

A QUARTERLY NEWSLETTER
OF THE VESTIBULAR
DISORDERS ASSOCIATION



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CONTENTS

3-6

PATIENT SPOTLIGHT

When Kimberly felt lost in a sea of uncertainty, writing became her anchor

6-7

RESEARCH SUMMARY

When your physical health is impaired, the odds of adverse mental health are higher

8-9

BALANCE AWARENESS WEEK

Shine a light on the struggles and needs of those suffering from balance conditions

10-11

LEAVING A LEGACY

Diane shares her choice to include VeDA in her will and leave an amazing legacy

12-15

TIPS & TOOLS

How finding and nurturing your creative self can help bring balance to your life

16

POETRY-4-BALANCE

Featuring *Boracherras* by Michael Cyr, one of the vestibular poetry contest winners

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WRITING IN THE WAKE

How Writing Became My Anchor in a Sea of Uncertainty

By Kimberly Warner, vestibular patient and author

I'll be honest, the last thing I wanted to do in the early years of living with Mal de Débarquement Syndrome was write. The constant sensation of rocking and bobbing jumbled my brain, like synapses flooded in stormwater. Words came as fragments, flotsam adrift on a sea I couldn't steady. Even thinking in complete sentences was a near impossibility. So for three years, I didn't write anything more than the occasional note-to-self in the margins of my calendar, usually to mark the date of my next doctor's appointment. At the time, I was looking for rescue, not reflection. Salvation meant finding a cure; I had no desire to lean into this unresolved, disorienting in-between, where process itself becomes the destination.

But around year three, a different kind of urgency emerged. I needed to start writing—not to be understood by others, not even to heal—but simply to stay connected to something solid within myself. To tether. To not forget. Because right around the time my dizziness began, I also learned that the father who



raised me wasn't my biological father. Two destabilizing currents, one in the body, one in the bloodline, collided. The ground beneath me shifted in every direction.

With my husband away at work, I sat at his computer, sometimes writing just a few sentences before lying down on the carpeted floor to recover. It wasn't easy. My brain had to learn how to focus again. But each time I returned to the page, I felt a small sense of purpose. In a life that had emptied out, writing gave me small footholds, moments of coherence inside the chaos.

Though my outer world felt like open



water, I found the inner landscape intimate, almost safe. I was weary of chasing cures and outrunning this dizzying new self. Writing became a kind of homecoming and invitation to trace my way back to the beginning: to the child's longings, the teenager's compulsions, the young woman's striving. Through the act of writing, I began to unwind the tangled threads of identity. To face, with curiosity and compassion, the mess and grace of living an unpolished, unplanned, unfixed life.

Four months later, I finished whateverit-was-I-was-writing. Something in me felt complete. I dragged the document onto an external drive and left it there. I didn't share it with anyone-not even my family. But as my story continued to evolve I began to feel ready to return to the words I'd once written. By then, I had been officially diagnosed by Dr. Shin Beh, thanks to the rise of telemedicine during the pandemic, and had begun building a relationship with my newfound biological family. It felt like the right moment to share the story with my mom, aunt, and brother, offering a window into my world. To say: This is what it's been like inside the waves. This is what I've been navigating.

Their response was wholehearted. With their blessing and encouragement, I began serializing the story on Substack,



posting one chapter a week for an inner circle of family and friends. I imagined it as a small, contained process. But what began as a quiet offering rippled outward. Over the course of two years, this intimate circle bloomed into a global community of generous, engaged readers.

And something remarkable happened: though many readers didn't have a vestibular disorder, or even chronic illness, they still recognized themselves in the current. They, too, knew what it was like to be unmoored in midlife. To lose orientation. To grieve an old self and begin again, unsure of the shape of what was coming next. In this collective drifting, and slow regrounding, we met each other.

When I reached the final chapter, I raised a glass to this unlikely fellowship. These readers had not simply witnessed the story; they had held it. They had held me. Without their quiet companionship, this fragile sprout of a narrative might have withered. Still dizzy? Yes. But wildly rooted into the loam of a thousand others? Yes, this too.

I put the memoir away again, this time with a full heart and a quiet sense of completion.

Six months later, an email arrived from a publisher who had been reading the serialized version all along. She asked if I would consider traditional publication.

And the rest, as they say, is history.

Today, you can pre-order Unfixed: A Memoir of Family, Mystery, and the Currents that Carry You Home (Empress Editions, out October 14th). What began as a private act of anchoring has become a public invitation—a lyrical exploration of identity, inheritance, and the deep wisdom of the body.

Unfixed: A Memoir of Family, Mystery, and the Currents That Carry You **Home** is a haunting exploration of identity, loss, and the unsteady ground of becoming.

