



WINTER 2019

BEGINNINGS . . .

ON THE ROAD TO RECOVERY, EMILY
HAS TO BECOME HER OWN ADVOCATE



VEDA

A QUARTERLY NEWSLETTER
OF THE VESTIBULAR
DISORDERS ASSOCIATION

On the Level is a quarterly publication of the Vestibular Disorders Association (VeDA). Information in this newsletter is not intended as a substitute for professional healthcare. VeDA does not recommend any particular course of treatment, clinic, or health care practitioner. The opinions expressed in these articles are those of the authors and not necessarily those of VeDA's staff, medical and scientific advisors, or board of directors. The publisher reserves the right to accept, reject, or edit any materials received for publication. No part of this publication may be reproduced without written permission. © All rights reserved.

BOARD of DIRECTORS

President: Holly Fisher, Ed.D. - Coppell, TX
 Vice President: Kamran Barin, PhD - Columbus, OH
 Treasurer: Rose Dunn, MBA, CPA - Maryland Heights, MO
 Secretary: Kathleen Stross, DPT - Pearland, TX
 Dennis Fitzgerald, MD - Philadelphia, PA
 Rebecca Rubin - Sherman Oaks, CA
 Patricia Gerend, MS - San Francisco, CA
 Ellis Kern - West Palm Beach, FL
 Jordan Tucker, DPT - Troutville, VA
 Robert Rubin, MD, PhD - Oxnard, CA
 Louise Geib, M. Ed - Atlantic Beach, FL (Trustee)
 Bryce Salvador - Westfield, NJ (Honorary)

EXECUTIVE DIRECTOR

Cynthia Ryan, MBA - Portland, OR

MEDICAL & SCIENTIFIC ADVISORS

Chair: P. Ashley Wackym, MD - New Brunswick, NJ
 Richard Clendaniel, PT, PhD - Durham, NC
 Joel A. Goebel, MD, FACS - St. Louis, MO
 Timothy C. Hain, MD - Chicago, IL
 Janet Helmski, PT, PhD - Chicago, IL
 Gary Jacobson, PhD - Nashville, TN
 Jeffrey Kramer, MD - Chicago, IL
 David Newman-Toker, MD, PhD - Baltimore, MD
 James Phillips, PhD - Seattle, WA
 Steven Rauch, MD - Boston, MA
 Jay Rubinstein, MD, PhD - Seattle, WA
 Michael Schubert, PT, PhD - Baltimore, MD
 Alain Semont, PhD, PT - Paris, France
 Neil T. Shepard, PhD - Rochester, MN
 Hinrich Staecker, MD, PhD - Kansas City, MO
 Jack J. Wazen, MD, FACS - Sarasota, FL
 Judith White, MD, PhD - Seattle, WA

WHAT'S INSIDE?

7

AN ALTERNATIVE TO BIRTHDAY GIFTS

7

NEW BALANCE SOCIETY &
BALANCE BENEFACTOR MEMBERS

8

VEDA ORIGIN STORY & THE
EVOLUTION OF SUPPORT GROUPS

10

INAUGURAL TRAVEL GRANTS
SUPPORT STUDENT RESEARCH

12

NEW PATIENT TOOLKIT

15

MIGRAINE-FRIENDLY RECIPE



Becoming My Own Advocate

By Emily Anderson

IN THE BEGINNING

My history with vestibular dysfunction goes way back, years before I labelled it as "vestibular." In 2012, I suffered from left ear pain and was diagnosed with Eustachian tube disorder as a result of flying while congested during a business trip. I experienced disequilibrium a few times over the next several years and discounted it as allergies after discussing it with my primary care provider and ENT. At that point, my dizziness always seemed to go away in a day or two. All I can surmise is that I must have still been able to compensate well.

