

SPRING 2025

FINDING SOLID GROUND

**How Rachel
Reclaimed Her Life
After A Stroke Left
Her Spinning**

PAGES 3-5



VEDA

**A QUARTERLY NEWSLETTER
OF THE VESTIBULAR
DISORDERS ASSOCIATION**



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FINDING SOLID GROUND

How Rachel Reclaimed Her Life After A Stroke Left Her Spinning

Before her stroke, Rachel Abbassi was a vibrant, driven woman who poured her heart and soul into her career as a marketing director. She thrived on the fast pace and constant challenges, always pushing herself to be better and rise higher. Work was her passion and purpose - she would arrive early,

stay late, and think about work even when she was at home. Rachel was the epitome of a career-minded go-getter.

Then, one seemingly ordinary day, Rachel's world turned upside down.

THE MOMENT OF PANIC

While taking her dog outside, she suddenly realized she couldn't form the words she was thinking. Panic set in as she struggled to communicate with her husband. In that moment, Rachel knew something was terribly wrong. Her husband rushed her to the hospital, where tests revealed she was having an active stroke.

The next hours were a blur as Rachel underwent emergency treatment, including a clot-busting medication that thankfully restored her ability to speak. But the relief was short-lived.

UNDIAGNOSED AND MISUNDERSTOOD

Once the immediate crisis passed,



RACHEL USING ACCESSIBILITY TOOLS AT THE MOVIES WITH HER NIECE



RACHEL WITH HER TWO CHILDREN, TRISTAN AND BAILEY



Rachel started experiencing debilitating new symptoms - excruciating headaches, blurred vision, and a constant sense of dizziness and imbalance. Her doctors were baffled, unable to connect these lingering issues to her stroke.

For months, Rachel felt lost and alone, as specialist after specialist dismissed her symptoms. She fought back tears of frustration, feeling anxiety and depression set in.

The once-driven Rachel now struggled to get through each day, unable to work or even perform simple tasks. Her identity and purpose had been ripped away.

THE DISCOVERY SHE NEEDED

Just as Rachel was about to give up hope, she stumbled upon an article about vestibular disorders and their connection to stroke. Finally, she had found an explanation for her mysterious

symptoms.

This discovery led her to a vestibular therapist who understood her condition and could provide targeted treatment. The therapist confirmed Rachel's suspicions and provided her with therapy to manage her symptoms.

While the therapy didn't "cure" Rachel, it gave her the tools to manage her symptoms and regain a sense of control.

MOURNING HER PAST SELF

Transitioning to life as a medically retired stroke survivor has been an emotional rollercoaster for Rachel. She mourns the loss of her former self and career, yet finds solace in new creative outlets like painting and sewing.

ACCEPTANCE IS KEY

Rachel emphasizes the importance of



NOW THAT RACHEL IS MEDICALLY RETIRED, SHE FINDS FULFILLMENT THROUGH NEW HOBBIES LIKE GARDENING, BAKING, JEWELRY MAKING, AND PAINTING

self-acceptance, learning to pace herself, and tapping into support systems - both from her devoted husband and the vestibular disorder community.

Rachel's hard-won wisdom is to keep moving forward, one small step at a time.

"Some days, I have to force myself to get out of bed, but I know I have to keep going," she says. "The pain and challenges are real, but so is the possibility of growth and finding joy in the little things."

Rachel's story is a testament to the resilience of the human spirit, and a beacon of hope for others facing the aftermath of stroke.

FINDING THE HELP SHE NEEDED

VeDA was a "saving grace" for Rachel.

When she first started experiencing the unexplained symptoms after her stroke, like debilitating headaches and visual disturbances, Rachel felt lost and misunderstood by her doctors.

It was an article published by VeDA about the visual challenges associated with vestibular disorders that finally provided Rachel with an explanation for her symptoms.

This VeDA article was a turning point for Rachel, as it led her to seek out a vestibular therapist who could properly

diagnose and treat her condition.

VEDA'S COMMUNITY CHANGED EVERYTHING

Beyond the emotional support, Rachel also found immense value in the VeDA community.