When a midlife DNA test reveals that the man who raised her isn't her biological father, Kimberly Warner is drawn into two parallel mysteries: one excavating the silence surrounding her beloved father's death, the other tracing the absence of a stranger whose blood shapes her very being. As she unravels the secrets hidden beneath her family's story, another rupture emerges-this time in her body. A mysterious illness takes hold, leaving her adrift in dizziness, and a growing awareness that her body knows truths language cannot hold.

Told through lyrical prose and imagined correspondence, Unfixed carries readers across decades and terrain, from the New Age spirituality of Warner's 1980s childhood to the

tidal unpredictability of midlife, where



certainty dissolves and the soul insists on truth.

This is not a memoir of resolution, but of reckoning. For anyone who has sought refuge in the known, Unfixed offers a quiet transformation: healing not as closure, but as relationship. Wholeness not as solidity, but as the willingness to remain present to what is.

With echoes of Inheritance, and the emotional undercurrents of Where the Crawdads Sing, Unfixed reveals the beauty and heartbreak of uncovering truths long buried. It is a celebration of the body's wisdom, the resilience of the human spirit, and a poignant reminder that even in the most uncertain lives, there is space for hope, connection, and becoming. And what feels like drift may be the current carrying us home.

KEY FINDINGS

Over half of the patients reported higher-than-normal anxiety, and about 42% reported higher-than-normal depression.

Those who felt they had poor physical function were:

- 5 times more likely to have anxiety.
- 3 times more likely to have depression.

This connection was especially strong in patients with:

- Benign Paroxysmal Positional Vertigo (BPPV) - 10 times more likely to report anxiety if they had trouble with physical function.
- Unilateral Vestibular
 Hypofunction (UVH) 10 times
 more likely to report both anxiety
 and depression if physical
 function was impaired.

Older adults were slightly less likely to report anxiety than younger people.

RESEARCH SUMMARY

PROMIS Outcomes: Higher Odds of Adverse Mental Health When Physical Function Is Impaired

SUMMARY

Many people who experience dizziness, vertigo, or balance problems also struggle with mental health issues like anxiety and depression. This study looked at 170 people who were referred to vestibular physical therapy to find out whether those who reported having trouble with everyday physical tasks were also more likely to feel anxious or depressed.

The researchers used a tool called PROMIS (Patient-Reported Outcomes Measurement Information System), which helps measure how people feel physically and mentally. They collected scores for physical function, anxiety, and depression from each participant.

KEY FINDINGS

The study findings are described in the table to the left.

WHY THIS MATTERS

This study shows that when people have vestibular disorders and feel physically limited, it can take a toll on their mental health. It highlights how important it is for physical therapists and healthcare providers to not only treat balance

problems but also screen for anxiety and depression.

The authors encourage physical therapists to work alongside mental health professionals so patients can receive complete care—both physical and emotional. Treatments like cognitive-behavioral therapy (CBT), when combined with vestibular rehab, may help patients recover more fully.

BOTTOM LINE

If you're dealing with dizziness or balance problems and also feel anxious or depressed, you're not alone. These issues are closely connected. Talk to your healthcare provider about your physical and emotional health-both deserve attention and support.

Summary edited by Erin Anson

Source: McConnell, C., Allen, P., & Anson, E. (2025). Patient-Reported Outcomes
Measurement Information System (PROMIS)
outcomes: Higher odds of adverse mental health when physical function is impaired. Journal of Vestibular Research, O(0), 1-8. https://doi.org/10.1177/09574271251335958



A Worldwide Movement for Vestibular Visibility

WHAT IS BALANCE AWARENESS WEEK?

Balance Awareness Week (BAW) is an annual campaign to shine a light on vestibular (inner ear and brain) disorders that affect balance, coordination, and quality of life. Many people with these conditions go undiagnosed or are misunderstood. BAW is a time to raise awareness, encourage early diagnosis, and promote better care and research—so no one has to navigate dizziness alone.

YOU CAN MAKE BAW AMAZING

- Share your story
- Enter the Fiona Flamingo Photo Contest
- Post using #BalanceAwarenessWeek
- Wear awareness gear VESTIBULAR.ORG/MERCH

JOIN FIONA'S FUNDRAISING FLOCK - AND MAKE A GLOBAL IMPACT

Fiona Flamingo is more than a mascot-she's a symbol of balance and resilience. This year, join her fundraising flock and help create real change for people living with vestibular disorders.

When you join, you'll get:

- A personal fundraising page to share your story
- Tools to spread awareness and raise support
- The chance to be part of a worldwide community

Ready to fundraise for change?