My life-changing vestibular event occurred in April 2017, four months after my father's death. I was driving in six-lane bumper-to-bumper Atlanta traffic (a typical work day commute) on my way to my first appointment of the day. Suddenly, the sun seemed intensely bright. My head felt very heavy, like a bowling ball and the traffic noise became sharp/loud/painful to my ears. My left ear felt full, as though it was going to burst, and suddenly I could not hear out of that ear. I felt a rush of disequilibrium, like I was drunk, and the sensation of being pulled to the left (which was a real problem given all the traffic in my path). I also felt incredibly nauseous and "foggy" (the best I can describe my disorientation and inability to think clearly), and was experiencing an odd "jumping" vision, which I now know is termed oscillopsia. I knew that I should not be driving, and somehow, by the grace of God, pulled over at the next exit and called my husband.

THE MAKING OF AN ADVOCATE

Something you should know about me is that I tend to attack things head on. I ask myself, "What is the problem, and what are the potential solutions?" This is how I approached this new situation. I phoned my ENT's office and shared my experience with staff, asking if this had something to do with my previous random vertigo attacks. The



ABOVE: EMILY IS BLESSED WITH A HUGE SUPPORT NETWORK, INCLUDING HER HUSBAND, JEFF, AND SON, JACOB.

person I spoke with was dismissive and said that there was no mention of any "random vertigo attacks" in my chart.

This made it clear to me that I needed to **advocate** for myself, find a **champion(s)** and **learn** as much as possible about what had occurred and how to **get well!**

Thankfully, I recalled a kind hearted ENT



at a satellite location. His audiologist recommended that we perform a VNG, which was the key to my diagnosis.

DIAGNOSIS

Initially, my diagnosis was general and vague. Following a VNG test my ENT told me I had suffered from left-sided unilateral vestibulopathy (uncompensated) accompanied by hearing loss and tinnitus. He said that the condition was temporary and would resolve within six months with vestibular rehabilitation therapy (VRT). It was not until I saw a neurologist two months into my three-time-a-week VRT regimen



ABOVE: VESTIBULAR THERAPIST, AAGNYA PATHAK, SUPPORTS EMILY THROUGH HER THERAPY. EMILY SAYS THAT VRT HELPED HER MAKE "REAL PROGRESS."

that the puzzle pieces came together and he suggested a diagnosis of vestibular migraine.

I'd like to personally thank Jesus for creating vestibular rehabilitation therapists; they are lifesaving angels on the front lines with the vestibular patient!

While awaiting VRT my symptoms continued to increase, leaving me with an unsteady gait and lack of balance at times (especially in the dark). I could no longer drive on busy highways (I had to call my family to come pick me up when symptoms arose), exercise unassisted, shop without wearing a hat to dim the grocery stores' fluorescent lights, or go out to a simple dinner with my family. Eventually I realized that I could no longer work, and I had to leave the job I loved.

I thought, "I don't have time for this!" and "I will get better no matter what I have to do!" I was angry and scared, but I knew that I had to rise to the occasion!

TREATMENT

Then something amazing happened - I made it through the first phase of VRT, the cornerstone of my treatment plan (which made me feel motion sick initially, as expected) and started to experience progress ... **real progress!** Through lots of VRT in the clinic and at home I slowly started to become reacquainted with my life again. During that time, I also saw a neurologist who experimented with several migraine prevention medications, settling on Propanolol ER60. The sinus-like headaches stopped and I could focus enough to safely drive locally again! My physical therapist recommended yoga/Tai Chi, and I delved into the world of anti-inflammatory eating, acupuncture and cognitive behavioral therapy to develop positive coping strategies.

I also found the friendship of another

vestibular patient, Jessica, whom I met via my business partner, Amanda. My relationship with Jessica was invaluable, especially in the beginning. She understood what was happening to me when no one in my personal life did. Not only was this validating, it helped me accept that what I was going through was normal and gave me hope that I, too, would survive and thrive.

The other treatment I self-prescribed was to **never give up**, to **accept help**, and to **educate** those that love me about my disorder.

BEFORE VD (VESTIBULAR DISORDER)

Before my vestibular disorder I was a psychotherapist for 13 years, followed by 14 years as an executive-level Biotechnology Account Representative for a large biotech company. I traveled from hospital to hospital educating physicians and clinical staff about various disease states, helping them to identify and treat disorders as early as possible based on guidelines. We also took part in many patient-based philanthropic efforts. Little did I know that I would start to relate to those patients; wanting the right diagnosis and to get better as quickly as possible.

