A Life Derailed

By Donna Conboy

I had a full life before vertigo, dizziness, vision loss and imbalance stole my freedom and financial security.

I have three biological children – two sons, Luke and Adam, and a daughter, Melissa. My home has always had an open door for at-risk youth, many of whom are dealing with addiction and trying to stay in school and out of gangs. I enjoyed being physically fit and loved my job. I wasn’t even 50 when all of a sudden I started feeling like an old woman.

I already held degrees in Exercise and Health Science and was pursuing my Masters in Applied Gerontology. I had worked as the Fitness Coordinator at the Boys & Girls Club, lead health classes at my local senior center, and most recently was a biometrics screener, which required constant travel. My jobs allowed me to meet new people, help at-risk youth, and bring about positive change.
A LIFE DERAILED...CONTINUED FROM PAGE 1:

Essentially, I was getting paid to "play."

Then, in 2013, while I was demonstrating a balance testing exercise, I noticed that I was falling to my right side. This was the first sign that something was very wrong with my vestibular system.

I had always been healthy, with the exception of migraines, which I’d had for the past 10 years. Then I noticed that I was having trouble driving at night and over bridges – lights were bouncing and I couldn’t see. I had planned on making an appointment with my doctor, but then my father passed away and I was consumed with grief and the logistics of managing his estate.

By the time I could spare a moment to take care of my own health, I could hardly walk and was falling down the stairs. However, there were no doctors available on my health plan, so I had to pay out of pocket just to get an appointment with a primary care physician (PCP).

My PCP had no experience with vestibular disorders, so she just gave me meds and referred me to a neurologist. My MRI came out normal, so the neurologist diagnosed me with BPPV and referred me to an ENT. The ENT gave me more meds, which didn’t help, then threw his hands up in the air and said he didn’t know what to do. Next, he asked me if I was experiencing anxiety – of course I was! Who wouldn’t, with the scary symptoms I’d been having and no one to tell me what was going on. The inference, however, was that my symptoms were all in my head. Next he ordered a VNG test, diagnosed me with vestibular hypofunction, and referred me to a physical therapist (PT).

DONNA WITH HER CHILDREN, LUKE, ADAM AND MELISSA, AND GRANDSON, LUCAS - THE LIGHT OF HER LIFE.
The PT was not specially trained in vestibular rehabilitation therapy, however. She did the Dix Hallpike maneuver to rule out BPPV and started me on visual therapy and basic balance training, but soon discharged me because she didn’t know what else to do and nothing she tried made any difference. Another dead end.

Finally, I learned about Emory University, which has a balance clinic renowned for its work with vestibular patients. Unfortunately, based on my VNG results, they said they didn’t think they could help me. I knew this was my only hope, so I persisted, and after two years was able to get an appointment with Dr. Jennifer Tirino in July, 2015. It took another year to get my testing completed.

Dr. Tirino had Emory do a complete battery of tests on me. I failed the posturography test miserably. My vHIT was off the scale (1 is normal; I scored 11), which indicated that I was legally blind when my head is in motion. I had zero reactivity to the caloric test (this time done with water; previous calorics had been done with air, which I now know is less accurate).

Dr. Tirino diagnosed me with complete bilateral vestibular loss, which is irreversible. She said she’d never seen a case so profound.

Of course, what I wanted to know was...what can you do about it? That’s when I learned that there are no easy fixes. Basically, I’m going to have to learn to live with it, to adjust to a “new normal.” In the meantime, I lost my job because I couldn’t travel, which means losing my health insurance (which wasn’t helping much anyway).

In April, 2014 I applied for disability and was denied, twice. I’m now waiting for a hearing so a judge can review my case.

I’ve had to pay for all of my therapy and most of my vestibular medical expenses out-of-pocket, $60,000 over the past three years. Now I’m faced with selling my house so I can use the equity to pay my monthly expenses. Basically, I’m broke.

As if anxiety over my health wasn’t enough, now I’m dealing with anxiety and depression because I don’t know how I’ll make ends meet for me and my family.

On the upside, I’ve been approved for a vocational rehabilitation program that will retrain me for limited part-time work that accommodates my special needs, though it will be at least 6 months before they can place me.

My children, extended children, and best friend, Alec, have been on this journey with me. It took over a year and the results of my tests for my oldest son to believe that my symptoms were real, that I wasn’t just being lazy. Now he has a child of his own, Lucas, who is the light of my life, though I hate that there are many things I can’t safely do.
with him because of my illness.

My youngest son, Adam, is 18-years old now. He is always worrying about me. He didn’t get the same opportunities other kids his age had because of my illness. I feel badly about that. He takes me hiking with my alpine sticks. He picks me up and encourages me to keep going when I fall. I can no longer look ahead while I walk so he stops and points out the things he knows I would enjoy.

