



**ON THE LEVEL  
NEWSLETTER**

## **PICTURE PERFECT SOLDIER**

**DIVING WAS EVERYTHING TO ADAM,  
UNTIL AN INJURY TO HIS INNER EAR  
TURNED HIS LIFE UPSIDE DOWN.**

**YOUR  
ANNUAL REPORT  
ENCLOSED**

**SPRING 2018**

**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: Louise Geib, M. Ed - Atlantic Beach, FL  
 Vice President: Holly Fisher, Ed.D. - Coppell, TX  
 Treasurer: Rose Dunn, MBA, CPA - Maryland Heights, MO  
 Secretary: Kathleen Stross, DPT - Pearland, TX  
 Gary Breitbord - Holliston, MA  
 Dennis Fitzgerald, MD - Philadelphia, PA  
 Matthew Crowson, MD - Durham, NC  
 Rebecca Rubin - Sherman Oaks, CA  
 Kamran Barin, PhD - Columbus, OH  
 Esteban Medina Orgaz - Vigo, Spain  
 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 Helminski, 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?

6

MAL DE DEBARQUEMENT RESEARCH STUDY  
 IRA REQUIRED MINIMUM DISTRIBUTION

7

STEPS-2-BALANCE

8

AMBASSADOR SPOTLIGHT

10

2017 ANNUAL REPORT  
 FINANCIAL REPORT & OUTREACH

12

2017 MILESTONES

14

THANKS TO OUR 2017 DONORS

18

CASE STUDY

## Picture Perfect Soldier

By Cynthia Ryan, Executive Director

By the age of thirty, Adam Fishman made the rank of Sergeant 1st Class. He had a flawless military career and was the picture perfect Soldier.

In November of 2015, Adam was on a scuba diving vacation on the Caribbean Island of Bonaire with friends. Adam is an expert diver, so he took the lead. On their first dive they went approximately eighteen feet down. While equalizing pressure to his ears underwater, he felt a pinch of pain and heard a rumbling sound in his left ear. When Adam surfaced from his dive, his left ear was clogged. He tried to get the fluid out from his left ear, but while the right ear cleared the left ear didn't.

Adam was focused on making sure his friends were alright, so he didn't worry about his symptoms until thirty minutes after surfacing, when he felt pain between his head and neck, as well as behind his left eye, that kept growing. He went to a dive doctor, who saw trauma on his eardrum from middle ear barotrauma, but said it was intact and that he could keep diving. He did, but he continued to feel miserable.

Nine months later Adam's ear was still "acting weird." However, it didn't cause any major problems, except when he bent over during yoga class.

Adam is a Broadcast Journalist and Public Affairs Specialist for the U.S Department

of Defense. In September, 2016, Adam went on a dive with an elite military team. He performed two dives that day and felt all right at first, but when he got back in the boat he began to feel pain in his ear. He knew that the dive had exacerbated his original injury.

On the flight home Adam felt a stabbing pain in his ear; it was frightening. New



ABOVE: ADAM INTERVIEWING A FELLOW SOLDIER

symptoms included nausea, motion sickness and blurry vision.

Adam went to his military primary care physician, who acknowledged trauma on the eardrum, but said that his symptoms were beyond his scope of expertise. Adam was referred to several military specialists, but all reported him "functional."

Three months later, Adam had his first ever panic attack. He'd been traveling and started getting debilitating migraines. His doctors





associated his symptoms with anxiety and prescribed more exercise - precisely the wrong thing for the real cause of Adam's condition.

Eventually, Adam saw Dr. Michael Hoa, a neurotologist at Georgetown University, who gave Adam a note that qualified him for a three-month rest "profile" (military-speak for assessing a soldier's functional capacity). Miraculously, Adam's migraines went away, proving that rest was needed for



**ABOVE:** ADAM ON THAT FATEFUL DAY THAT ENDED HIS DIVING CAREER

his recovery.

However, Adam's doctors continued to order more exercise, so Adam began to play hockey with a local men's team. He enjoyed the adrenaline rush and camaraderie, which gave him the sense that he was feeling better. Then, tragedy struck. Another player's elbow connected with Adam's jaw, dislocating it, and thrusting the jawbone into his middle ear. A gush of warm fluid came

out of his right ear - his remaining good ear now also impacted.

Since then, Adam's symptoms have worsened, with vertigo, tinnitus, brain fog, and horrible migraines becoming virtually constant.

Still without a clear diagnosis, Adam was looking for some validation, someone to believe him. A military medic and civilian physician's assistant suggested that he might have a perilymph fistula (PLF) - a tear in the thin membrane that separates the air-filled middle ear with the fluid filled inner ear. Unfortunately, PLFs can be so small they are undetectable with common tests. The only way to confirm this diagnosis was to operate.

A stroke of luck sent Adam to audiologist, Dr. John ("Jack") King, at the National Intrepid Center of Excellence. Dr. King confirmed that there was something very wrong with Adam's vestibular system. He introduced him to Dr. Peter Weber, a neurotologist at Boston Medical Center, who told Adam, "I can help you."

"I was desperate, suffering, and had lost all hope," said Adam. "Those four words breathed new life back into me."

Adam had PLF surgery on his right ear August 4th, 2017. "Later, Dr. Weber told me it was a mess in there," says Adam. "He confirmed there was indeed an injury, and felt the operation was necessary."

Unfortunately, through no fault of Dr. Weber,

his PLF patch failed a few days after surgery. With time and rest, it eventually began to re-adhere. It took three months before Adam was able to do anything.

Adam knew that he needed to be able to get back to work; he needed to perform up to military standards.

