



# VESTIBULAR

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## DISORDERS ASSOCIATION

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## **About VEDA**

### Mission Statement

To inform, support and advocate for the vestibular community.

### Vision Statement

We envision a global community where vestibular disorders are widely recognized, rapidly diagnosed and effectively treated

### Values

VEDA recognizes our responsibility to be a champion for the vestibular community and to achieve measurable results.

In valuing all members of the vestibular community –

- VEDA serves all people with vestibular disorders with dedication, understanding and compassion.
- VEDA engages vestibular professionals with respect and appreciation for their service.
- VEDA values its donors and is committed to ethical and responsible stewardship of donor's funds.

In conducting our business, VEDA operates with transparency and credibility and is always trustworthy.

In valuing our staff, Board, Medical Advisers and volunteers, VEDA actively promotes integrity, respect for different perspectives, innovation and accountability.

### History

In 1983 a group of vestibular patients and professional providers from Good Samaritan Hospital in Portland, Oregon, established a support group named the "Dizziness and Balance Disorders Association of America" (DBDAA). The organizers adopted the following goals:

- To collect and disseminate information about vestibular disorders and related topics.
- To educate the public and health professionals about vestibular disorders and their effects.
- To establish and nurture a support network for people and families affected by dizziness and balance disorders.

Health professionals connected to DBDAA wrote patient-education brochures and a 40-page book, *Balancing Act* (1992), to explain in ordinary language the anatomy and function of the inner ear and to describe inner-ear problems, symptoms, diagnoses, treatments, cures, and coping strategies. An expanded version of this book was published in 2001.

In 1989, a team from *The Today Show* conducted interviews with DBDAA board members, staff, and others in Portland. After discussion of vestibular disorders aired on the Dr. Art Ulene segment of *Today*, DBDAA received about 2,000 requests for information. At that point, the board hired a full-time director and decided to change the organization's name to the Vestibular Disorders Association (VEDA) as part of its effort to make "vestibular" a household word.

VEDA has reached millions of people with information and support. In 2013 alone our website received almost 2 million visitors.

#### Organizational Summary I (Short)

VEDA is the leading international organization that people turn to for help with vestibular (inner ear balance) disorders. We are an authoritative source of information, publishing information that is clear, reliable, and scientifically objective. VEDA supports people with vestibular disorders by connecting them to health care specialists and support networks. VEDA promotes awareness for vestibular disorders through testimony and advocacy.

#### Organizational Summary II (Long)

**VEDA leads and educates.** VEDA is trusted as the leading international organization that people turn to for help with vestibular (inner ear balance) disorders. We are an authoritative source of information, publishing information that is clear, reliable, and scientifically objective.

Our publications about vestibular disorders include information about diagnosis and treatment, social and work impacts, and practical advice for coping with symptoms. Our member newsletter, *On the Level*, features up-to-date articles, information about current research, other news, and personal stories from people with vestibular disorders.

#### **VEDA supports people so that they aren't struggling alone.**

- VEDA connects doctors and other health care specialists with patients through its popular provider directory of professional members.
- VEDA connects people with vestibular disorders to communicate about their experience through support groups and social networking opportunities as part of basic membership services.

- VEDA connects the greater public with vestibular disorder awareness through testimony and advocacy, such as presentations to community and government groups.

### Organizational Summary III

Balance is easily taken for granted. However, when the fragile vestibular organs of the inner ear are damaged by illness or injury, anyone can lose the ability to balance—not just physically, but the demands of school, work, family, and independent living. These profound impacts are often made worse by the disorder’s invisibility to others and the extended amount of time it takes to get an accurate diagnosis.

More than 35% of US adults aged 40 years and older (69 million people) experience vestibular dysfunction at some point in their lives; many of them go on to develop a chronic vestibular disorder. For almost 30 years, VEDA has been a highly respected source of scientifically credible information on vestibular disorders. Through our publications and online community, VEDA has reached literally millions of vestibular patients with critical information and support.