Sign up at VESTIBULAR.ORG/FLOCK

BALANCE AWARENESS ROCKSTARS FROM 2024



From Portland to Paris, Denmark to Tunisia, people around the world are standing up for vestibular awareness, research, and better healthcare.

Everywhere, someone is experiencing unexplained dizziness.

Everywhere, someone is being told "it's all in your head."

Everywhere, someone is searching for answers—and finding VeDA.

Together, we can make vestibular disorders visible. Learn more at **VESTIBULAR.ORG/BAW**

people lar AR VISIB ACROSS THE WORLD!

VERTIGE'S "BALANCE RUN"

₽ TUNISIA



Diane Kimmel has felt the impact of vestibular healthcare in her own life. In this note, she shares why she chose to leave a legacy to support others on the same journey:

"Including the Vestibular Disorders Association (VeDA) in my will was a natural decision because this organization has made a meaningful difference in my life and the lives of so many others living with dizziness, imbalance, and invisible chronic illness. By making a legacy gift, I know that I'm helping ensure that future generations will have access to trusted information, compassionate support, and advocacy for better healthcare. It gives me peace of mind to know that my values will live on through VeDA's mission.

I chose to make this gift through a revocable trust, specifically the Kimmel Family Trust, because it allows me to retain control over my assets during my lifetime while ensuring that my wishes are clearly documented and easily carried out. It also protects both my spouse and me—if one of us passes away before the other, the trust provides continuity and financial security for the surviving partner. It's a flexible and thoughtful way to support the causes we care most about—like VeDA—without compromising our own needs or the needs of our family."

Dear friend,

I want to take a moment to share a special opportunity to deepen your impact on the vestibular community—one that **costs nothing today** but can **make a lasting difference for years to come**.

August is Make-A-Will Month, a time to reflect on the people and causes that matter most. For Diane Kimmel, that meant including the Vestibular Disorders Association (VeDA) in her estate plans. After living with vestibular symptoms and finding support through VeDA, she wanted to ensure others would continue to have access to the same trusted information and compassionate care that helped her along the way.

Diane made her gift through a revocable trust—a simple and flexible way to support the causes closest to her heart while still meeting her family's needs. Diane's legacy is one of hope, ensuring that future generations will not have to face their vestibular journey alone.

This August, I invite you to join Diane by including VeDA in your will or trust. Even a small percentage can create a big impact, helping people with dizziness and imbalance find answers, community, and a path forward.

Thank you for being part of this mission. Together, we can build a future where no one has to navigate vestibular challenges in the dark.



With gratitude,

Cynthia Ryan, VeDA Executive Director

P.S. If you are considering leaving a lasting legacy by including VeDA in your will, you will find everything you need at VESTIBULAR.ORG/LEGACY

FINDING AND NURTURING YOUR CREATIVE SELF

By Karen R. Mizrach

Maybe I over-celebrated finishing a paint-by-number of a crane. However, it took a lot of energy, balance, patience, neck stability and brain power, and it took over a month to complete. So, the wobbly little dance I did after removing it from the easel, felt entirely appropriate.

It's not easy when, unexpectedly, we have to rethink how we pass the time, but it's important to find activities that give us a sense of accomplishment on our healing journey, and it's nice if we can find something to do in the safety and comfort of our homes. This eliminates the stress of wandering out into the world for yet another vestibular challenge.



Making the time to try new things that benefit the soul and mind is crucial to living a content and interesting life. While the outlet of creativity will be different for everyone, having at least one outlet will positively impact your life in numerous ways.

- Lily's Literature

You don't have to be a talented artist to find your creative side. All of us have the ability to create something. The trick is to find something that is calming and rewarding.

I remember a bit of anxiety as I opened my first paint-by-number kit, not sure exactly how to approach the task. But after I watched a few YouTube videos and read the instructions (duh), I thoroughly enjoyed it. Watching the image emerge and the colors work together was satisfying. No talent, special knowledge or formal education was required.

GETTING STARTED

Visualizing is a powerful tool we can use - we all have the ability to visualize or create images in our minds. This mental image influences our feelings, our thoughts, our actions. And our actions create results in our life. 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.



A **vision board** is a wonderful beginning if you are unsure how to start finding a creative outlet. It is brainstorming with images, words, objects and ideas put in a collage format. Using magazines, printouts, photos, drawings, stencils, objects, etc., this process of deciding actually becomes its own activity, and work of creativity. Many people enjoy creating several vision boards. Each one can have a separate topic or goal.

Once you've decided what you'd like to do, begin to **gather the necessary equipment and materials**. If it's a new activity to you, a kit may provide an easy start.