I loved my job and the company I worked for. However, I had to leave my role and utilize short-term disability after five months of treatment when we realized that it was not likely that I'd be capable of managing the heavy level of traffic that was normal for my daily commute. This is when my ENT told me that the damage is permanent, but that VRT

THE OTHER TREATMENT I SELF-PRESCRIBED WAS TO NEVER GIVE UP, TO ACCEPT HELP, AND TO EDUCATE THOSE THAT LOVE ME ABOUT MY DISORDER.

could help me live a quality life and more easily address decompensation when it occurs.

IMPACT

As you can surmise from my story, my vestibular disorder has impacted my entire life. However, by choice and not giving up, sticking to my treatment plan, and surrounding myself with positive influences and prayer, I have seen a positive impact even with my new normal. Despite not being able to drive

in heavy highway traffic to perform my previous job and other activities that require modifications, I have experienced some awesome gains: greater joy from things that once seemed small, a new perspective, recognition of my inner strength, closer friendships and new opportunities to use my skill sets and gifts from God. I am now paying it forward as a VeDA Ambassador and Support Group facilitator, and volunteering at church while searching for a job that only requires local driving or a virtual career opportunity. Even once I find the right career that can accommodate my challenges I will keep paying it forward - I get as much out of it as the receiver.

SUPPORT NETWORK

I am blessed beyond measure with a huge support network, including my hubby, son, family, girlfriends, a vestibular-diagnosed friend, previous coworkers and leaders, VeDA, a counselor, physical therapist, yoga instructor and faith community.



VEDA

When I began VRT I also started my quest to understand vestibular disorders. VeDA was the first and biggest nonprofit group I found on the internet that was backed by scientific research. This really resonated with me. I read everything I could on the VeDA website and was welcomed with open arms by sweet Cassey Parrish, VeDA's Patient Support Coordinator. As I started to manage my disorder better I knew I wanted to contribute and help others living with vestibular disorders.

VeDA's online information and new member patient questionnaire helped me greatly in articulating myself with my treatment team. It has helped me address every aspect of my disorder. I can still recall the first time a V-Pal (VeDA's pen pal network) reached out to me to



ABOVE: EMILY (FAR RIGHT) MAKES SURE TO SPEND TIME WITH FRIENDS, EVEN IF IT MEANS TRAVELING ON WINDY MOUNTAIN ROADS.

offer support. I was overwhelmed by this act of kindness and struck by the sense of "okay-ness" it gave me. The mere fact that I knew I was not alone in this helped so much when I was first diagnosed!

WORDS OF WISDOM

1. Adopt the motto, **Never give up!** And revel in successes however small they seem at the time. They lead to bigger ones later on.
2. The mind is a powerful vehicle for a vestibular-diagnosed person's journey to healthy living and dealing with decompensation(s).
3. Surround yourself with a group of champions, a strong support network of family, friends, coworkers and providers.
4. Join VeDA.
5. Do your treatment! VRT, VRT, VRT... oh did I mention VRT?! And anything else your treatment team has indicated. Be compliant.
6. Advocate for yourself and don't be shy to teach your doctors/team if necessary. If they don't "get it" please visit the VeDA website and search for a trained professional.
7. Join an online or in-person support group.
8. Pay it forward one day, in whatever manner makes sense for you.
9. Stay active - yoga, Tai Chi and Pilates all have been documented to benefit core strength and people with balance challenges.
10. **Keep the faith!**

I wish all reading this to experience a Life Rebalanced!

All I Want For My Birthday Is...

World peace, right?

Maybe in 2022.

In the meantime, another tchotchke (you know, something you'll never use) is gathering dust on your shelf, a shelf you have no energy to keep clean.

Friends and family want to shower you with gifts, but you just don't need another coaster set, candle holder, or bobble-head doll.

WHAT TO DO?

Here's a win-win: Ask your loved ones to make a donation to VeDA in your honor. They get that warm-fuzzy feeling that they've done something special for you, and you get to know that you've helped a vestibular patient discover a life rebalanced.

You can build a birthday fundraising page at vestibular.org/fundraiser, or go to Facebook and create a fundraiser.