### Board of Directors

The VEDA board of directors provides leadership and strategic direction to the organization, helping to identify programs and projects that will further VEDA's mission and improve the quality of life for people with vestibular disorders. Board members are geographically dispersed, but share a passion for advocating for the vestibular disorders community. The board is diverse in terms of personal and professional background, skills and experiences. Many board members suffer from one or more vestibular disorders; others have a loved one who has been diagnosed with a vestibular disorder; some are professionals in the vestibular field. The board meets monthly - once in Portland, Oregon and 11 times via teleconference. Board members utilize their personal connections to expand the reach of VEDA's message, participate in fundraising efforts, and make a significant financial contribution to the organization.

### Staff

VEDA’s small staff is committed to supporting vestibular patients and healthcare providers by providing high quality programs and services that serve the needs of the vestibular community.

VEDA’s staff is headquartered in Portland, Oregon, but our reach extends across the globe.

## Medical Advisors

VEDA's medical and scientific advisors represent the best and most well-respected professionals in the vestibular community. Our advisors hail from such notable institutions as Massachusetts Eye and Ear Infirmary, Johns Hopkins University School of Medicine, and Oregon Health Sciences University. With experience in direct patient care, research and teaching, our advisors provide oversight to VEDA's published materials, ensuring data that is accurate, timely and scientifically relevant.

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## **Programs**

### Patient Education & Outreach

VEDA provides information to people seeking to learn about vestibular disorders. What is a vestibular disorder? Why do I feel dizzy or disoriented? How can I find a doctor who will help me figure out what's wrong with me? Will I ever get better? Where can I connect with others who have similar symptoms? VEDA's free publications answer these questions and more. We provide scientifically validated information about specific types of vestibular disorders, diagnosis, treatment and coping mechanisms. Our quarterly newsletter, *On the Level*, reports on current news about vestibular disorders, provides tips for daily living, and shares personal stories from our members. Through our website and social media outlets we share links to scientific articles and public interest stories relevant to our readership. We keep people informed by providing a basis for understanding vestibular disorders, while keeping them connected to breaking news. VEDA is the authoritative source for information and education about vestibular balance disorders.

### Patient Support

If you're dizzy and feeling like no one understands what you're going through, you're not alone! VEDA can help.

VEDA creates a community of support for people struggling with the daily impacts of living with a vestibular disorder. We provide support, information and resources that help patients understand their symptoms and find a healthcare provider who can diagnose their condition and get them on the road to recovery.

Vestibular disorders can cause overwhelming dizziness, vertigo, and other symptoms that can't be seen and are difficult for others – sometimes even close friends and family members – to understand. VEDA creates a community of support for people struggling with the daily impacts of living with a vestibular disorder.

Through VEDA, you can connect with other vestibular patients in many ways. For people who prefer the personal contact of an in-person support group, VEDA provides an online

support group directory. If there is no support group in your area, VEDA can help you get one started. Anyone can join our active Facebook community, and VEDA members may elect to join "V-PALS" to be connected directly to other vestibular patients through email.

You can follow VEDA on Facebook, Twitter and Pinterest, where you can read about the latest news and research, get access to our resources and connect with others.

### Membership

VEDA's membership program offers vestibular patients and healthcare providers the opportunity to participate in a dynamic community while supporting VEDA's outreach and advocacy efforts.

VEDA members receive a complimentary subscription to VEDA's quarterly newsletter, *On the Level*, with information about vestibular research, rehabilitation, and more. Professional members receive a free listing on our popular online provider directory, helping them connect with patients looking for a caring healthcare provider who understands what they are going through. VEDA also supports professional members by providing free co-branded publications that they can distribute to their patients.

As a VEDA member you are helping VEDA promote awareness for the challenges of living with a vestibular disorder. VEDA is supported entirely through membership dues and donations. Our membership program is essential to helping us achieve our goal of reducing the time it takes to diagnose a vestibular disorder so that patients can receive effective treatment.

### Professional Provider Referral

VEDA's online provider directory connects people to medical professionals by specialty and geographic region. This interactive tool is free and easy to use, and helps people focus their search for medical practitioners who have experience with vestibular disorders.