Always a hard worker, Adam put a lot of pressure on himself. Eventually, the stress got to him and his muscles began to spasm, so he went in for a massage. Somehow, during the massage his patch ruptured again, and fluid began leaking from his ear.

Since then, Adam has been recuperating slowly. He has good days and bad days, and when the barometric pressure system changes he's thoroughly miserable.

Adam is getting used to living with uncertainty. He knows there are no guarantees, and he's committed to keeping a positive perspective.

He feels that this experience has made him a better person. "Now I can empathize with others who are going through something difficult that no one else can see," he says. "These injuries have humbled me."

It's also brought him closer to his girlfriend. "She's stuck by me, even when I thought my life as I knew it was over."

Whether or not a new patch will hold is up in the air. On the days he feels better he thinks about not going through with the surgery, but another part of him wants to risk it in the hope that he can regain some

**"YOU HAVE TO TELL YOURSELF, I WILL FEEL BETTER AGAIN."**

**- ADAM FISCHMAN**

semblance of his former self.

Navigating the medical system is a challenge for many vestibular patients, but even more so for Adam, who is constrained by military protocol and regulations. Pulled in different directions by his military primary care doctor and his civilian vestibular specialist, Adam has had to engage two

military patient advocates to help him figure out how to get the care he needs.

"It's scary when you're relying on people in the medical field who don't know what's going on," says Adam.

In the meantime, Adam tries to hold onto the good days. "I savor every single moment," he says. "Rather than trying to fight it, I try to embrace it. Having a life outside of being a vestibular patient helps." One of Adam's favorite quotes is, "We cannot direct the wind, but we can adjust the sails." Adam is adjusting his sail, and continuing on his journey toward a life rebalanced.



## Mal de Debarquement Research Survey

By Cherylea Browne, PhD, BMDSC

Mal de Debarquement Syndrome (MdDS) is a neurological condition characterized by an abnormal sensation of motion. The most common subtype of MdDS is motion-triggered, which typically occurs after disembarking from a vehicle (e.g. cruise, car, train, etc.). However, it has been acknowledged that some patients develop MdDS spontaneously, or after certain experiences (e.g. surgery, childbirth, intense stress, etc.). This subtype is named spontaneous or other onset.

Experts from Europe, Australia and the United States teamed up and created comprehensive questionnaires for MdDS patients. These questionnaires focused on various aspects of the condition and aimed to identify similarities and differences between the two subtypes. Through this international collaboration, they were able to obtain a large sample size (given the rare nature of MdDS), with 370 respondents.

In the first manuscript that has arisen from this data set, subtypes, diagnostic procedures/experiences, onset and psychological features are discussed. The results show that currently both MdDS subtypes are still poorly recognized and that those with the spontaneous/other onset subtype are more often misdiagnosed than the motion-triggered subtype. Thus, this manuscript proposes new comprehensive diagnostic guidelines regarding both subtypes, particularly for neurologists and other vestibular specialists. In addition, the results indicate that stress, anxiety and depression should be closely considered when treating MdDS patients.

#### REFERENCE:

V. MUCCI, J. M. CANCERI, R. BROWN, M. DAI, S. YAKUSHIN, S. WATSON, A. VAN OMBERGEN, V. TOPSAKAL, P. H. VAN DE HEYNING, F. L. WUYTS, C. J. BROWNE ([HTTPS://LINK.SPRINGER.COM/ARTICLE/10.1007%2FS00415-017-8725-3](https://link.springer.com/article/10.1007%2FS00415-017-8725-3))

## Retirement That Supports Your Values

Did you know that once you reach your 70th half-birthday you are required to start taking an annual distribution from your IRA (retirement account)? These distributions are counted as income, which can affect your taxes.

You can lower your taxable income by donating your IRA RMD (required minimum distribution) to a registered charity like VeDA.

Contact your tax consultant to find out if this type of gift is right for you.

Questions? Call VeDA at (800) 837-8428 or email [veda@vestibular.org](mailto:veda@vestibular.org).

# TAKE A STEP-2-BALANCE

FOR MANY, LIVING WITH A VESTIBULAR CONDITION IS A DAILY OBSTACLE COURSE.

Each day we rise to the challenge of adapting our lifestyle to regain greater control and balance in our lives. There are good days and bad days on this journey no one expected to take. But every step forward in mastering this new normal, is a step in the right direction. What may have initially felt insurmountable eventually becomes routine. Mountains turn into molehills. We discover new ways of moving, eating sleeping, and dealing with stress that make every day a little better than the one before. We learn how to recalibrate our bodies (and minds) to keep forging on. And like all journeys, we will hit road bumps along the way as new challenges present themselves. Sometimes it feels like for every two steps forward there's a step backward. While frustrating, these momentary regressions are simply new obstacles to overcome. New lines in the sand to eventually leap over. As we've done before, we push ourselves to take one more step forward—walking, running, dancing, climbing, or stretching a little further. Because what matters isn't how far we go, it's that we keep crossing new milestones on the path toward a life rebalanced.

Steps-2-Balance is VeDA's annual call to all those living with a vestibular condition,

### How Does It Work?

- Identify a personal balance-related goal or challenge
- Self-organize an activity between May 12-20, 2018
- Register your personal activity at [vestibular.org/S2B](http://vestibular.org/S2B)
- Set a personal fundraising goal
- Invite others to join in your activity and to support VeDA
- Document and share your Steps-2-Balance experience via email and/or social media



**STEPS-2-BALANCE**  
MAY 12-20, 2018

to challenge themselves in taking a step forward on their journey back to balance. From May 12-20, 2018, VeDA is asking vestibular patients across the country to set a personal balance-related goal and to self-organize an activity to achieve it. While many vestibular patients are restricted in their everyday mobility, we also know that many forms of exercise or movement can help patients improve their balance. So regardless of where a patient is on their personal road to recovery, we hope anyone can find an opportunity to take a "step" forward and participate in Steps-2-Balance.