She attended the VeDA conference, which she described as a "week of enlightenment" where she could connect with and learn from others experiencing similar struggles. This sense of community was crucial, as Rachel had felt so alone in dealing with her "invisible illness" prior to finding VeDA.

Through VeDA, Rachel was also able to connect with another stroke survivor, David, who had faced vestibular issues. Being able to talk to someone who truly understood her experience was incredibly meaningful for Rachel, who had previously felt misunderstood by her medical team of professionals.

WHY RESOURCES MATTER

VeDA provided Rachel with the information, resources, and community support that were pivotal in helping her navigate her post-stroke vestibular disorder. The organization was instrumental in Rachel finding the right diagnosis, treatment, and sense of belonging during a very isolating and challenging time.



Dear friend,

I want to take a moment to express **my heartfelt gratitude for your generous support** of the Vestibular Disorders Association (VeDA).

Rachel Abbassi's story (pages 3-5) is a powerful example of how your contributions are making a tangible difference. After suffering a stroke, Rachel's world was turned upside down by debilitating dizziness, headaches, and vision disturbances. Despite her best efforts, she spent months searching for answers, only to be met with frustration and uncertainty.

Then, everything changed. Rachel discovered an article published by VeDA that explained the connection between vestibular disorders and stroke. For the first time, she had an explanation for her symptoms—and a path forward. This vital information led her to the right specialist, who helped her regain control over her life.

But **your gift provided Rachel with more than just knowledge—you gave her a community.** At VeDA's donor-funded conference, she found a network of people who truly understood her journey.

Your generosity made this possible. On behalf of Rachel and so many others, thank you for being a part of this life-changing mission.



With gratitude,

A handwritten signature in black ink that reads "Cynthia Ryan". The signature is written in a cursive, flowing style.

Cynthia Ryan, VeDA Executive Director

P.S. I am pleased to introduce you to the newest member of VeDA's staff. Paul has joined the team to help grow VeDA's funding, making it possible to make even more change for people who suffer from vestibular disorders.



"I believe the great power of giving is the impact we can have collectively to make real, lasting change possible. Working toward a shared goal helps tackle big issues at the root, not just the surface. Plus, it creates a ripple effect, inspiring others to join in and keep the cycle of generosity going."

- Paul F. Morris, VeDA's new Development Director

MEET PAUL

VEDA'S NEWEST TEAM MEMBER

VeDA's small staff of 6 just added its 7th member! Paul F. Morris is excited to join VeDA in the new grant-funded role, Development Director.

Paul's focus at VeDA is to help raise the much-needed funds to truly address the needs of the vestibular community.

Paul lives in Beaverton, Oregon with his family, just a short drive away from VeDA's headquarters in Portland, Oregon.



Over a 30+ year career in fundraising, Paul's work has resulted in tens of millions of dollars being raised for a wide spectrum of not-for-profit organizations. He has led successful development efforts in direct health services at the state and national levels; regional theatre; architectural preservation; a statewide organization offering chess to low-income students; and more! In his consulting practice, Paul worked with clients nationwide with a focus on planning/systems, annual and major gift support, and grants.

If you would like to get to know Paul better, please reach out to him at development@vestibular.org.



STEPS-2-BALANCE

MAY 18-24, 2025

Steps-2-Balance (S2B) is about taking a step forward in your journey toward recovery.

When you are struggling with dizziness or imbalance, it's easy to become demoralized and feel like you'll never feel "normal" again. Recovery is a long road, and just thinking about taking one more step might feel like climbing a mountain - impossible.

By participating in S2B you are joining the global vestibular community in celebrating every win and milestone, large or small, because every step matters.

HOW TO PARTICIPATE:

1. Identify one step you can take in your vestibular recovery and plan to do that during the week of S2B.
2. Register and create a peer-to-peer fundraising page.
3. Organize or join an event in your local area.

We'll kick off and wrap up S2B with virtual celebrations you can join from wherever you are! Join the video call to hear from and share with vestibular warriors who are taking a "step to balance" from all over the world!