### Advocacy

#### **Summary**

VEDA speaks up for people with chronic vestibular disorders by advocating for better education of primary care providers and emergency room personnel, insurance coverage for treatment of vestibular disorders, and disability benefits for people that are no longer able to work due to their vestibular disorder. VEDA speaks for the vestibular community with information that is scientifically validated and relevant.

#### **Advocacy Plan**

The fundamental barrier to more rapid and accurate diagnosis of vestibular patients is rooted in the almost total lack of awareness of vestibular disorders pervasive throughout

the general population, people with undiagnosed dizziness and balance symptoms, and even the medical community. The pervasive lack of awareness of vestibular disorders significantly complicates the process of seeking a diagnosis.

Despite the existence of a highly professional community of vestibular specialists, the medical community at large is the source of serious barriers to vestibular diagnosis.

VEDA has identified the “top 20” barriers to vestibular patient diagnosis – barriers that represent significant challenges for vestibular patients – especially those who have yet to be diagnosed - and the vestibular professionals who will ultimately diagnose and treat them. These barriers are the priority focus for VEDA’s advocacy efforts as we work towards our unifying purpose: *To reduce diagnosis times and pre-diagnosis doctor visits for vestibular patients while improving treatment effectiveness.*

### Resources for Professionals

As a healthcare professional specializing in vestibular disorders, you want to provide the best quality care to your patients. You understand the unique challenges faced by patients with chronic dizziness and can provide them with expert care and support.

VEDA partners with healthcare providers to promote awareness for vestibular disorders, increase access to information about diagnosis and treatment, and help patients find specialists in their area.

VEDA wants to help you grow your business and foster positive client relationships. Our popular online provider directory connects you to new patients. Professional members can manage and enhance their directory listing by adding a bio, list of certifications, photo, and more. VEDA also helps you better serve your clients with free electronic publications that can be co-branded with your clinic’s name, address and phone number.

VEDA offers group membership discounts to clinics and hospitals, so that all of your clinicians can be listed in our provider directory.

### Research Collaboration

VEDA supports evidence based research in vestibular medicine by posting clinical studies recruiting participants on our website and encouraging patients to participate. There are many worthy research studies being conducted at major universities and balance centers across the country. VEDA has relationships with many of the professionals conducting research and seeks to partner with them in a variety of ways. VEDA hopes that by raising awareness about vestibular disorders we will facilitate higher levels of government funded research.

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## About Vestibular Disorders

The vestibular system includes the parts of the inner ear and brain that process the sensory information involved with controlling balance and eye movements. If disease or injury damages these processing areas, vestibular disorders can result. Vestibular disorders can also result from or be worsened by genetic or environmental conditions, or occur for unknown reasons.

Because of difficulties posed by accurately diagnosing and reporting vestibular disorders, statistics estimating how common they are, how often they occur, and what social impacts they have range widely. Yet even the lowest estimates reflect the fact that vestibular disorders occur frequently and can affect people of any age.

One recent large epidemiological study estimates that **as many as 35% of adults aged 40 years or older in the United States—approximately 69 million Americans—have experienced some form of vestibular dysfunction.**<sup>1</sup> According to the National Institute on Deafness and Other Communication Disorders (NIDCD), a further 4% (8 million) of American adults report a chronic problem with balance, while an additional 1.1% (2.4 million) report a chronic problem with dizziness alone.<sup>2</sup> Eighty percent of people aged 65 years and older have experienced dizziness,<sup>3</sup> and BPPV, the most common vestibular disorder, is the cause of approximately 50% of dizziness in older people.<sup>4</sup> Overall, vertigo from a vestibular problem accounts for a third of all dizziness and vertigo symptoms reported to health care professionals.<sup>5</sup>

Symptoms of chronic dizziness or imbalance can have a significant impact on the ability of a disabled person to perform one or more activities of daily living such as bathing, dressing, or simply getting around inside the home, affecting 11.5% of adults with chronic dizziness and 33.4% of adults with chronic imbalance.<sup>6</sup> The painful economic and social impacts of dizziness are significantly underestimated.<sup>5</sup>

Vestibular disorders not only profoundly affect adults, but also children. Once thought to be exceptionally rare, pediatric vestibular disorders are receiving increasing attention from clinicians as an overlooked problem.<sup>7</sup> In addition to impairments of motor development and balance, vestibular deficits may cause poor gaze stability that inhibits children from learning to read. Despite new awareness of pediatric vestibular disorders, children are currently not typically screened for them, and as a result frequently fail to receive medical treatment for their symptoms.