My daughter, Melissa, is amazing! She has been and continues to be my rock. My extra kids have also been very supportive. I hate to think that they may lose their “safe space” if I have to sell my home.

Friends? They stopped calling because I had to cancel our plans all the time. I’m lucky, though – I have Alec. He has been my best friend and cheerleader. His unconditional, supportive attitude is a driving force that helps me adapt and overcome.

I still struggle daily with vertigo, dizziness, and imbalance. My eyes don’t work together, so I do vision therapy with Dr. Joe Rouw, a vision therapist. He and his wife have taken a personal interest in my case and have been studying possible therapies. We work on gaze stabilization and depth perception, and he is helping me try different prism lenses. I also do vestibular rehabilitation therapy exercises at home.

My muscles and joints often ache and I fatigue easily. Dr. Tirino says that for a normal person what I deal with would be like walking on a balance beam for eight hours straight. It’s completely draining, and some days I don’t know how I manage.

This disease has changed me so much. It’s hard to hold onto the person inside you. I used to hike and travel. Now, sometimes, I don’t know who I am. Just yesterday my oldest son said to me, “I don’t recognize you.”

The biggest frustration has been the complete lack of information, resources, and misunderstanding about vestibular disorders, not just among my friends and family, but within the medical community.

I am grateful to VEDA for being there for vestibular patients struggling with the uncertainty of their condition. I’m glad I found a community of support, and happy I can share my story.
Feeling Confused and Abandoned
By Linda Zonana

During the first couple of years following my initial episode of intense vertigo, I had several strong attacks, each followed by weeks of exhaustion, nausea, imbalance, disorientation, and worry about whether I would ever function normally again. My diagnosis was Menière’s, but nothing seemed to make much difference: not medication, not dietary changes. Feeling desperate, I made an appointment with a new doctor, who specialized in the inner ear. We met and he ordered some tests. When I returned for a follow up meeting, I began telling him how deeply my symptoms affected my life. He cut in to ask, “Well, have you had another attack?” I felt tongue-tied at that. It seemed to me I was almost always having an attack, in the sense that most days I was affected to some degree. But I didn’t feel able to say, “No I haven’t had lying-on-the-floor vertigo this week, but I feel awful most of the time.” I knew that, with Menière’s, you supposedly would be exhausted after an attack and wake up the next day feeling fine. I never woke up the next day feeling fine. The fact that my case was different, and that he didn’t seem to have noticed or been curious about it was very off-putting to me.

A few years after that encounter, I interviewed 50 people to learn about their experiences with vertigo. The strongest common thread among those people, and one that I shared, was confusion about what was wrong, even if a diagnosis was given, along with the feeling that no protocol was helping much - often accompanied by a feeling of being of little interest to the medical folks, and a consequent sense of abandonment. Vestibular disorders share issues in common with recurring or chronic diseases, but with an added twist. They impact your perception in profound ways. You are experiencing a major assault on the integrity of your person, yet it can seem as if it arouses little concern on the part of the doctor. Perhaps this is because these disorders are rarely fatal, or because there isn’t always definitive treatment. And too, people presenting with vertigo are often a challenge to diagnose. Menière’s and BPPV are the most common labels, but there is a host of other possibilities. And those diagnosed as Menière’s and BPPV don’t always have the expected cluster of symptoms or course of illness.

BPPV is the most readily treatable vestibular disorder, thanks to the ingenious development of the Epley Maneuver. You would think these maneuvers would be familiar in every emergency room, but apparently not. Thus, many people with BPPV struggle for ages, especially if their situation does not fit the neat description of “brief episodes of mild to intense vertigo.” Over at least 20 years of intermittent symptoms, Frieda would experience weeks of vertigo, especially while lying down, but the worst of it for her was disturbances in balance. She would be unable to stop her body from being pulled to one side, felt “as if walking through a thick viscous substance.” She was unable to walk on uneven ground, and couldn’t drive. No doctor offered a diagnosis until a couple of years before we talked, when a doctor noted she had nystagmus, which made

CONTINUED ON PAGE 6
her “feel validated.” He administered the Epley Maneuver, which showed no immediate benefit, but happily her symptoms resolved soon thereafter.

Yvonne is another person who lived for years with complex symptoms before getting relief via the Epley. She would experience vertigo, “feel like the earth was opening up to swallow [her],” and “see walls moving in at [her].” She thought doctors were annoyed with her, and was told her symptoms were psychological. “I felt extremely abandoned,” she said. After about 30 years of this she was finally seen by a “wonderful doctor” at a large city hospital. He administered the Epley, which she still needs from time to time. She says, “I’m no longer just my illness.” She feels more confident, no longer bewildered and ashamed.