Questions? Contact Michelle Eyres at (800) 8378428 or michelle.eyres@vestibular.org.



YOU MADE A DIFFERENCE!

Balance Benefactors are donors who gifts total \$500 or more. **Balance Society Members** have cumulative lifetime gifts that exceed \$5,000. VeDA would like to recognize donors who have recently joined these esteemed lists.

New Balance Benefactors:

Susan Barthel
David Calabrese
Robert B. Curtis
Kris Dowhen
Mary Graves
Teresa Hughes
Scott McCall

Cindi Odle
William T. Rice
Jesse Sowell
Nancy Weaver

New Balance Society Members:

Eugene Opittek
The Kurz Family Foundation

VeDA's Origin Story & the Evolution of Support Groups

By Cynthia Ryan, Executive Director

In 1983 a group of vestibular patients and healthcare professionals 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 healthcare professionals about vestibular disorders and their effects.
- To establish and nurture a support network for people and families affected by dizziness and balance disorders.

In 1989 the all-volunteer group 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.

What started as a local support group has expanded into an international organization. However, our mission is still laser-focused on patient support.

MISSION STATEMENT

To support and empower vestibular patients on their journey back to balance.

How has the nature of patient support changed?

Before the internet the only way for vestibular patients to connect with others was through in-person support groups. Support groups provide a unique and critical service: acceptance. This forum allows individuals to ask questions and to learn in a non-judgmental and safe environment. Participants know that everyone attending the support group meeting understands and has compassion for the functional difficulties of getting through each day. As a result, less frustration and energy are spent on proving or defining limitations. More energy is available for appreciating the character and companionship offered by others, and recognizing personal self-worth.

Unfortunately, there aren't enough brick-and-mortar support groups to meet the needs of all vestibular patients. In addition, some patients cannot attend an in-person

support group, either because they can't leave their house due to the nature of their symptoms, or due to transportation limitations.

Recognizing this need, VeDA's volunteer Patient Support Committee started organizing online support groups, which meet "live" via video conference or phone.

"It is wonderful that you have this (support) group. I felt so alone when I got my diagnosis of Benign Paroxysmal Positional Vertigo. I was happy to find your support group just to see other faces and not to feel so alone with the disorder. You are providing a well needed service." - Karen Aiken

Social media has spurred other ways for vestibular patients to connect. There are several "closed groups" on Facebook facilitated by vestibular patients looking to give people a place to share their experiences and get feedback and support from their peers. The beauty of these groups is that people can access them whenever and wherever it is convenient for them. One such group called "Vestibular Disorders Support Group" has grown to over 8,700 members. With so many participants, there is a great deal of shared knowledge and experience.

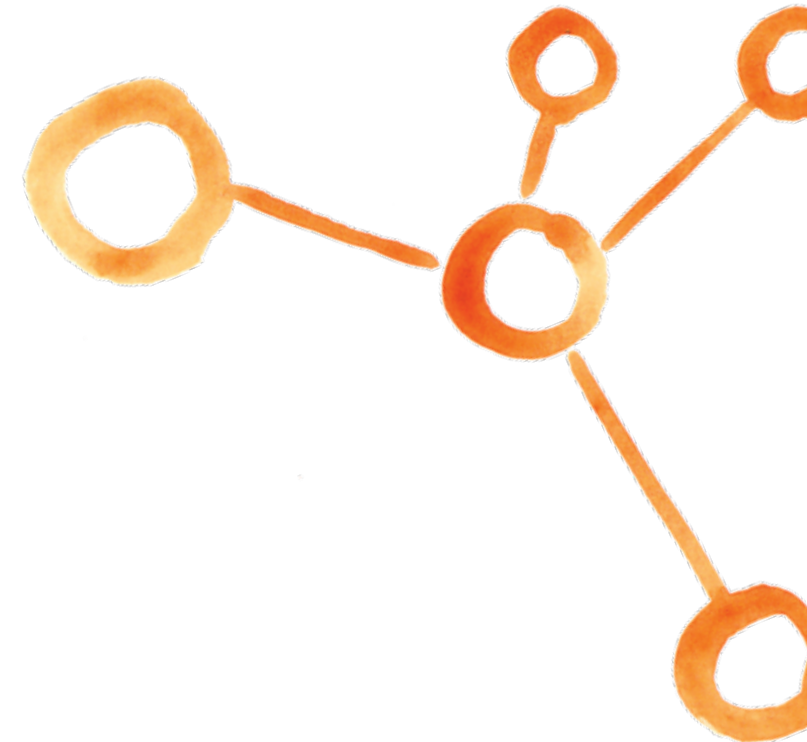
There are also ways to connect with other vestibular patients one-on-one. VeDA donors can join "V-Pals" - a pen pal network. Members of V-Pals receive a monthly email with a list of the names and email addresses