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## **BAW**

Balance Awareness Week (“BAW”) is VEDA signature annual event whose purpose is to raise public awareness about vestibular disorders. Our goal is to “Defeat Dizziness” by encouraging people who have experienced symptoms like dizziness or vertigo to become informed about their condition and seek help from a vestibular specialist. By increasing awareness we aim to reduce the time it takes patients to receive a diagnosis and put them on the road to recovery.

BAW takes place during the third week of September. In its 18<sup>th</sup> year, the event raises funds and awareness at a global level through a grassroots campaign supported by corporate sponsorships, professional member engagement, and peer-to-peer fundraising. Patient members share their stories on VEDA’s website and through social networking. Each year VEDA highlights the stories of two special patients who have faced significant challenges in overcoming their vestibular disorder. These stories are shared through national media channels to raise awareness and provide hope to others who may be suffering from dizziness and the other effects of a balance disorder.

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## **Needs Statements**

**“How many people suffer from vestibular disorders?”**

### **Message: VESTIBULAR DISORDERS AFFECT MILLIONS**

According to the National Institutes of Health (NIH), 40% of the US population over 40 years will experience a balance disorder in their lifetime. Dizziness is the 3<sup>rd</sup> most common major medical symptom reported, yet the majority of cases remain unexplained.

More than 12 million people over 65 experience a dizziness or balance problem that significantly interferes with their life. In addition, falls are the leading cause of injury death for people over 65, and according to the Centers for Disease Control (CDC) an estimated \$19 billion is spent annually to treat fall related injuries.

**“I’ve seen several doctors but none of them know what’s wrong with me.”**

**Message: IT CAN BE DIFFICULT TO GET A SPECIFIC DIAGNOSIS**

A further complication for vestibular patients is the difficulty of diagnosing vestibular disorders. As a result vestibular patients often spend 3-5 years seeking a diagnosis. It is not uncommon to see 7-9 doctors in different specialties before receiving a diagnosis. Once patients do receive a diagnosis, treatment is frequently not effective.

There is an urgent need to address the needs of vestibular patients for information and improvement in diagnosis and treatment.

**“My vestibular disorders has changed my life. How do I learn to cope?”**

**Message: YOUR VESTIBULAR DISORDER DOESN’T HAVE TO DEFINE “YOU”**

Upon receiving a diagnosis of a vestibular disorder a person might feel relief at having a name for what is wrong with them. However, this relief may be accompanied by the sobering and overwhelming news that the debilitating symptoms may possibly remain or recur indefinitely.

In order to move forward from this point the patient and his or her family need to grieve. Without addressing the need to grieve a person with a chronic illness gets stuck and is unable to move forward. Successful coping is impeded by denial and anger resulting from one’s attempts to get one’s “old self” back or to live as if the disorder were not present. That’s not to say that anger and denial disappear with the grieving process, but that grieving allows them to be recognized for what they are.

A vestibular disorder can rob you of a sense of control over your life—so the goal of coping is to find every way possible to take back that control. To do this, you need a frame of mind for thinking about the disorder in a way that allows you to impose restrictions on how it will affect you.

It is important to recognize that a chronic illness is an entity unto itself and that it assumes a presence in your life. The illness makes demands on resources of physical and emotional energy, time, and money. By acknowledging the illness as a separate entity, you take it outside of yourself so that it doesn’t define who you are and so that you can determine how you are going to relate to it.

The goal of this strategy is to create a positive form of reference. For more information, including specific coping tools you can use, read VEDA’s [“Coping with a Vestibular Disorder”](#) short publication.