## Every Step Is A Step-2-Balance

By Amanda Rodriguez

I was running about 200 miles a month before it happened. I was the type to clean my baseboards regularly. I was a project person. I was a freelance journalist, constantly interviewing people, constantly working on deadline.

And then on an afternoon in 2014, I felt dizzy. I was lightheaded and foggy. It went away for a few days and then came back. Then, one day, it stayed.

I tried to shake it off at first. I tried to work



ABOVE: AMANDA'S FAITHFUL COMPANION KEEPS HER ACTIVE.

through it, but eventually, I had to see a doctor. And then another doctor. In total, I visited some seven doctors and specialists. There were many diagnoses. Inner ear infection. Anxiety. Stress. Dehydration. I had a range of tests. An EKG said my heart was fine. An MRI said my brain was clear. Blood tests were all normal.

On my worst days, I slept all day long. When I had to get up, I dragged my fingertips across the wall to steady me. The dizziness was constant. The room rocked around me, slowly

teetering and rolling. I couldn't bend down without making the dizziness worse. Cleaning was impossible because I had to look down. Showering was hard because I had to look up. Working was impossible because I couldn't focus.

Finally, an inner ear specialist said the dizziness could be linked to my migraines— something I had dealt with since middle school. I was sent for eight weeks of vestibular rehabilitation and then another specialist prescribed 12 more weeks. I spent weeks shaking my head back and forth and focusing on a playing card, trying to train my brain to accept dizziness and movement. The rehab offered little help.

I underwent videonystagmogram (VNG) testing, a terrible (but telling) test where hot and cold air is shot into your ears to provoke vertigo. They suspected a vestibular problem. I had never heard the word “vestibular” before. I didn't know there was such a disorder.

I found a doctor at The University of Texas Southwestern Medical School in Dallas who specialized in vestibular disorders. I was placed on a four-month waiting list. In October of 2015, just two weeks after I was wait-listed, his office called me and said they

could see me the next day. It was an answered prayer.

After a two-hour exam with the specialist, he confirmed my diagnosis. I had vestibular migraine.

We tried a few medications, and then finally the winner. It had been a nearly two-year journey.

After the diagnosis, I found VeDA. Their website spelled out exactly how I felt. The tools they provided and resources and information

renewed hope in me. I wasn't the only one struggling with what seemed like an unheard of disorder.

My husband and I poured over the information together. He had been supportive every step of the way. He took over responsibilities of cooking and cleaning. He took the dogs to daycare so I wouldn't have to worry about them all day. He left me encouraging notes. He told me not to give up when the dizziness was so bad I cried. He kept me steady.

He wasn't the only one in my tribe. A group of my friends once picked me up after I had stopped driving and took me out of the house. One friend picked me up after a doctor's appointment. Another friend agreed to drive me home after the VNG testing, when my vertigo was provoked and I was sure I would throw up in her car. I've had friends pray for me and encourage me and walk this journey with me.

Some days, it's still hard. I get a little dizzy on long days. I have to be careful of certain triggers: crazy weather, flashing lights, not getting enough sleep.

But I'm working again, writing again. I was hired to be an assistant track coach at the middle school and high school level. I'm constantly on my feet, chasing students around a track— something I never thought I could do.

And best of all, I'm running again. In December 2017, I ran the BMW Dallas Half Marathon. It was my second half marathon (the first I ran early in my dizziness and I slogged through with a foggy head). But

this half marathon in Dallas was a comeback race for me. Where I had been overcome with dizziness in that first half marathon at mile 7, at mile 7 in Dallas, I felt exhilarated. I picked up my pace. I finished strong.