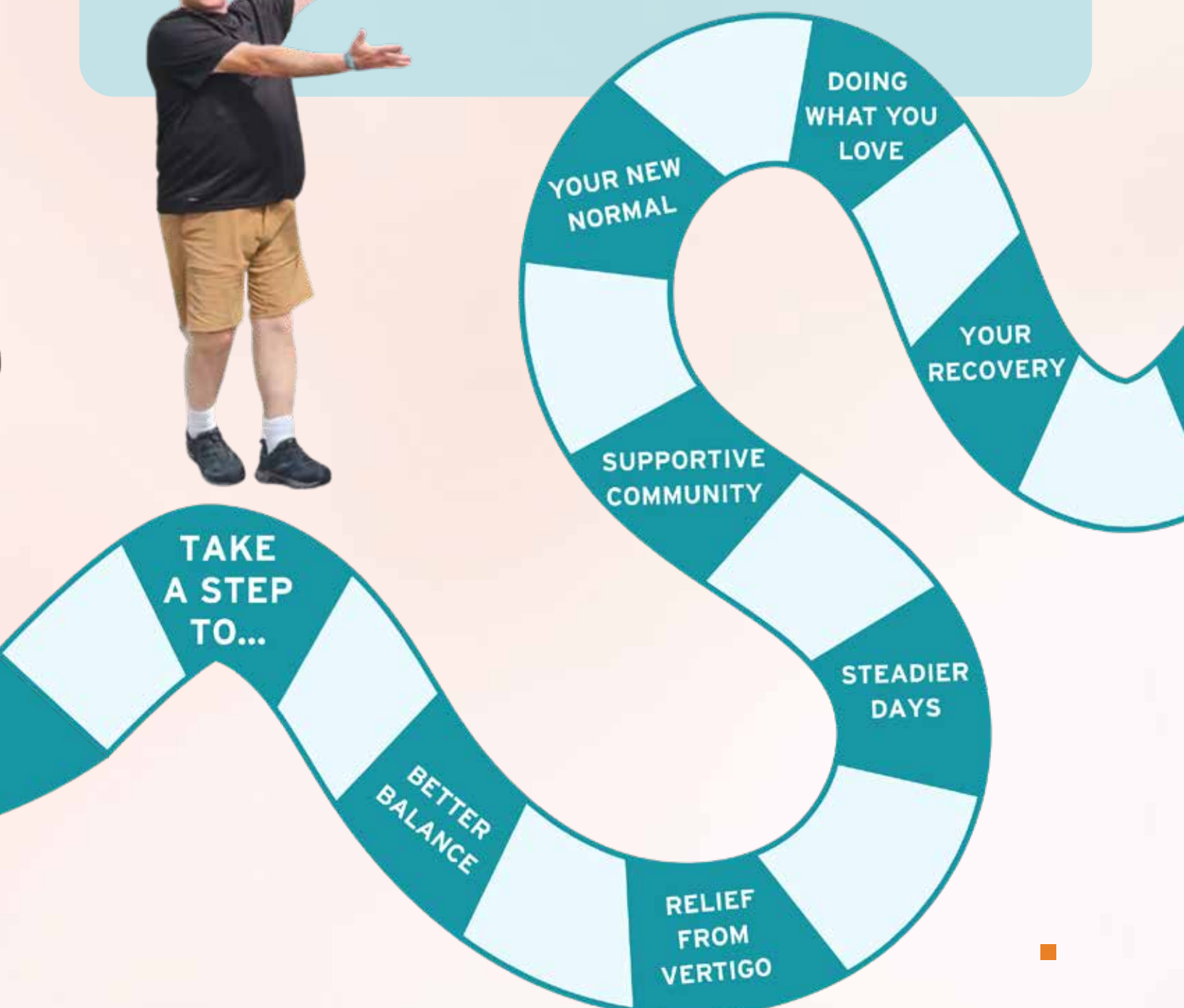
Register for free to learn more about how you can make a difference at

VESTIBULAR.ORG/S2B



"I support VeDA during Steps-2-Balance by creating a peer-to-peer fundraising campaign and asking my friends and family to make a donation to an organization that has been instrumental in my recovery, and the recovery of so many other people who struggle daily with vestibular symptoms."