**Compared to BPPV, despair and confusion are apt to be greater with Menière’s.** Sally had stronger and more pervasive symptoms than mine, and like me, the dietary regimen did not help. She’d feel “a roar rush into [her] head, accompanied by “fierce vomiting” and intensifying vertigo. Her husband took her to see an ENT, who put her on a diuretic, but it was a month before she felt okay. Over the next year she had repeated attacks but no matter what was done they kept getting worse. Another ENT was consulted, but both doctors seemed distant and didn’t explain much or seem concerned. She became depressed and says her whole personality changed. Sally decided increased hearing loss was worth the risk of gentamicin and arranged for the injections, which have enabled her to return to her old self, aided also by physical therapy.

Kim began having dizzy spells decades ago. She says that she “got out of bed and stepped onto a carnival ride” that threw her across the room. The intense attack lasted 10 minutes but she was nauseated all day. Such attacks happened occasionally during her 30s. The frequency stepped up in her 40s, but when she consulted a doctor she was told, “Lots of people get dizzy.” She said, “I felt so disregarded.” As matters grew worse, she wondered if she might have to quit her job, and worried she might have to go on disability. A year and a half before we spoke she had her most severe attack ever and met with an ENT who diagnosed her with Menière’s and recommended dietary restrictions along with a Scopolomine patch and a diuretic. She continues to have some mild symptoms, but now, after 35 years, her life is “wonderful.”

**Those with less common vestibular disorders may have an especially hard time getting an appropriate diagnosis, or in feeling support from their doctors.** Lila experienced increasingly disabling and long-lasting symptoms over a period of 15 years. She was diagnosed first with stress, then Menière’s, then bilateral vestibular loss over that time. She was reduced to using a wheelchair or crawling. She suffered with “jello brains – magnified by every body motion,” couldn’t read because of “bouncing vision,” her “eyes flew – objects slid past,” and when lying down, her vision would “break up like a kaleidoscope.” She was angry about the uselessness of the various medications she tried, and about being seen as having a psychiatric condition. Her story ended well, with a good response to Valtrax and Valium she was able to walk again and return to work.
Knowing your experience is shared by others helps in dealing with vertigo, as does knowing there are variations in the way symptoms are experienced. Such awareness can help you be clearer and more assertive with the medical world, enable you to press for alternative treatment, or initiate a discussion about the details of your symptoms. If possible, it’s best to search for a practitioner who listens and acknowledges what you say. If you feel dominated by or dismissed by your doctor, it can help to bring someone along to support you.

Please note that each situation in this article had a good outcome, although often after too many years of struggle. Not all vestibular patients are so lucky.

*MAYO CLINIC WEBSITE, 5/28/15
Decoding the Symptomatology of Vestibular Disorders

By Dr. Matthew G. Crowson, MD

The signs and symptoms of vestibular disorders can be vexing. The constellation of symptoms that can affect one individual may vary vastly in degree, type, and severity in another. This complexity creates challenges for health care providers serving patients afflicted with vestibular disorders. Over time, vestibular specialists have sought to differentiate and categorize vestibular symptoms to discern between different disorders so that they can more readily identify and treat them. A recent review article by one of the contemporary leaders of vestibular medicine, Dr. David Newman-Toker, has comprehensively outlined the advances in the classification and categorization of vestibular symptoms to help providers see through the complexity, and deliver effective and appropriate treatments.

As with many medical afflictions, taking an accurate history and a review of associated symptoms is tantamount to arriving at an accurate diagnosis. Historically, vestibular providers have clung to the notion that the quality of vestibular disturbance – true vertigo, unsteadiness, disequilibrium or pre-syncpe (i.e. a feeling that one is about to faint) – is key to unlocking the diagnosis. Dr. Newman-Toker asserts that there is little evidence to suggest a description of the vestibular symptom quality leads to an accurate diagnosis. Providers, let alone patients, have a difficult time differentiating between the different quality types of vestibular complaints. Room-spinning vertigo to one individual may seem more like ‘listing’ and floating to another.

More recently, Dr. Newman-Toker notes that providers have been honing in on the timing and triggers for vestibular symptoms as a more accurate diagnostic tool. Do the vestibular symptoms occur all the time? Or, are they more episodic with symptom-free periods punctuated by symptom flares? For instance, brief vestibular dysfunction elicited by sudden head movements or positional changes is more aligned with positionally-dependent disorders such as benign paroxysmal positional vertigo (BPPV). Alternatively, brief vestibular dysfunction that is spontaneous and not associated with positional changes may be more aligned with disorders such as Meniere’s Disease.