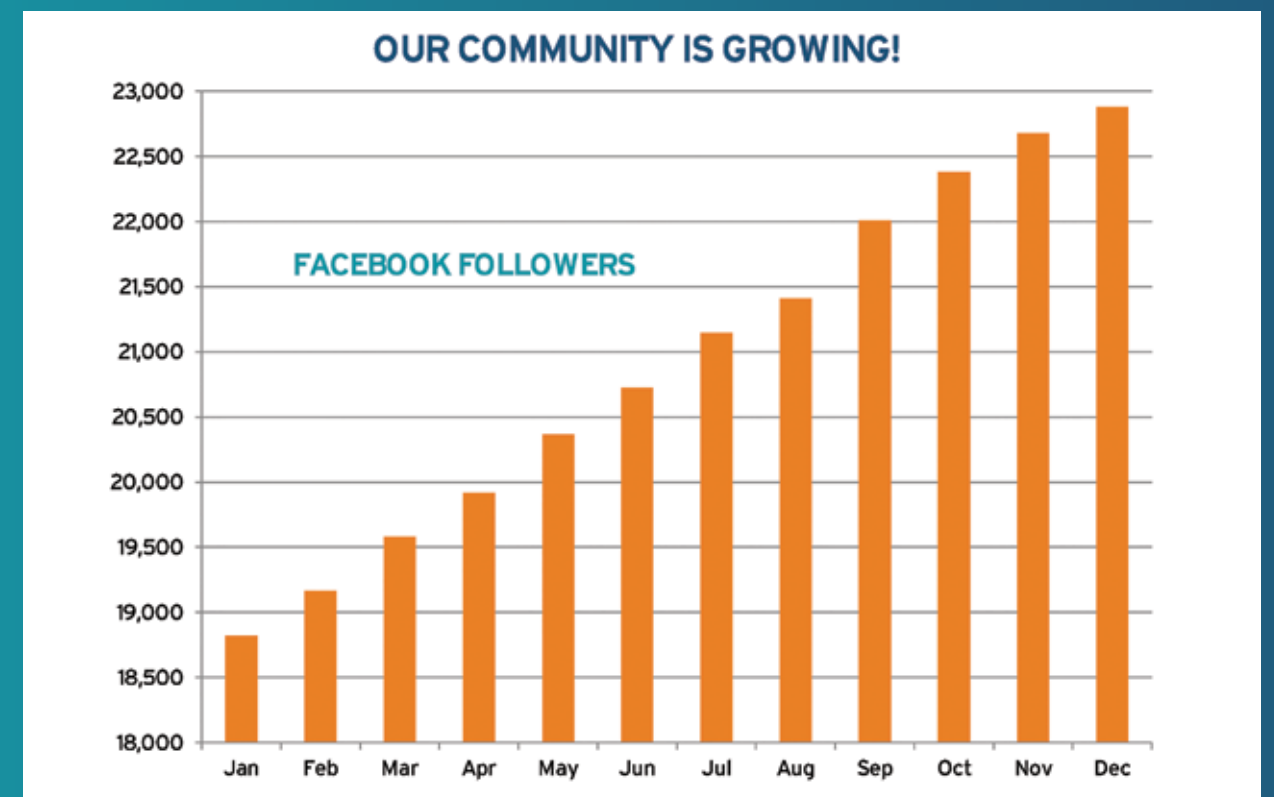
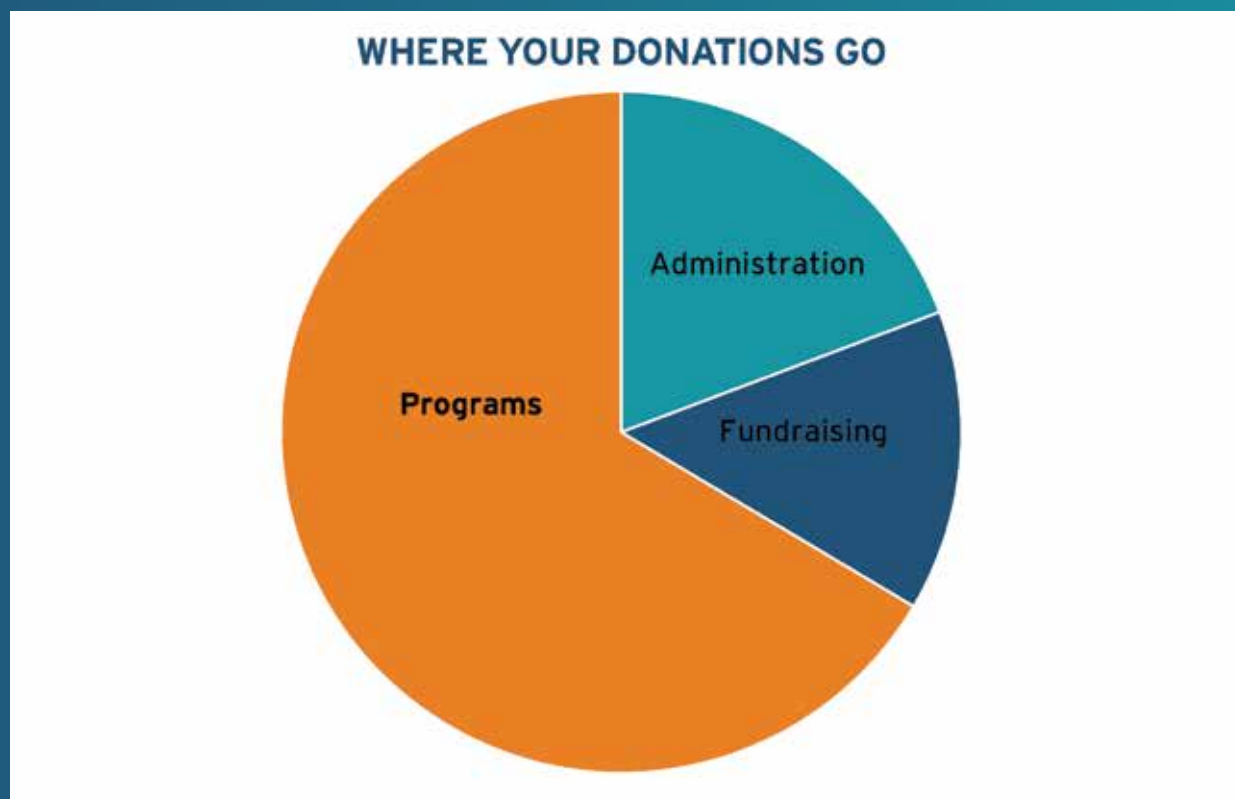
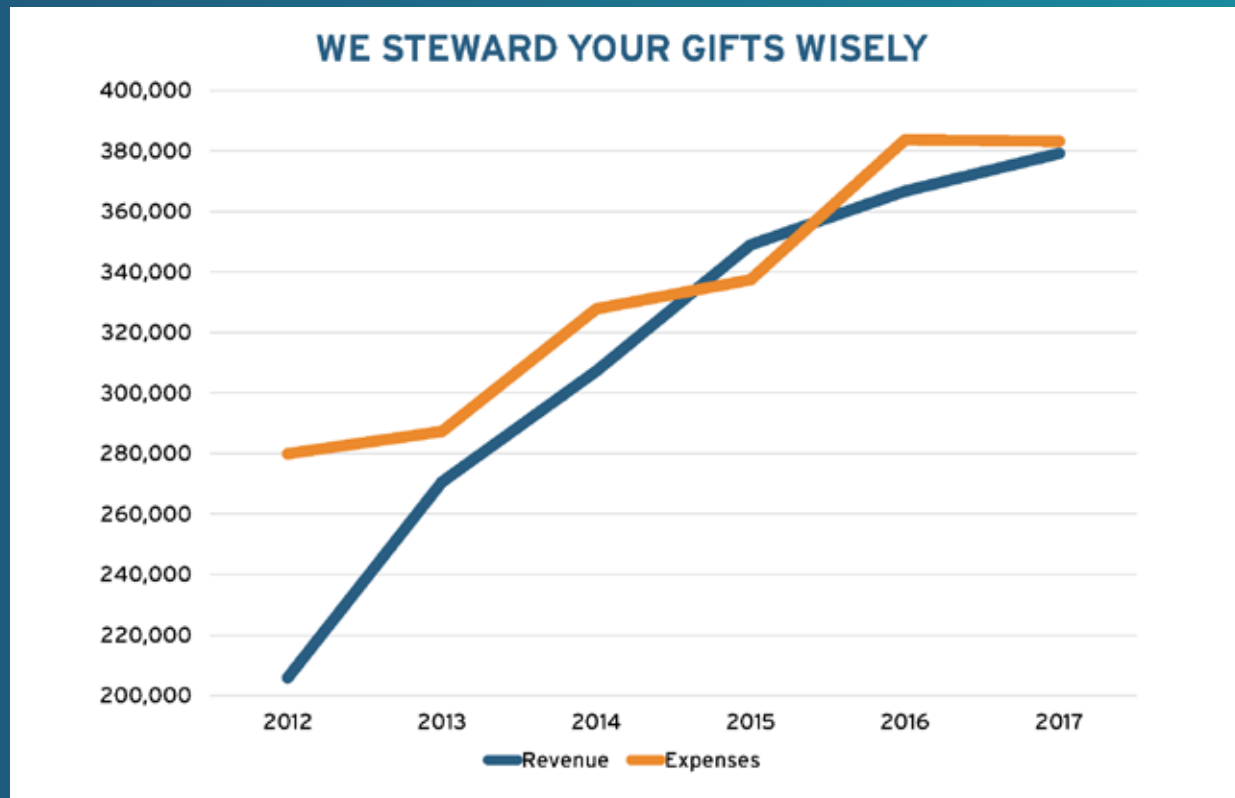
That's why for my Step-2-Balance goal, I'm planning on running a 10K (6.2 miles) in less than 59 minutes. That's a 9:29 pace, a pace I haven't run since before I became dizzy. I've been too afraid to push the pace for too long of a distance, but I'm ready to push my