of other patients that they can reach out to.

Whatever type of support network that works best for you, remember, you are not alone.

You can search for a support group in your area at vestibular.org/SG, or sign up for V-News, VeDA's free monthly e-blast, at vestibular.org/subscribe to receive a listing of upcoming support group meetings.

**SUPPORT GROUPS
PROVIDE A
UNIQUE AND
CRITICAL SERVICE:
ACCEPTANCE.**



VEDA ANNOUNCES RECIPIENTS OF THE INAUGURAL 2018 TRAVEL GRANT AWARDS FOR VESTIBULAR RESEARCH

VeDA supports students who are working to improve care for vestibular patients by providing grants to cover travel expenses so they can present their original research at professional medical conferences. This inaugural program was funded by a donation through the estate of Julius and Marjorie Schnapp. Following is a summary of the projects approved for funding.

Britteny Medina



The purpose of this study was to evaluate the performance characteristics and the clinical utility of the video head impulse test (vHIT) in assessing vestibular function or hypofunction in dizzy patients and to determine if including a catch-up saccade (CS) analysis would increase the sensitivity and specificity of the test. Secondary objectives included describing the characteristics of certain peripheral vestibular pathologies in relation to vHIT and other tests of the vestibulo-ocular reflex (VOR) function. The medical records of 171 patients were analyzed. vHIT results, specifically VOR gains and CS percentages, calorics testing, bedside head thrust testing (HTT), rotary chair results along with the patient's final diagnosis were recorded. Results: Catch-up saccade (CS) percentages were significantly greater for patients with a peripheral vestibulopathy than for patients with a central vestibulopathy. vHIT results with normal gain and a cut-off value of 36% CS increased sensitivity of the vHIT to detect a peripheral vestibular loss from 53% to 78%. Conclusions: Incorporating correction saccade percentage in the interpretation of vHIT results improves diagnostic accuracy in identifying a peripheral vestibulopathy.

Corey Shayman



Spatial auditory cues can supplement vestibular cues to improve postural sway and gait. However, the mechanisms of auditory-vestibular integration are not well understood. In this study, seven participants completed a psychophysical task, in the dark and under three sensory conditions. Vestibular-only perceptual thresholds dominated at high frequencies. Auditory-only thresholds dominated at low frequencies. The results suggest that individuals integrate auditory and vestibular cues in a frequency-dependent manner, analogous to visual-vestibular integration.

Conner Rouch



Due to close proximity of vestibular organs and cochlear implant placement, previous research has shown before-after differences in vestibular function. The overarching idea of this study is to examine if there is a change in cervical vestibular evoked myogenic potentials (cVEMPs) due to cochlear implantation or electrical stimulation. We will analyze an existing database and compare cVEMPs pre-implantation to post-implantation with the processor off as well as with the processor on and functioning. Our subject population focuses on young children who have been either unilaterally or bilaterally implanted. Previous research on this topic has focused on adults and older children. Our hypothesis is that:

1. Post-implantation there will not be a change in cVEMPs when compared to pre-evaluation testing.
2. After cochlear implantation, there will not be a change in cVEMPs when cochlear implant sound processor is on compared to when the processor is off.