What happens in the cases where vestibular symptoms are from a more sinister origin? Differentiating between benign peripheral vestibular disorders and dangerous conditions such as cerebrovascular and cardiovascular disease can be challenging. Dr. Newman-Toker summarized evidence to suggest that vestibular symptoms that have distinct reproducible triggers are more apt to be benign. When there is an issue with the heart, such as insufficient cardiac output from an arrhythmia, the symptoms are more apt to happen spontaneously. Eliciting descriptions of associated symptoms, such as shortness of breath, chest-pain, and palpitations, is also critical for identifying dangerous sources of vestibular symptoms.

Further clues to decoding a vestibular disorder can be made from evaluating for nystagmus – idiosyncratic eye movements that can be spontaneous or contextual. For instance, nystagmus observed in a patient looking far off to one side (gaze-evoked) is likely to be benign if horizontal, symmetric and brief. However, vertical or asymmetric nystagmus with the same stimulus may indicate a pathologic cause – especially if it occurs when a patient does not need to look far off to one side for the nystagmus to
appear. More advanced techniques such as the ‘head thrust’ head impulse test (HIT) can also be helpful in quickly assessing and localizing a horizontal semicircular canal hypofunction. This test is completed by an examiner guiding rapid accelerations of a patient’s head while the patient attempts to maintain gaze on a fixed object. If the examiner notes the eyes must play ‘catch-up’ with the sudden head movements, this may indicate peripheral vestibular hypofunction. Performance of these basic maneuvers to assess for nystagmus requires little time, expense and equipment, but can be tremendously helpful in identifying peripheral or central vestibular syndromes.

KEY CONCLUSIONS:
- The history of the vestibular symptom, review of associated symptoms, and a general medical history should be in every provider’s routine in evaluating patients with vestibular symptoms.
- Focus on the timing and triggers of the vestibular symptoms, not the quality or description of the dizziness. Are the symptoms present for seconds, minutes, hours, days, or weeks?
- Not all vestibular dysfunction stems from benign conditions. Potentially dangerous causes such as cerebrovascular disease (e.g. transient ischemic attacks, stroke), serious infections, malignancy, and cardiovascular disorders need to be ruled out. Dangerous conditions tend to produce spontaneous vestibular disruption without an obvious trigger.
- Several bedside maneuvers, such as assessing for spontaneous or gaze-evoked nystagmus, and nystagmus elicited by the head impulse test are cheap, quick, and can be informative.

While we summarized just one review on the symptoms of vestibular disorders, contemporary medical literature is rife with different methods and perspectives on this topic. A VEDA project that is currently underway is seeking to mine the literature to consolidate the collective wisdom of these methodologies. Informed by this search, VEDA is working with a team of specialists to generate a simplified diagnostic framework for peripheral vestibular disorders to assist front-line clinicians in the initial evaluation of patients presenting with vestibular symptoms. It is our hope that a streamlined diagnostic protocol will help quickly orient clinicians to more effectively serve this patient population, and identify the appropriate referral resources to treat their conditions.

REFERENCE
FINANCIAL REPORT

THANK YOU FOR YOUR GENEROUS SUPPORT!

EXPENSES

YOUR GIFTS ARE STEWARDED WISELY
OUTREACH

WEBSITE VISITORS

BECAUSE OF YOU, WE ARE THE #1 RESOURCE FOR INFORMATION ON VESTIBULAR DISORDERS ON THE WEB!

FACEBOOK FOLLOWERS

THANK YOU FOR BEING PART OF OUR GROWING COMMUNITY!
2016 Milestones

NEW PATIENT TOOLKIT

DEVELOPED A WEBSITE TOOL THAT GUIDES NEW PATIENTS THROUGH THE STEPS OF DIAGNOSIS, TREATMENT AND RECOVERY.

NEW ARTICLES

PUBLISHED 3 ARTICLES ON HOW TO APPLY FOR SHORT/LONG-TERM DISABILITY AND SOCIAL SECURITY, WITH TIPS FOR VESTIBULAR PATIENTS.

“ROAD TO BALANCE” INFOGRAPHIC

LAUNCHED AN INFOGRAPHIC SHOWING HOW THE BRAIN COMBINES INFORMATION FROM THE INNER EARS, EYES AND MUSCLES TO HELP CONTROL BALANCE.

WEBINARS

PRESENTED A WEBINAR ON THE EMOTIONAL & COGNITIVE IMPACTS OF VESTIBULAR DISORDERS, SUCH AS ANXIETY, DEPRESSION & BRAIN FOG.

PRESENTED A WEBINAR ON HOW TAI CHI AND TAI CHI WALKING CAN HELP IMPROVE BALANCE AND PREVENT falls.
Thank You For Your Support!