own boundaries again. And ready to cross that finish line.

“ON MY WORST DAYS, I SLEPT ALL DAY LONG. WHEN I HAD TO GET UP, I DRAGGED MY FINGERTIPS ACROSS THE WALL TO STEADY ME.”



# 2017 Annual Report



# 2017 MILESTONES

YOUR GIFTS HELPED US ACCOMPLISH ALL THIS AND MORE!

Upgraded website & V-News to be mobile-friendly



Created legislative advocacy plan and toolkit



New logo design

Launched online support groups



Introduced disability infographic & webinar



50% increase in Dizzy Dash participation



# VEDA



# THANKS TO OUR DONORS

THE GENEROSITY OF **YOU**, OUR DONORS, IS ONE OF VEDA'S GREATEST BLESSINGS. YOUR SUPPORT GIVES US THE RESOURCES WE NEED TO HELP VESTIBULAR PATIENTS DISCOVER LIFE REBALANCED. **YOUR COMPASSION TRANSFORMS LIVES!**

## VISIONARIES \$10,000+

Susan Papa

## GUARDIANS \$5,000 - \$9,999

Anonymous

Dalum Family Foundation

Amy Downing

## PATRONS \$1,000 - \$4,999

Anne E. Leibowitz Fund

Anonymous

**Dr. Deanne Bonnar**

Barbara Cantacuzino

Joyce Chadderdon

Elizabeth Commerford

Christina and Scott Duncan\*

Louise Geib

Patricia Gerend

Jennifer Gittins-Harfst

The Headley Charitable Fund

**Dr. Janet Helminski**

Merilee Holst

Ellis Kern

The Klapper-Hickey Family Fund

Lester Knight

**Kurz Family Foundation**

Laura R. Stanford Fund

Dale Leibowitz

Lew Leibowitz

Louis Leibowitz Charitable Trust

The Margaret and Charles Paul Fund

John Miller

**The Phyllis and Perry Schwartz Foundation**

Robert and Sharon Reyes Foundation

**Dr. Grayson Rodgers**

Anne Rorimer

**Dr. P. Ashley Wackym**

## FRIENDS \$500 - \$999

Andrew Altersohn

Anonymous (4)

**Dr. Fred Arrigg Jr.**

Caren M. Backus

Gary Breitbord

Kimberly Carson

Jill Cowley

Norman Discher

Rose T. Dunn

**Dr. Susan Fee**

Stephen Fisher

Jeffrey Fuchs

Gail Gallagher

Gary and Beverly Henry Family Foundation

Manish Gaudi

**Janit Greenwood**

Claire and Raymond Haddad\*

Jerry Haslam

Margaret Higgins

Veronica Howard

Nancy Kimball

**Dr. Jeffrey Kramer**

Susan Krawietz

Etrily Laitphlang

Thomas Lewis

Julie Marshall

Iris Osman

**Dr. Steven D. Rauch**

Luis Rey

**Dr. Donald Risucci**

Salinger Family Fund

Edwin L. Siegel

Tom Smith

Colleen Sorensen

Mina Stachowiak

Timur and Janice Tecimer

Elizabeth Trame

Gerda Wassermann

**Dr. Jack Wazen**

William T. Rice and Janice E. Woodruff Charitable Fund

## ADVOCATES \$250 - \$499

AmazonSmile Foundation

Anonymous (7)