Pamela Dunlap



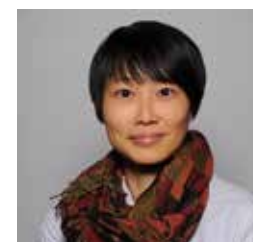
This study uses data from the National Ambulatory Medical Care Survey to 1) examine the rate of benign paroxysmal positional vertigo (BPPV) visits and physician treatment recommendations for BPPV over time, and 2) identify factors associated with physical therapy (PT) referral for BPPV in the United States. Our analysis found that the number of BPPV visits increased from 2004-15. The PT referral rate increased from 6.2% in 2004-06 to 12.9% in 2013-15. In multivariate analyses, referral to PT varied by insurance type, reason for visit, provider specialty, other treatment recommendations, and office location, suggesting potential opportunities for improving the quality and value of care for persons with vestibular disorders.

Daniel J. Romero



Vestibular evoked myogenic potentials (VEMPs) can be elicited using a variety of stimulus delivery methods. The most common methods are air conduction (AC) and bone conduction (BC). The cVEMP is a vestibular evoked potential that measures activity from the vestibulocollic reflex, assessing the integrity of the saccule and inferior vestibular nerve. Unfortunately, clinical bone vibrators have significant output limitations for low-frequency transient tone burst stimuli required to elicit VEMPs, thus limiting the clinical utility of BC VEMPs. The purpose of this study is to compare the BC cervical VEMP (cVEMP) across different clinical bone-conduction transducers. The potential advantages and limitations of BC cVEMPs will be discussed. We will illustrate the maximum output for a transient signal from each BC transducer as a function of frequency along with recorded cVEMPs from a sample of young, normal participants. Expected outcomes will add valuable information regarding limitations and effectiveness of clinically available bone vibrators, with the goal of improving the accuracy of identifying otolith dysfunction in patients.

Hsin-Wei Huang



Tai Chi is receiving increasing research attention with its benefit of improving flexibility and balance. The objective of this review was to examine the evidence concerning the impact of Tai Chi as a practical therapy for vestibular rehabilitation on individuals with balance and vestibular disorders. Methods: A systematic review using four electronic databases was conducted. Randomized clinical trials (RCTs) and quasi-experimental studies were included. Results indicate positive effect of Tai Chi practice on dynamic postural stability in balance of its practitioners. Conclusion: Tai Chi may be a useful therapy for vestibular rehabilitation as it improves dynamic balance control and flexibility of individuals with balance and vestibular disorders.

NEW PATIENT TOOLKIT

BECOME YOUR OWN HEALTHCARE ADVOCATE

Vestibular disorders are underdiagnosed and undertreated. Many patients visit multiple healthcare practitioners over months or even years before they receive an accurate diagnosis. You need to become your own healthcare advocate to navigate an uninformed medical system so that you can get the care you need. Here are seven simple steps to diagnosis, treatment and recovery.

(Visit vestibular.org/toolkit for links to the resources mentioned in this article.)

1 LEARN MORE ABOUT YOUR SYMPTOMS AND POSSIBLE DIAGNOSES

The more you know, the better you can communicate with your healthcare provider.

1. Causes of dizziness: There are many reasons a patient can experience dizziness, vertigo, and imbalance. Learn more about the possible vestibular and non-vestibular causes of dizziness.
2. Symptoms: The symptoms of a vestibular disorder can be difficult to describe, especially when they are exacerbated by fatigue and cognitive impairment. Learn more about possible symptoms of a vestibular disorder so you can develop a vocabulary that describes how you are feeling.
3. How are vestibular disorders diagnosed? Become informed about the various diagnostic tests and procedures your doctor may perform to determine if you have a vestibular disorder.
4. Types of vestibular disorders: "Vestibular disorder" is an umbrella-term that covers many different conditions affecting the inner ear and brain that lead to vertigo, dizziness, imbalance, and other symptoms. Learn more about some of the more common vestibular diagnoses and see if any of their descriptions are similar to your experience.
5. Vision and hearing problems: Many vestibular patients also experience vision and hearing problems. It is important to address these issues as part of your overall wellness plan.

2 COLLECT DATA ON YOUR MEDICAL CONDITION

Now that you have some understanding of vestibular disorders you can begin to apply that knowledge to your own condition.