- David Morril, VeDA Ambassador



PHYSICAL ACTIVITY AND VESTIBULAR MIGRAINE

RESEARCH SUMMARY

*Reviewed by
Denise Schneider, DPT, FAAOMPT*

Vestibular migraine (VM) is a condition that causes dizziness, vertigo, and balance issues, significantly impacting daily life.

Distinguishing VM from other dizziness-related conditions can be challenging due to overlapping symptoms. The study “Self-reported Physical Activity Differentiates Vestibular Migraine from Other Causes of Dizziness” examines whether differences in physical activity levels can help differentiate VM from other vestibular disorders.

PURPOSE OF THE STUDY

The study investigates whether self-reported physical activity levels can serve as a diagnostic tool for differentiating VM from other dizziness-related conditions.

Since vestibular disorders often lead to physical limitations and avoidance behaviors due to fear of imbalance or symptom worsening, the researchers aimed to determine if physical

activity patterns vary between VM patients and those with other vestibular conditions.

METHODOLOGY

The researchers collected data from individuals with dizziness, assessing their self-reported physical activity levels.

They then compared the activity patterns of those diagnosed with VM against individuals with other vestibular conditions. The study focused on aspects such as the frequency, intensity, and types of physical activities reported by participants.

KEY FINDINGS

The study found that individuals with VM tend to exhibit distinct physical activity patterns compared to those with other



Reduced Physical Activity in VM Patients	Those diagnosed with vestibular migraine reported lower levels of physical activity, likely due to sensitivity to movement and fear of triggering symptoms.
Differences in Activity Avoidance	VM patients were more likely to avoid specific activities that involve head or body movement, whereas those with other vestibular conditions exhibited different avoidance behaviors.
Potential Diagnostic Tool	Since VM patients displayed unique patterns in physical activity levels, tracking these behaviors could help doctors in distinguishing VM from other vestibular disorders.

causes of dizziness. See chart above for specific findings.

IMPLICATIONS AND CONCLUSION

The study highlights the importance of considering self-reported physical activity levels when evaluating patients with dizziness. Since VM presents differently in terms of activity engagement and avoidance, incorporating physical activity assessment into diagnostic criteria could improve accuracy and lead to better treatment strategies.

For clinicians, this research suggests that understanding a patient’s lifestyle and activity limitations can provide additional diagnostic clues. It also emphasizes the need for tailored

management plans that encourage safe physical activity while minimizing symptom triggers. Future research could explore how physical rehabilitation programs might benefit VM patients and help improve their activity levels over time.

Overall, this study provides valuable insights into the relationship between physical activity and vestibular disorders, offering a potential new approach for distinguishing VM from other causes of dizziness.

Source: Joffily L, Mayet U, Kaski D. Self-reported physical activity differentiates vestibular migraine from persistent postural perceptual dizziness. *Journal of Vestibular Research*. 2025;0(0). doi:10.1177/09574271251318971

MANAGING ENERGY AND ACTIVITY

By Karen R. Mizrach

"Your energy is unique. Embrace it. Use it wisely."

- Robin Sharma, monk

We've learned from childhood to set lofty goals, to achieve, and to fit as much as possible into a day. To go, go, go. But for those of us with a vestibular disorder, and perhaps for all people, this becomes a no-win lifestyle. Instead let's create a beneficial pattern of alternately using and restoring energy, rather than depleting all energy and then struggling to recover. It's a bit of a mindset shift, but also requires a different way of planning.

TYPES OF ACTIVITY

Each life activity fits into a category. Being aware of activity types can help us organize our days, and support our efforts to heal and stay healthy. The list below includes five categories of activity. As we begin to prioritize how we will use our available energy, it's crucial to recognize that each of these activities requires a different intensity and type of energy. And at times they may overlap, requiring more than one level of energy.