**Dr. Kamran Barin**

Jamie Beard

Gina Boonshoft

Larry Bowman

Lora and Neal Buck\*

**David Calabrese**

Juta Carpenter

Nina Cohen

**Dr. Gaye Cronin**

Tom D'Agostino

Sanjay Dave

Dori Ann Davis

Tama Deitch

Sherrie Derr

Matthew J. Donachie

Karla Droste

Emanuel Fund/Nina Cohen

Rev. Sue Fisher Seeger

Holly B. Fisher

**Dr. Dennis Fitzgerald**

Marsha Frazier

Johanne Gibson

Kendra Gilkes

Clare Glassell

Barry Goldman

Scott Harper

Dori Ann Davis

Molly-Jane Rubinger

Amy Jaffe

Dr. Gary Kaihara

Randy Kaufman

Allan Keene

Mary King

Gerilyn Kusnierek

Victoria LeFevre

Arlene Magdall

Katie Mahoney

Christine McHugh

**Dr. Esteban Medina Orgaz**

Dr. Daniel Merfeld

Dr. Donna Montgomery

Deborah Munno

Doug Nielsen

Karen Opalka

Donna Plunket

Rubinstein/Hall Family Fund

Cynthia Ryan

Amy Shuler

Dean Smith

Kimberly Smith

Rev. Andrew Stanko

Amol Tembe

Margaret Tetreault

Prof. Meenakshisundaram Umaiorubahan

Lawrence Williamson

Sheelah Woodhouse

WWS Physical Therapy, Inc

Marie Yang

## ASSOCIATES \$100 - 249

Robert Ammann

Anonymous (34)

Karen Arenson

**Dr. Coral Armstrong**

Scott Audette

Judy Axthelm

Sue Baker

Janice Barnes

Jean Barrell

Pat Barry

Samantha Bartling

Tom Basista

Anna Bell

Kevin Belli\*

B. Richard Benioff

**Brenda Berger**

Louise Bergstresser

Stuart Berman

Sheila Bernard

Donald Bestwick

Lara Bishop

Kristi Blake

Robert Bledsoe

Sylvia Bordzuk

Liza Botkin

Julia Ann Bourne

Carol Brand

Patricia Breglio

William Brewer

Jennifer Briscoe

Dale Brockman

Nancy Bronson

Stacey & Jason Buckner\*

Charles E. Burgess III

Francine Burnham

**Paul Burnside**

Alan Butchman

Carol Callaghan

Mary-Catherine Calvert

Toni Campoamor

Silvia Canessa

Carol Cannon

Richard Capobianchi

**Robert Carroll**

Dr. Virginia Casper

Victor Castellanos

Tim Centola

Nancy Chadderdon

Philip Cherry

**Jeff Choun**

Christina Christensen

Patricia Cohen

**Nancy Comstock**

Kathleen Cooke

Marion Coughlin

Bernd Crasemann

Debbie Craven

**Betty Cress**

Brenda Crews

Beverly Crisp

Dr. Matthew Crowson

Diana Cruz

Everett Curry

Jacqueline Cursi

Robert Curtis

Elisabeth D'Alessio

Elizabeth David

Davis Research in honor of Cynthia Ryan

Linda L. Davis-O'Leary

Michele Degan

James DeMaio

Susan Dennison

Dr. Vincent Desiderio Jr.

Paul Diamond

Richard Dougall

**Theresa Dunagan**

Andrew Edmonds Jr.

Ellen Korpi Charitable Gift Fund

Shernaz Engineer

Heloise R. Erdman

Carrie Farmer

Ethel H. Feltham

Barbara Ferring

Tova Fink

Maxyne Finkelstein

Jo Fisher

Lucille Fisher

Gerald Fitzgerald

Dr. Margaret Fitzpatrick

Norma J. Flynn

Pat Fortunato

Judith Foster

Mark Gallagher

Margaret Garman

Deborah Garrett

Bernard Gerbarg

Phyllis Gervais-Voss

Heather Gilbert

James Gill Jr.

Dr. Kathleen Gill-Body

Linda Gindt



Carolyn Glasier  
Helen Glunz  
Wendy Godfrey  
Ruth Goehring  
Melissa Gorden  
Rajat & Marguerite Goswami  
Doris Graf  
Mary Graves  
Jeffrey Gray  
Barbara Grimes  
Catherine Grochowski  
Barbara Guadagno  
Alice Hampton  
Walter Hargraves Jr.  
Alison Harrell  
Donna Hartwig  
Joyce Havens  
Dr. Rick Heald  
Catherine J. Hellner  
Pam Hengst  
James Henwood  
**Cynthia Hernandez**  
**Don Hickey**  
Ross Hoddesson  
Fred Hoffman  
Lynn E. Holden  
Cynthia Hookstra  
Vicki Hotte  
Barbara D. Houlton  
Nancy Howe  
**Douglas Huffman**  
Hugo Family Charitable Fund  
Kip Hunter  
**Debra Hutton**  
George Ide  
Andreas Ioannou  
Dr. Gary P. Jacobson  
Ed Jankowski  
Janine Jewell  
Jian Jin