1. Medical history: Prepare for your doctor's visit by filling out VeDA's comprehensive medical history form, which includes questions that will help a healthcare practitioner accurately evaluate your symptoms.
2. Patient logs: Keeping track of your symptoms, activities, what you eat and drink, and medications can help you see trends that may aid your medical provider in determining a diagnosis and prescribing effective treatment.

3 FIND A VESTIBULAR HEALTHCARE SPECIALIST

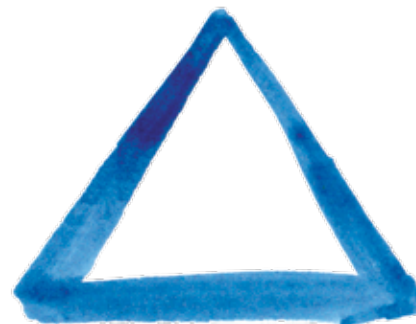
Getting an accurate diagnosis is the key to finding effective treatment and getting on the road to recovery. But where do you start? Learn more about the various specialists who diagnose vestibular disorders, and find a qualified healthcare provider in your area.

1. Healthcare specialties: Several types of health care professionals may become involved in the diagnosis, treatment, and management of dizziness and balance disorders, such as an otolaryngologist/ENT or neurologist (for diagnosis), audiologist (for testing), and physical therapist (for treatment). Look for a specialist who had additional training and experience with vestibular diagnosis and treatment.
2. Vestibular healthcare provider directory: Use VeDA's provider directory to find a vestibular specialist near you. You get the best results by entering your zip code. If you know the type of provider you want to see (e.g. an ENT) you can enter the specialty for more specific results.

4 DEALING WITH CONCURRENT SYMPTOMS

Vestibular disorders come with a host of concurrent symptoms, including physical and emotional fatigue, brain fog and nausea. A holistic healthcare plan addresses all these issues.

1. Coping with a vestibular disorder: Finding out that you have a chronic vestibular disorder can rob you of your sense of control over your life. Learning how to cope can help you move forward.
2. Emotional impacts of vestibular disorders: Vestibular disorders affect patients physically and psychologically. Anxiety, depression, and social isolation are just a few common issues that vestibular patients face on a daily basis. Learn more about these issues and how you can cope with them.
3. Cognitive impacts of vestibular disorders: Many vestibular patients have trouble with thinking, memory, and other cognitive processes, which can be very frustrating. Learn why, and discover some possible coping strategies.
4. Dealing with nausea: Nausea is a common and unwelcome side effect of dizziness. While there are medications that address nausea in its acute phase, these may interfere with long-term recovery of your other vestibular symptoms. Stress reduction techniques can alleviate nausea naturally.
5. Dietary considerations: A few simple changes to your diet, such as reducing your sodium intake and avoiding migraine triggers, can help some vestibular patients manage their symptoms.
6. Fatigue, stress & responsibility: Many vestibular patients struggle with chronic fatigue. Learning how to manage your stress and balance your responsibilities can help you preserve your precious energy resources.



5

FIND A SUPPORT NETWORK

You are not alone. Millions of people experience vestibular dysfunction. By sharing with others, your own experience is validated, which gives you hope, as well as useful tools for coping with the daily impacts of a chronic illness.

1. **Support groups:** There are a limited number of in-person support groups dedicated to helping vestibular patients. You can use VeDA's support group directory to search for a support group in your area. VeDA also offers tools for individuals who are unable to attend "brick-and-mortar" (i.e. in-person) support groups, or do not have one available in their area. Contact VeDA if you are interested in attending an online support group.
2. **Facebook:** VeDA shares current information on our Facebook page about research, coping tips, and patient stories. Follow VeDA on Facebook, or join one of many other Facebook groups that offer support to vestibular patients.
3. **One-on-one support:** VeDA's Patient Support Coordinator, Cassey Parrish, can help you find resources to fit your needs and refer you to a vestibular specialist. Cassey understands what it is like to suffer from multiple invisible chronic conditions. She can also connect you with other vestibular patients who can share their experience with you.
4. **Online forum:** Ask questions and share your experience in an anonymous setting through our online forum. Contact VeDA for more information about how to access the forum.
5. **V-PALS:** As a donor, you can request access to VeDA's pen-pal network - a list of vestibular patients who have agreed to share their email with others who wish to connect with another patient directly.
6. **Family support network:** The friends and family members who care for vestibular patients provide essential support. Without firsthand experience, these individuals are challenged to learn about vestibular disorders in order to lessen the impacts of their loved one's illness. VeDA has resources to help your friends and family understand what you're going through.
7. **Psychological impacts of vestibular disorders:** Vestibular disorders impact patients physically, mentally, and emotionally. Learn how to cope with the less visible symptoms of a vestibular disorder through counseling and self-care.