**“I Feel Hopeless”**

**Message: “YOU ARE NOT ALONE”**

More than 35% of US adults aged 40 years and older (69 million people) experience vestibular dysfunction at some point in their lives. Dizziness is the 3rd most common major medical symptom reported. With numbers like this, know you are not alone and VEDA is here to support you. VEDA provides resources and a community that you can rely on as part of its basic membership.

- VEDA connects you to doctors and other health care specialists through its popular provider directory of professional members.
- VEDA connects you with other people with vestibular disorders to share experiences in support groups and social networking opportunities.
- VEDA provides living with vestibular disorder resources such strategies for everyday challenges, educational resources to help you get informed, and disability resources that may be available to you.

### **“People Think I’m Crazy”**

#### **Message: IT’S NOT ALL IN YOUR HEAD**

Vestibular disorders can be hard to diagnose, especially when there are no physical signs other than dizziness. When you experience symptoms such as dizziness that go undiagnosed, your doctor, family members and/or friends may tell you it is "all in your head." Despite what others tell you, you know something is not right. VEDA can help provide the support and resources you need. We at VEDA know it is not all in your head.

### **“Where Are My Peers?”**

#### **Message: NEED FOR MORE TRAINED VESTIBULAR PROFESSIONALS**

A major complication for vestibular patients is the difficulty of diagnosing vestibular disorders. As a result vestibular patients often spend 3-5 years seeking a diagnosis.

There is an urgent need to address the needs of vestibular patients and, as a result, an imperative need for more trained vestibular professionals. VEDA partners with healthcare providers to promote awareness for vestibular disorders, increase access to information about diagnosis and treatment, and help patients find specialists in their area. By becoming a professional member of VEDA you'll be joining a community of vestibular professionals to help elevate awareness for vestibular disorders and improve treatment outcomes.

### **“My relative/spouse/friend’s dizziness is ruining our relationship”**

#### **Message: Emotional and mental stress on loved ones is normal and can be managed successfully.**

When a loved one is dizzy their world is literally, “turned around and upside down”. One of the most difficult challenges for family and friends is not being about to physically see this effect in their loved one sometimes so the disorder can be put to the side or easily forgotten in the course of daily life, work and social activities and obligations. This can lead to feelings of frustration, anger, helplessness, misunderstanding and resentment in the dizzy person and their loved ones, which is a natural and normal reaction to an invisible and unnatural disorder – especially when having balance is just a natural state of being human! VEDA provides assistance for family members and caregivers to the vestibular patient through our support network, information for patient caregivers and encouragement from other members that are also supporting a loved one navigating through a balance disorder.

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## **Why Support VEDA**

### Why Support VEDA 1

By supporting VEDA financially, you help us reach out to people with inner ear balance disorders by providing information and support and connecting them with vestibular specialists so that they can get diagnosed quickly and on the road to recovery. In short, with your help, VEDA improves the quality of life for hundreds of thousands of vestibular patients every year. Your gift enables us to achieve our mission: to inform, support, and advocate for the vestibular community. Together we can work toward a global community where vestibular disorders are widely recognized, rapidly diagnosed, and effectively treated.

### Why support VEDA 2

Many vestibular patients are overwhelmed and confused. They need guidance to help them understand their experience and the daily challenges they face. Your gift enables us to connect patients to healthcare professionals sooner so they can receive a diagnosis and begin the most effective treatment. Together we can make a difference to the hundreds of thousands of people suffering from vestibular disorders!

### Why support VEDA 3

As a private nonprofit organization, VEDA receives no government funding. Individual contributions and membership dues support our programs and help us to achieve our mission: to inform, support, and advocate for the vestibular community. VEDA continues to hear from its members that the resources we provide have been life changing. With your help we can continue to improve the quality of life for hundreds of thousands of people suffering from vestibular disorders.

### Where does your money go?

VEDA is entirely supported by donations and membership dues. We steward our funds responsibly by keeping our operations small and focusing on programs that produce quantifiable results and help us achieve our mission.

In 2012, 39% of our funds were spent providing information and support; 45% helped us expand our outreach and advocacy efforts; 8% was used to raise funds to support our programs; and 9% went toward management and administration.

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