**Barbara Ann Johnson**  
William Johnston  
Lloyd A. Jordan  
Richard Jorgenson  
Rick Kahley  
Maureen Kavanaugh  
Susan Kellett  
Elizabeth Keul  
Christopher L. Keyes  
Beatrice Kidwell  
**Cynthia Killam**  
Kimberly Clouse VIA Global Gives  
Ellen Kirchheimer  
Barbara Kirkaldy  
Kathryn Kittredge  
Kristin Knapp  
Deborah Koch  
Harold F. Kongabel  
Jean Korf  
Mary Ann Kramer  
Lawrence Kreicher  
Barbara Krisfalusy  
Carol Krueger  
Tracie Lamb  
Sherron Laurrell  
*Donna LeGrow\**  
**Dr. Joel Lehrer**  
Robert Lemon II  
Patricia Lenke  
Patrick Leoni  
Lil Levy  
Jill D. Lewis  
M. Louise Liberati  
Edith Lord-Wolff  
**Mayte Lozano-Chapa**  
**Eileen Lumb**  
**Tamara Lynch**  
Leslie Maitland  
Kathleen Makenas  
Kristina Malloy  
Kenneth Marks

Dr. Sue Maurer  
Louis Mauro  
Lawrence Mayer  
Nicole McBurnett  
Joseph McCarthy  
Cathleen McGarity  
**Jean McGovern**  
Mary McIntyre  
Brian McMahon  
Barbara McMaken  
Wendi McNeilly  
**Cliva Mee**  
Elizabeth Merck  
Deborah Miller\*  
Stephen Miller  
Dr. Robert Molinari  
Lauren Monks  
Connie Monroe  
Suzanna Montaña  
Allen Montecino Jr.  
Jack Moody  
Mordecai Rosenfeld  
Phyllis Moriarity  
Nancy Mullins  
Dr. Robert Murray  
James Nelson  
Keith Nelson  
Laura Nelson  
Sandra Newton  
Denise Nichols  
Jimmy Nickell  
Joan Noguera  
Jeff Nowak  
**Stephen Nowell**  
Lisa Nutt  
**Kathryn O'Connell**  
Elaine O'Keefe  
Mary Olsen  
Paul Olson  
**David Oppenheim**  
Jolene Orr

William Ottman  
**Michael Pair**  
Isabella Park  
Kendall Park  
Richard Park  
Kristy Partney  
Susan Paul  
Mary Pawlak  
Anthony Peacock  
Susan Penn  
Kathy Perigloisi-Miller  
Lori Perkins  
Barbara Pike  
Germain Planchais  
Dr. Christopher Platt  
POA Pharma North America  
Tom Polley  
Rev. Margaret Pounders  
Von Praska  
Walt Pressey  
Cindy Price\*  
James R. Probst  
R. Gump Builders  
Helene Raab  
Rocio Ramirez Muniz  
Krishna Ramsundar  
Bill Remmich  
Laura Renker  
Laura Renz  
**Deborah Richardson**  
Pam Rideout  
Catherine Riley  
**Sandra Roberts**  
Victoria Roggenbeck  
Savannah and Carlos Romero  
Jocelyn Ross  
**Linda J Roth**  
Terri Rothstein  
Carol S. Rowland  
Lisa Ruben

**Rebecca Rubin**  
Irene Sallustio  
**Theodore Santarsiero**  
Peter Scaperotta  
Pop Schaefer  
Daniel B. Scherer  
Stephanie Scherr  
Elaine Schlissel  
Otilie Schmid-Sanders  
Dr. Donna Schroeder  
Patricia Schultz  
Josette C. Schuur  
Randi Schweitzer  
Pam Scott  
Paul Seegers  
Jane Selby  
**Kimberly Sheahan**  
Riki Sheehan  
Gloria Shupert  
Dr. Warren D. Sickman  
Margo Simmons  
Marni Simon-Blake  
Louis G. Sloss Jr.  
**Steven Smith**  
Dr. Thomas Sollas, Jr.  
Linda Sorg  
Sound Hearing and Balance, LLC  
Jesse Sowell  
Kellie Spangler  
James Sparkman  
Robert W. Spence  
Dr. James Srygley  
Stan and Judy Dempsey Fund  
Dr. Gary L. Stanton  
Andrew D. Starkey  
Starr Family Fund  
Brenda Steen  
Donald Steffen  
Mary P. Stephenson  
Margaret Stika-Walsh

Helen Stoll  
Lawrence Stone  
Ruth Stone  
Strive Physical Therapy  
Michele Stromer  
Barbara Strongin  
**Kathleen Stross**  
Myrna Sunberg  
Dr. Maja Svrakic  
Swearengen Charitable Fund  
Randolph Szabla  
Jane Terhorst  
The Pittsburgh Foundation's Elsie O. MacKenzie Fund, in honor of Dr. F. Owen Black  
**Janis Thompson**  
Donald Thurston  
Esther Tolhoff  
**Toole Family Charitable Fund**  
Don Tran  
Dr. Gian Carlo Treggi  
**Thomas Tressler**  
Susan Trilling  
Marisa Turano  
Ronny Udelson  
United Way of Central Indiana, in honor of Paul Brandenburg  
Leslie Vail  
Juan E. Vasquez  
Dr. Jim and Nancy Verdolino  
Silvia Vidal  
Vicki Vinson  
Shirley Votaw  
**Susie Vybiral**  
**Steve Wachtel**  
**Cynthia Wade**  
Dr. Priscilla Wallack  
Mildred Walter

Lisa Wangler  
Joyce Weber  
Vanessa Weddell  
Wendy Wetherall  
Burma Williams  
Mary Williams  
Judy Willis  
Rubye Windram  
Donna Winter  
Linda Witthoef  
Holly Yoder  
James Youngblood  
Julie Yurko  
Lynne Zank  
Fred Zemke  
Linda Zonana  
Ronald Zweig  
**MATCHING GIFT COMPANIES**  
AARP Matching  
Ameriprise  
Amundi Pioneer Asset Mgt  
BHP Bilton  
Cambia Health Foundation  
The Capital Group Companies Charitable Foundation  
Costco  
Google, Inc.  
Intel Corporation  
Merck Foundation  
Microsoft Matching Gifts Program  
Portland General Electric Employee Engagement Fund  
Prudential Foundation Matching Gifts  
**CORPORATE MEMBER**  
Lifemark Health Corp.