- Physical (walking, exercise, chores, some self care etc)



- Social (relationships, visitors, phone conversations, out for lunch, workplace etc)
- Cognitive (work, financial tasks, reading, computer etc)
- Self Care (showering, grooming, dressing, eating etc)
- Computer/TV/phones (online groups, watching TV, phone scrolling etc)

The goal is to prioritize and pace ourselves to be able to engage in a variety of activities each day or each week, depending on your level of health and known triggers at any given time. There may be days you barely manage one activity, and then days where you can fit in a few more. Each individual will prioritize and manage activities differently.

PRIORITIZING

When other people can simply do things, I have to attack it and make a plan



like I am strategizing a war. (Christine Miserandino - Spoon Theory)

Completely deleting is also not failure.

Once we identify our usual activities, prioritizing them does two things. It helps us decide which are the most important, and also when each will be done. Here is a good way to approach prioritizing.

- Identify what you want/need to do on any given day or week. Keep it simple and basic.
- Decide what activities are most important to you and put a star next to those. Ignore the rest for now.
- Include rest as a priority. Knowing yourself, you can decide how much and where this will occur. It's a very important piece of the pie. (See pacing ideas below)
- Realize that as you go through this process, you will cross some things off the list for another day. That's perfectly fine. Delaying is not failure.

TIP: Only put five to seven items on your daily list, to begin. One of those is feeding yourself, one is rest, one is moving your body, and the others will be your other choices. Check them off when they are done. Eventually you will be able to add more.

PACING

Pacing involves separating your activities throughout the day to avoid exceeding your body's limits. (Chronius Health)

As you plan when you will do activity, alternating high energy and low energy items, remember to also alternate types of energy. For example, getting dressed and eating breakfast might require a rest

before running an errand. After running an errand you may choose to read a book or make a phone call. Avoid lumping together too many physical activities and social efforts. This leads to exhaustion and can trigger symptoms.

- Rather than cramming in a bunch of chores, errands or exercise in a single day, decide on a weekly “menu” of when, how long and how much, based on your set priorities.
- Allow yourself a rest time in between activities. Even if the rest is simply sitting for 15 minutes in a quiet room with your eyes closed.
- Look at the big picture of the day and space things out. Try to get a visual image of the day with ups and downs of energy used. Be confident that you will bounce back throughout the day to enjoy another activity.



TIP: Take your shower in the evening. The warm water is relaxing and the next morning you don't have to spend energy and time on that. And a bonus is that for 12 hours you are hair product, lotion, deodorant, toxin free when you climb into bed.

STRESS MANAGEMENT, SUPPORT AND REST

“It's not stress that kills us, it is our reaction to it.”

- Hans Selye

While you are prioritizing, pacing yourself and managing energy, it's important to monitor stress, accept that rest is necessary, and establish a support system. In fact, finding and maintaining a good support system is one of the best stress reducers. Spend some time identifying what helps you calm your nervous system. There are many ways to do this and resources to aid in the effort. Here are just a few thoughts.

- Put **support systems** into place that nurture your sense of connectedness. Time with friends, family, support groups, counseling, online social groups are all options. This could even be a few minutes on a FaceBook group you enjoy.
- Try **breathing techniques** and/or basic meditation techniques that calm your nervous system and dampen anxiety. These can be one of your rest options.



TIP: Sit outside every day for at least a few minutes. Greet a neighbor, notice nature around you, or simply close your eyes and listen to the world.

- Explore vagus and trigeminal **nerve modulators** to address stress and vestibular symptoms.
- Learn how to **rest**. Rest is not laziness. It is energy restoring. Find the type of rest that renews you during the day, and become an expert!
- Find ways to **get outside of your own head** and problems. Read, check on a friend or watch a movie. A distraction is an amazing calmer.

FINAL NOTE

One important point as you embark on this process - Do not compare your abilities, energy and activities to the old you or to other people. Start with where you are and move forward. You want to feel empowered to manage life, not to let life spin you in circles (literally).