Getting supplies is a fun step in the process. Enjoy learning about the items used, and take your time. There is no rush. There is no pressure or deadline. Luckily, most everything you'll need is available online. If you are able to shop

and get out, it can be fun to browse through a store to see your options.

Depending on your chosen venture, decide where in the house will be your creative space. Maybe it will be a corner of the dining table, or a kitchen counter, or your deck. When you have the space ready, this will be where you put the materials, ideas, and vision board. Make the area appealing and try to keep it cleared of unrelated objects. If you need to share this space with other family members or activities, buy a container to keep your creative supplies is so they are easy to pull out when inspiration strikes.

When you find the outlet that you love, you'll know it, as it will feel like a creative and energizing process to you.

- Lindsay Aman, PageFlutter

JUMPING IN

Try your first project - Remember, it's a process of trying to find a good fit and feel, so don't worry if the first effort isn't right. Try a few things and see if one of them triggers an interest or pleasure. Notice what activity gives you a sense of complete focus and calm.

Trash - The efforts that don't please you



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or bring an "ahh, I love this" feeling can be thrown away. Persevere, but don't pressure yourself to do something that is not fun. And don't keep a pile of unfinished, unloved projects. Trash them! Keep moving.

Pace Yourself - Even if your energy allows you to spend just 15 minutes on something - potting a plant, making a salad dressing, or writing a poem - do that and feel the accomplishment. Once you find a passion, you'll increase your endurance.

Never compare - Avoid comparing your efforts to your former abilities or competing with your old self. Let that go. Embrace the here and now. Celebrate your successes!

My not-real-art crane painting now hangs



MY FIRST TWO PAINT-BY-NUMBER PROJECTS, FIRST A CRANE THEN A BEACH SCENE

above my bed, and always brings a smile. I loved the slow pace. I loved the colors and watching it come to life. All that love makes it a memorable creative endeavor. The few I did that didn't please me went directly in the trash. No regrets or self judging. We keep moving forward.

Creativity is not just something we do in our free time—it's essential for emotional well-being. By embracing artistic outlets, we can find a deeper understanding and healthier relationship with our emotions.

-Jenna Rainey

PROJECT IDEAS

Here are some examples of creative projects that may bring you satisfaction and give you a sense of purpose and an occasional escape from illness.



Painting/Drawing: Coloring books, doodling, decorating a paint-by-number journal, watercolor, sketching. Try watching YouTube tutorials to get inspiration.

Cooking: Try making salad dressings, salsa, roasted veggies, granola. Get some pretty jars to store your creations.

Needlework: Crocheting, needlepoint, knitting, embroidery. If necessary, use a travel pillow to support your neck, maybe a pillow under your arm, and relax the shoulders.

Container Gardening: Herbs, flowers, small trees. Buy beautiful containers, good soil, a small shovel, and gloves.

Music: Instrument, listening, playlists. Explore online lessons, samples of all types of music and genres you haven't listened to before. Discover new musical artists.

Crafts: Clay building, mosaic, decoupage, rock painting/decorating.

Writing: Journaling, short stories, memoir shorts, poems. Online classes and writing groups can help you get started. If you discover that you have a gift, you could create a blog.

Photography: Make greeting cards, frame your favorites, use for vision boards. You can set up still lifes in your home and edit old photos that need some love.

CONNECT WITH OTHERS

If you're looking for a community of creative (or creative wanna-be) vestibular peers, check out VeDA's online support group *Creativity in Vestibular Recovery*. This group welcomes new member to join via video call on the first Thursday of every month at 3:00 pm ET.

VESTIBULAR.ORG/CREATIVITY

HONORING THE IMPACT OF BALANCE BENEFACTORS

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MS. JANE BERNSTEIN
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MR. ROBERT J GOLDEN

MS. JENNIFER HICKMAN-RONQUILLO

MS. JOAN KIRCHHEIMER
MS. LYNDSY WALTERS

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.

Visit **vestibular.org/OTLdonate** to make a difference today. Your gift matters!

BORACHERRAS

By Michael Cyr

Sometimes she was a coin flipped into a deep well,
Sometimes loose marbles on a
Lazy Suzan
Reality was a suggestion
Each step falling through a crust of snow

Her sister had them
She'd lock herself in her room for
two days,
But otherwise didn't mention
them much
Her mother had them
She called them "Boracherras"
Little drunk spells

Eyes clamped like hurricane shutters Whirling, centrifugal violence She could only wait to bottom out, Earthbound and empty

"Boracherras" by Michael Cyr is one of the 5 poems awarded the winners of the 2025 Poetry-4-Balance contest that took place during Poetry Awareness Month in April.

You can read the rest of this and previous years' winning poems at **VESTIBULAR.ORG/P4B.**

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