THE GENEROSITY OF YOU, OUR DONORS, IS ONE OF VEDA’S GREATEST BLESSINGS. YOUR SUPPORT GIVES US THE RESOURCES WE NEED TO PROVIDE HELP AND HOPE TO MILLIONS OF VESTIBULAR PATIENTS.

YOUR COMPASSION TRANSFORMS LIVES!

VISIONARIES
$10,000+
Susan Papa

GUARDIANS
$5,000 - $9,999
Dalu Family Foundation, in honor of Amy Downing

FRIENDS - $1,000-$4,999
Anne E. Leibowitz Fund

Dr. Deanne Bonnar
Amy Downing
Christina & Scott Duncan*
Jennifer Gittins-Harfst
Laura Stanford
Sue Hickey & Sheldon Klapper
Merilee Holst
Charles Johanson Jr.
Ellis Kern
Nancy Kimball
Lester Knight
K urz Family Foundation
Etrily Laitphlang
Isabel Leibowitz
Lew Leibowitz
Louis Leibowitz
Charitable Trust

PATRONS - $500-$999
Andrew Altersohn
Jennifer Briscoe
Lora & Neal Buck*
Stacey & Jason Buckner
Barbara Cantacuzino
Dr. Ricardo Ceballos-Lizarraga
Joyce Chadderdon
Elizabeth Commerford
Dr. Gaye Cronin
Paul Fichera
Stephen Fisher
Jeffrey Fuchs
Gail Gallagher
Patricia Gerend
Jill Gordon Craig
Janit Greenwood
Natasa Jeremic
Dr. Gary Kaihara
Dale Leibowitz

Seta Nazarian
Albrecht
Doug Nielsen
Iris Osman
Dr. Steven D. Rauch
Dr. Donald Risucci
Dr. Jay Rubinstein
Salinger Family Fund
Colleen Sorensen
Mina Stachowiak
Annabel Stoner
Sheelah Woodhouse

ADVOCATES $250 - $499

Terri Baltus
David Bernardo
Gioia Bonomi
Larry Bowman
Dale Brockman
Alice Brumbaugh
Toni Campoamor
Stanley Cohen
Bernd Crasemann
Sanjay Dave
Dori Ann Davis
Sherrie Derr
Norman Discher
Holly B. Fisher
Marsha Frazier
Rebecca Gale
Allen Gavin
Carolyn Glasier
Claire & Raymond

Haddad*
Veronica Howard
Amy Jaffe
Frank Jameson
Marielena Kamienski
Randy Kaufman
Ellen Korpi
Victoria LeFevre
Dr. Joel Lehrer
William Manofsky
Julie Marshall
Gennaro Marsico
Christine McHugh
Mark Muir
Carol Murphy
NHL Alumni Assoc.
in honor of Bryce Salvador
Susan Novins
Donna Plunket
Luis Rey
Rebecca Rubin
Molly-Jane Rubinger

Cynthia Ryan
Paul Schweitzer
Lynn Severance
Dean Smith
Dr. Thomas Sollas, Jr.
Dr. James Srigley
Margaret Stika-Walsh
Wendy Switalski
Amol Tembe
Gerd Wassermann
Lawrence Williamson

Sustaining Circle members make monthly gifts that provide reliable funding for VEDA to carry out our mission throughout the year. Sustaining Circle members’ names are indicated in bold.
ASSOCIATES
$100 - $249

Rev. Cynthia Abrams
Corey Aldrich
Dr. Coral Armstrong
Randy Atlas
Lizbeth Barnea
Jean Barrell
Samantha Bartling
Tom Basista
June Battaile
Linda Bauer
Ken Bazzle
Vicki Behrend
Kevin Belli*
B. Richard Benioff
Brenda Berger
Stuart Berman
Donald Bestwick
Jorita Black
Kristi Blake
Robert Bledsoe
Sandra Blount
Liza Botkin
Jennifer Bowden
Paul R. Brandenburg
Patricia Breglio
Nancy Bronson
Judy Brown-DuPaul
Alfred Bryden
Francine Burnham
Paul Burnside
Alan Butchman
Peter & Joyce Campbell
Jacqueline Cane
Richard Capobianchi
Juta Carpenter
Valerie Carrick
Robert Carroll
Victor Castellanos
Tim Centola
Nancy Chadderdon
Marsha Charles
Lois Christman
Charles Clancy
Patricia Cohen

Donna Conboy
Clifford Coss
Susan Cottington
Marion Coughlin
Dr. Sterling James Crabtree Jr.
Elizabeth Craig
Beverly Crisp
Robert Curtis
Elisabeth D’Alessio
Elizabeth David
Michele Degan
James DeMaio
Judy Dempsey
Dr. Vincent Desiderio Jr.
Joseph DeVerna
Janet Dutra
Lucille Easley
Andrew Edmonds Jr.