Finding the balance between how much activity you can do and how much rest you need helps you achieve these activities without crashing. (Long Covid Physio)



HONORING THE IMPACT OF BALANCE BENEFACTORS

MR. BRUCE WYRE

DR. KRISTEN JANKY

You can help people who are in crisis because of dizziness, vertigo, and imbalance get an *accurate diagnosis* and *effective treatment* and save them from their spinning nightmare.

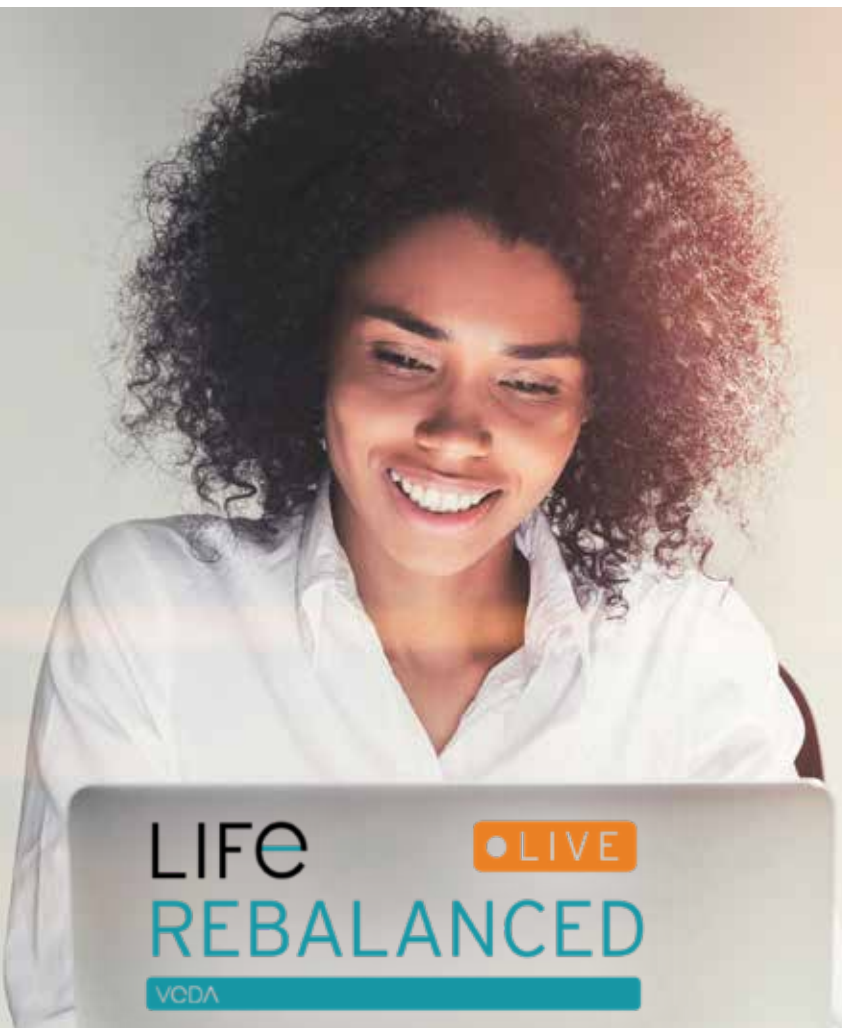
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DID YOU MISS THE CONFERENCE? NO PROBLEM!

VeDA's virtual conference, Life Rebalanced Live (LRL) took place this last March and was packed with expert insights, patient stories, and invaluable information for anyone navigating a vestibular disorder. If you missed it, don't worry—you can still access the full recordings and transcripts! Get lifetime access to every session and panel discussion, and catch up on the important topics that matter to you. Plus, your purchase helps VeDA continue offering LRL free in 2026!

Here are some words from people who attended:

"It is so worth the time. You are able to glean something from every session."

"Go for it! You will be glad you did, just knowing that you are 'not alone on your journey' and may come away with ideas of new things to try, that have helped others!"

Purchase recordings now at **VESTIBULAR.ORG/LRL-RECORDINGS**