6

STAY INFORMED

1. Join VeDA's mailing list to receive V-News, our free monthly e-newsletter (<https://vestibular.org/register>).
2. Follow VeDA on Facebook, where we post links to research articles, coping tips, patient blogs, inspirational messages, and VeDA program updates (<facebook.com/vestibulardisorders>).

7

TAKE ACTION

1. **Participate in research:** One way to help future generations of vestibular patients is to participate in research aimed at reducing diagnosis times and improving treatment outcomes. You can find clinical trials that are recruiting participants on VeDA's website (<vestibular.org/take-action/participate-research/current-research-studies>), or visit the U.S. National Institutes of Health website and use "Search for Studies" to find an applicable study (<clinicaltrials.gov>).
2. **Join VeDA's patient registry:** VeDA reports on the vestibular patient experience by collecting data through a patient registry. You can help by sharing your confidential medical history (<vestibular.org/registry>).

Migraine-Friendly Butternut Squash Chili Recipe

By Alicia Wolf, The Dizzy Cook

This chili is perfect for game days, especially on top of corn chips with a little bit of cheese! Comforting and cozy, you can make this recipe ahead of time and freeze it.

Course: Dinner, Servings: 4 people

INGREDIENTS

- 1 lb. ground beef (see notes for vegetarian alternatives)
- 2 shallots, peeled and chopped
- 2 medium cloves of garlic, peeled and minced
- 1 14 oz. can chopped tomatoes (look for one with only tomatoes as the ingredient, like Carmelina)
- 1 tbsp. tomato paste (check sodium levels)
- 1.5 tbsp. chili powder (look for a good brand without cocoa, like Morton & Bassett)
- 2 tbsp. cumin
- 1 tbsp. honey or sugar



YOU
CAN
HELP.

DONATE

Your gift helps VeDA support vestibular patients, reduce diagnosis times, and improve treatment outcomes. You can donate online or return your check in the enclosed envelope.

To donate, visit vestibular.org/OTL.

RENEW YOUR MEMBERSHIP

If you are a healthcare provider and your membership is expiring soon, you will be receiving an invitation to renew. Please return the enclosed envelope to continue receiving this newsletter and other membership benefits.



- 1.5 cups low-sodium broth
- 1/2 tsp. smoked paprika
- 2 cups cubed butternut squash
- 1 tbsp. olive oil
- Kosher salt and pepper to taste

INSTRUCTIONS

1. Add 1 tbsp. of olive oil to a heavy bottomed pot and heat on medium. Add chopped shallots and garlic, sautéing for a minute or two until fragrant. Then add your ground beef and cook, breaking it up into small bits. If you have leftover liquid from the beef, use a paper towel wrapped around a spoon to soak it up.
2. Once your beef is cooked, add the butternut squash, tomato paste, chili powder, cumin, honey (or sugar), and smoked paprika. Stir to combine, still over medium heat. Then add your chopped tomatoes and broth with 1/2 tsp. kosher salt (optional). Stir again and bring the dish to a simmer.
3. Allow to simmer on low heat for 30 minutes, then serve warm.

RECIPE NOTES

This recipe freezes really well. Just use some broth to reheat it in a Dutch oven.

To make this vegetarian, omit the meat and either double the butternut squash or add 2 (14oz.) cans of cannellini beans or 1 cup dried beans soaked overnight and cooked in a crockpot.

For a twist, serve this on top of tortilla chips with some cheese, radish, green onions, and a dollop of whipped cottage cheese (for migraine safe).



FOR OTHER MIGRAINE-FRIENDLY RECIPES, VISIT ALICIA'S WEBSITE AT THEDIZZYCOOK.COM.