Edwardo Gonzalez
Eric & Denise Gordon
Jeff Gordon
Susan Gough
Doris Graf
Jeffrey Gray
John Greeley
Dianne Gregg
Barbara Grimes
Catherine Grochowski
Patricia Hackmiller
Kristi Haigh
Alice Hampton
Dorrette Hanson
Scott Harper
Alison Harrel
Jonathan Hartl
Joyce Havens
John Headley
Lt. Col. Donna Heinz

Pam Hengst
Cynthia Hernandez
Margaret Higgins
Alice Hirsh
Fred Hoffman
Vicki Hotte
Dr. Jeffrey Hudgens
Douglas Huffman
Dr. Susan Hummel
Beth Ibarra
George Ide
Ronald Jewell
Dr. Maria Lucia Jimenez
Michael Johnson
Richard Jorgenson
Nancy Kaster
Susan Kellett
Holly Kelley
Donna Kiley
Cynthia Killam
Mary King

Ellen Kirchheimer
Shawn Kirwin
Clair Klock
Deborah Koch
Mary Ann Kramer
Charles Kravetz
Lawrence Kreicher
Barbara Krisfalussy
Dr. Gerald Labriola
Tracie Lamb
Diane Lee
Donna LeGrow*
Robert Lemon II
Patricia Lenke
Patrick Leoni
Linda Lerner
Victoria Lerner
Barbara Levine
Lil Levy
Thomas Lewis
M. Louise Liberati
Kay Long
Eileen Lumb
Suzanne Luzzi*
Walter Lyon
Arlene Magdall
Katie Mahoney
Leslie Maitland
Kathleen Makenas
Maneesha & Vishal Ghiya Fund
Dr. Steven Maness
Dr. Alexander Mark
Kenneth Marks
Dr. Sue Maurer
Louis Mauro
Jeffrey McCarthy
Joseph McCarthy
Gordon McCoy
Cathleen McGarity
Jean McGovern
Hugh McLean
Barbara McMake
Wendi McNeilly
Cliva Mee
Dr. Daniel Merfeld
Chuck Michael
Deborah Miller*
Stephen Miller

Thank You!
Patricia Mineur
Dr. Robert Molinari
Connie Monroe
Suzzanna Montaño
Marsha Moore
Claudia Mottola
Deborah Munno
Christopher Murphy
Keith Nelson
Robert Nentwig
Denise Nichols
Susan Nichols
Joanna Nilsen
Mary O’Brien
Timothy O’Brien
Elaine O’Keefe
Mary Olsen
Paul Olson
Karen Opalka
Jolene Orr
William Ottman
Michael Pair
Molly Parrish
Kristy Partney
Margaret Paul
Susan Paul
Kathy Perigloisi-Miller
Lori Perkins
Barbara Pike
Germain Planchais
Tom Polley
Irwin Polls
Walter Pressey
Cindy Price
Maggie Qiu
Barbara Ranhand
Chava Reiss
Laura Renker
Lee Ann Riesen
Catherine Riley
Dennis Rinne
Gary Rogers
Rebecca Rosenberg
Jocelyn Ross
Terri Rothstein
Tom Roy
Sarah Rutherford
Theodore Santarsiero
Janet Saulsbury
Peter Scaperotta
Elaine Schlissel
Patricia Schultz
Paul Schwartz
Glenn Schweitzer
Paul Seegers
Laurence Sewell
Dr. Rona Shapiro
Loretta Siciliano
Marni Simon-Blake
Kimberly Smith
Steven Smith
Jeffery Smolinski
Lewis Snitzer
Steve Snyder
Linda Sorg
Jesse Sowell
James Sparkman
Dr. Gary L. Stanton
Tony Staser & David Moss
Brenda Steen
Donald Steffen
Janean Stellern
Elizabeth Stengel
Nami Stevens
Kathryn Stoddart
Lawrence Stone
Ruth Stone
Barbara Strongin
Allison Stuart
Myrna Sunberg
Dr. Maja Svrakic
Randolph Szabla
Julie Takeda
Dr. Hui Tang
Margaret Tetreault
The Pittsburgh Foundation, in honor of Dr. F. Owen Black
BreeAnn Thomas
Russell Thomasson
Lawrence J. Toole
Susan Trilling
Ronny Udelson
Paul Brandenburg
Leslie Vail
Renee Veloric
Shirley Verstegen
Silvia Vidal
Theodore Vora
Shirley Votaw
Christa Vragel
Susie Vybing

