering an experienced support group leader to be a mentor
- ♦ Helping support groups connect with a professional providers in their area
- ♦ Providing administrative templates
- ♦ Offering a free patient membership to support group leaders and discounts for first time members

### Future plans for the VEDA Support Group Network include:

- ♦ Creating an online depository of resources where support group leaders can share documents
- ♦ Initiating an online forum where support group leaders can get feedback from other support group leaders on topics like how to recruit guest speakers
- ♦ Develop online trainings for support group leaders



**Would you like to start a support group?**

**VEDA can help!**

Contact Kerrie Denner at [Kerrie.Denner@vestibular.org](mailto:Kerrie.Denner@vestibular.org) or call (800) 837-8428 to inquire about joining the VEDA Support Group Network.

# Do Support Groups Really Work?

## Testimonials from Support Group Leaders & Members

"I am a psychotherapist who has worked for many years with people who have vestibular disorders. A sentiment that I have heard expressed repeatedly by both patients and family members is that the connection with a vestibular support group has been invaluable during the process of getting a diagnosis, and then in learning coping mechanisms for living with a chronic illness.

"For many years I have been a speaker at a vestibular support group. Since I am aware of the importance of the group to vestibular patients, I derive enormous satisfaction from knowing that I have made a meaningful contribution to the attendees of the group. It is a small investment of my time that yields a large amount of gratification!" - **Molly-Jane Rubinger, LSW**

"The meeting the other night really helped me. I felt heard and understood... Sometimes I feel like I'm all alone with this disorder, and hearing other people's stories and sharing my own reality brings healing." **Maureen L., Chelmsford, MA**

"I was so ready to give up before I spoke to you (the support group leader). I thank you so much for your time and support. Just knowing I could talk to someone who had similar symptoms made a great big difference." **Support Group Member, Marshfield, MA**



"It was really great to hear the "human" side to vestibular disorders and to have a group to tell my patients about. It was great to hear about some of the coping strategies and it really helps me to further understand the struggles and frustrations associated with living with dizziness and vertigo." **Physical therapist, Brookline, MA**

## Seattle Dizzy Group Excited to Join VEDA's Support Group Network



In the next few months, Seattle Dizzy Group plans to partner with VEDA and join their national support group network. This exciting change will offer greater opportunities and valuable benefits for Seattle Dizzy Group, including expanding our ability to provide support, resources, and services for group members. Partnering with VEDA will also increase our advocacy efforts as we work together to raise awareness for the benefit of the entire vestibular community and help improve the quality of life of people suffering from vestibular disorders. As a part of the VEDA Support Group Network, dizzy group members will also enjoy VEDA membership discounts. As you can see, there is much for Seattle Dizzy Group to gain from being a VEDA Support Group!

**Talk to someone who understands.**

**Join a support group!**

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match your gift.*

## THANK YOU!



**"It is not how much we  
give, but the love we put  
into giving."**

**- Mother Teresa**

*\*We apologize to anyone who sent a donation during the first quarter of 2013 and is not acknowledged here. We have had a delay in receipt of our mail due to an office move. Your donations are appreciated and will be acknowledged in the Summer 2013 newsletter.*

The Vestibular Disorders Association relies on our members and donors to help us serve people with vestibular disorders by providing information, a support network, and elevating awareness of the challenges associated with these disorders.

**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.



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of people every year. Thank you!

You can renew your membership and make an additional gift to  
support VEDA's life-changing work at <https://www.vestibular.org/membership>, or send your payment to 5018 NE 15th Ave, Portland,  
OR 97211 with the enclosed self-addressed envelope.

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- ☐ 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)

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Thank you for supporting the Vestibular Disorders  
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time it takes to accurately diagnose vestibular  
disorders and improve treatment outcomes,  
helping patients live happy, productive lives.



**VESTIBULAR**  
DISORDERS ASSOCIATION

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(800) 837-8428 \* [info@vestibular.org](mailto:info@vestibular.org)  
[www.vestibular.org](http://www.vestibular.org)

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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.

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## VEDA Welcomes Development Director, Tony Staser!



VEDA is excited to announce the appointment of our first ever development director, Tony Staser, who will be helping us raise awareness for our mission and funds to expand our programs. There are so many wonderful things we could say about Tony, but instead let's let him speak for himself—take it away Tony:

I am thrilled to be the first development director with VEDA! It is a very exciting time for the organization and I am so thankful to be a part of it. Several of my family members suffer from vestibular disorders, so I am aware of the challenges patients face and glad I can be part of the important work VEDA is doing to reduce diagnosis times and improve treatment effectiveness. I have had the opportunity to work with the medical community through several national non-profit organizations, experience I can put to good use on behalf of VEDA.

I look forward to getting to know everyone involved with VEDA.

I am especially excited for this year's Balance Awareness Week (Sept 16-22). I will be providing guidance and encouragement to those of you who wish to participate in this event. This year, we have a goal to raise \$40,000 and need your help! Please contact me if you have interest or questions.

I am looking very forward to my first year and helping get VEDA to the next level so we can provide more programs and services to those we serve.

With gratitude, Tony Staser