**MATCHING GIFTS**

AARP
Aon Foundation
Cambia Health Foundation
Merck Foundation
Microsoft
Portland General Electric Employee Engagement Fund
Prudential Foundation
The Capital Group Companies Charitable Foundation
Williams

*Indicates a donor who secured a matching gift.*

**BALANCE BENEFACORS**

Kathleen Deming
Norita Nelson
Kathleen M. O’Connell
Ottlie Schmid-Sanders
Marjorie Schnapp
Robert Ulmer

**CORPORATE MEMBER**

Lifemark

**CORPORATE PARTNER**

Otonomy

**BALANCE AWARENESS WEEK SPONSORS**

balanceback
Micromedical Technologies, Inc.
Otometrics/Audiology Systems
Balance Chicago
Natus Balance & Mobility
POA Pharma North America

**CORPORATE SPONSOR**

Fitterfirst
The Vestibular Project

**IN-KIND DONORS**

KEEN Footwear

PLEASE VISIT VESTIBULAR.ORG/ANNUAL-REPORT FOR A COMPLETE LIST OF MEMBERS & DONORS.
The Heart of an Ambassador

By Cynthia Ryan, Executive Director

David Morrill is the chair of VEDA’s Ambassador Board, and an amazing individual. I am constantly in awe of David’s kindness, patience, persistence, enthusiasm and dedication to many causes.

I was reminded of David’s doggedness after a recent incident where David slipped on the ice and fell. Rushed to the emergency room, David’s first thought was to ask his wife to call VEDA so we knew he wouldn’t be able to make it to a committee meeting the next day. He is always thinking of others above himself.

I was introduced to David by Dr. David Newman-Toker, a neurologist with Johns Hopkins University, who David had contacted because of his research. Dr. Newman-Toker studies diagnostic error in the emergency room, specifically vestibular disorders and stroke. David suffers from permanent vestibular damage due to a missed stroke, an event that changed his life forever.

In August 2013, David experienced a sudden onset of vertigo. He got up from the dinner table and felt like the room was spinning. He was nauseated and had trouble walking, so his family took him to the emergency room.

David was diagnosed with “vertigo” (not a diagnosis at all, but a symptom). The ER doctor prescribed Meclizine, sent him home and told him his condition should improve within a few days. But instead, it got worse, so he went back to the emergency room about 48 hours later by ambulance. The ER doctors ordered an MRI, which revealed a large blood clot on his brain stem. More than two days after his symptoms began David was diagnosed with a stroke.

At the time, David was working as a Food Service Specialist. When, after six weeks, David was still not well enough to return to work, he lost his job and his medical insurance. David also volunteered as an emergency medical technician (EMT). The fire department he volunteered for did a fundraiser to help David and his family.

At first David was angry and frustrated; he didn’t know where to put his energy. Then he found purpose in volunteering.

“David puts his heart into everything he does,” says Cheryl, his wife of 36 ½ years.

Cheryl is a Disney fan. Just before his stroke David was going to take her to Disney World for her
birthday, but the trip was canceled because David couldn’t travel. Three years later, David brought Cheryl and their whole family to the magical world of make believe. David still struggles with his balance, so he had to use a wheelchair during the visit, but insisted on taking a picture of himself standing to motivate others to do something they didn’t think they would be able to do.

David was the founding member of VEDA’s Ambassador Board, which would never have taken off without his leadership. He participates in VEDA’s Patient Education and Support Group Committees, leads a vestibular support group in Maine, and has recently started leading an online support group. He is also the facilitator of a Facebook group that lends support to vestibular patients all over the world.

David was one of the key members of the “Dream Team,” a group of patients who are petitioning the World Health Organization for increased awareness around vestibular disorders. He is also a volunteer for the American Heart Association, and was recently recognized at one of their galas. David and his family have hosted information tables at several health fairs, most recently an event called, “What Women Want,” where he had a booth to promote specific ways women can advocate for their own healthcare.

I would like to thank David for being such a caring and compassionate person, always willing to lend a hand, selfless and hard-working, in a word, amazing! David, you are an inspiration to us all.

Your friend,
Cynthia
In an instant your life changed. Dizziness, vertigo, imbalance, fatigue, anxiety – these became your “new normal.” You began a quest to find out what was going on with your body. Eventually, you found the right doctor who told you that you have a vestibular disorder. Next comes a host of lifestyle changes. Little things become a huge effort, and you wonder if you’ll ever get your “old” life back.

Three years ago Katie Mahoney conceived the idea of the Dizzy Dash. Katie had lost much of her life to vestibular neuritis. She never gave up, and began walking her dog to get moving again. Every day she pushed herself to go a little further, until eventually she was able to walk five kilometers.

FIND OUT MORE ABOUT THE DIZZY DASH AND REGISTER AT VESTIBULAR.ORG/DIZZYDASH.

We invite you to set a goal – big or small – to accomplish something you didn’t think you could do. Share your goal on a personal campaign page, and participate in the Dizzy Dash Facebook group to let us know how you are progressing. Together we can build a community that will support you in reaching your goal.

SET A GOAL
SHARE YOUR STORY
TAKE BACK YOUR LIFE

All funds raised through the Dizzy Dash will support the growth of VEDA’s new online support group teleconferences.

GET YOUR LIMITED EDITION DIZZY DASH T-SHIRT!

Sport your official Dizzy Dash t-shirt or sweatshirt to raise awareness about vestibular disorders. Visit teespring.com/dizzy-dash-2017 today! Order soon to receive your t-shirt by May 20th.

Join with other vestibular patients who are DOING something to ACHIEVE a personal goal while SUPPORTING each other and HELPING to raise awareness about vestibular disorders (D.A.S.H.).
YES! I WANT TO HELP PEOPLE SUFFERING FROM VESTIBULAR DISORDERS.

VEDA is entirely supported by donations and membership gifts. Your donation helps VEDA provide information on vestibular disorders to millions of people every year. Thank you!
You can make a gift to support VEDA’s life-changing work online at vestibular.org/otl or send your payment to 5018 NE 15th Ave, Portland, OR 97211 with the enclosed self-addressed envelope.

Donation:
☐ $250  ☐ $200  ☐ $150  ☐ $100  ☐ $50  ☐ $25
☐ Other $________
☐ I would like to join the Sustaining Program and contribute this amount every month
☐ Please make my donation anonymous

Method of Payment:
☐ Check (payable to VEDA in US Dollars)
☐ Visa  ☐ MasterCard  ☐ American Express

Options:
☐ Please send me information about including VEDA in my Will or Estate Planning.
☐ My company will match my donation.
  Company Name: ____________________________

NAME _______________________________________________________
BILLING ADDRESS _____________________________________________
CITY, STATE, ZIP _____________________________________________
E-MAIL ____________________________
PHONE ____________________________
CREDIT CARD # ____________________________  CSV CODE __________
EXP. DATE ________________________

Thank you for supporting the Vestibular Disorders Association! With your help we can reduce the time it takes to accurately diagnose vestibular disorders and improve treatment outcomes, helping patients live happy, productive lives.

Sponsors & Corporate Partner

Micromedical
T E C H N O L O G I E S I N C.

Balance Chicago

Balance & Mobility

Sensorion

OTONOMY

Targeted Medicines for the Ear

natus

VEDA WOULD LIKE TO THANK OUR BALANCE AWARENESS WEEK SPONSORS AND CORPORATE PARTNER FOR THEIR GENEROUS SUPPORT. FOR INFORMATION ABOUT BECOMING A SPONSOR, CONTACT VEDA AT (503) 294.9085 OR EMAIL VEDA@VESTIBULAR.ORG.
My Dizzy Dash Goal  
*By Barbara Roggenbeck*

My goal for the 3rd annual Dizzy Dash is to hike 5K on a trail around Bozeman, Montana with my friends and family. Montana is a mecca of wildlife and outdoor sports that I want to explore despite my constant battle with dizziness. It is important to me to overcome my fear of outdoor activities and start enjoying nature with my loved ones.

Before my dizziness started I was fearless, athletic, and always ready for an adventure. I still dream of the days before the dizziness started when I could do things like travel to New Zealand with my husband and enjoy an eight hour hike to Franz Josef glacier without a care in the world.

In 2011, one month after having my first baby, the dizziness started and it never stopped. I feared daylight with all the disturbing visual distortions and the constant drunken stupor that did not cease until I closed my eyes. I feared my own baby waking in the night because rocking him to sleep was torture. I feared leaving my house.

I was diagnosed with vestibular migraines after six months of questioning my sanity along with countless doctor appointments. The proper medication and avoidance of triggers helps me control my symptoms and I function like my old self most days. I made it through the remainder of a PhD program while raising my son. Four years later I was even able to defend my thesis five months pregnant with my second little guy. However, I still have bad days and I still live in fear of trying new things that could trigger symptoms because of this disease.

I want to participate in the Dizzy Dash with my fellow VEDA members to begin fighting my fear of trying new activities. Regardless of the caliber of motion you choose, whether it be to walk from the couch to the sink or the front door to the driveway, or to run a triathlon, let’s help each other achieve our goals.

**WHAT’S YOUR GOAL?**
Support Barbara at vestibular.org/barbaraDD