## BAW SPONSORS

Auris Medical AG  
Balance Chicago  
KEEN Footwear  
Micromedical Technologies, Inc.  
Natus Balance & Mobility  
Neuro Kinetics  
Otometrics  
Otonomy, Inc.  
Sensorion  
Sound Pharmaceutical

## CORPORATE SPONSOR

Fitterfirst

## IN-KIND DONORS

KATU-TV  
KEEN Footwear

## BALANCE SOCIETY

Kathleen Deming  
Kathleen M. O'Connell  
Otilie Schmid-Sanders  
Marjorie Schnapp  
Robert Ulmer

## KEY

**bold: Sustaining Circle (monthly giving program)**

*italic: Balance Benefactor (\$250+ during the past 3 years)*

*aqua: B.E.S.T. = Balance & Equilibrium Society Trustee (lifetime \$5K+)*

\*askerisk: secured matching gift

## Self-Study For Recovery of Persistent Vertigo: A Case Study

By Joey Remenyi

Vestibular Audiologist, Founder and Director of Seeking Balance International

### MEET RANDI

- Female age 60
- First diagnosis in late teens of Benign Paroxysmal Positional Vertigo (BPPV), and shortly after, migraine
- Reports frequent sick days
- Describes symptoms as constant, severe dizziness, feeling 'out-of-body,' disoriented, and anxious
- Over the years, was diagnosed with Persistent Postural Perceptual Dizziness (PPPD) and cervicogenic neck-related dizziness
- Currently seeing a neurologist to manage a final diagnosis of vestibular migraine
- No disability pension and recently unemployed

### THE JOURNEY TOWARD RECOVERY

Randi noticed that her dizziness symptoms were becoming more frequent, impacting her ability to function in daily life. She reported increasing anxiety and loss of confidence.

Her original symptoms of positional dizziness

started to change into different types of dizziness. She noticed feeling disembodied, disoriented and she was unable to tell up from down.

Randi's neurologist ordered scans to rule out any sinister conditions, but there were no abnormal findings. She had audiology and vestibular testing (which she described as "torture"), and again, all tests came back with normal results.

Randi reported feeling confused and disappointed. She was becoming unsure of herself and worried, "Am I making this up? What is wrong with me?"

Randi told her neurologist that she did not want to rely on medications or psychiatric therapies. She wanted to build resilience and be proactive.

The neurologist suggested that vestibular therapy was recommended, rather trialling more medications.

A local vestibular clinic quoted her \$125 per session for three sessions a week to get started. She was living alone, had no health insurance, no current employment, and did not have anyone to drive her to appointments, making that treatment option inaccessible.

Randi was feeling helpless. Previous medications, bedside exercises and vestibular physiotherapy had been ineffective.

Randi was looking for skills and tools to help her understand her anxiety and to manage the intermittent nature of her condition.

She found videos on recovery of vertigo and tinnitus using integrative medicine and self-study programs. This included physical vestibular exercises as well as mental, emotional and spiritual

aspects of recovery for persistent vertigo and tinnitus symptoms.

Randi began to learn about the concept of neuroplasticity while using these educational videos and free resources.

She resonated with the idea of building new neural pathways and finding ways to ease chronic stress. She opted to try a 12-week in-home therapy program using videos, audios and worksheets.

Randi became excited to learn more about her body and the process of using neuroplasticity to rewire her brain and heal. She began learning about the science and mechanisms behind her persistent symptoms.

Eventually, Randi said that her symptoms became less overwhelming and frightening.

She began to weave neuroplasticity exercises into her daily tasks and to feel more at ease in her body. Randi was now experiencing less anxiety and fear. Her symptoms were no longer constant or as severe. She was recovering.

"Now when I go through my day, I try to turn everything I am doing into proprioceptive exercises. The sensations no longer fill me with dread or terror."

Randi's perceived disability score prior to starting her in-home therapy was a maximum score of 100. This



MEET EILEENE, A VEDA MEMBER AND MENIERE'S PATIENT FOR OVER 30 YEARS.

## YOU CAN HELP.

### DONATE

Your gift helps VeDA support vestibular patients, reduce diagnosis times, and improve treatment outcomes. you can donate online at [vestibular.org/donate](http://vestibular.org/donate) or return your check in the enclosed envelope.

### RENEW YOUR MEMBERSHIP

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



high score reflects the consistent impact of her vestibular migraine symptoms on the functional, positional and emotional aspects of her life.

After completing half of the program, her symptom score reduced to only 24.

### **WHAT WERE THE RECOVERY CHALLENGES?**

Randi had a history of sleeping problems that she described as her greatest difficulty. She used a sleep skills audio at night and anxiety tools to help ease muscle tension and soothe her nervous system.

"It helped me so much," says Randi. "It seemed too good to be true."

Randi says that she had tried everything, seen so many doctors, and suffered for many years with vestibular migraine. Prior to starting in-home therapy, she said that she felt that she was losing control and lacked support.

"It is very serious when you feel 100% debilitated," says Randi. "You need a supportive voice to bring you back and 'talk you off the ledge'."

Computer screens can aggravate Randi's symptoms, so on good days she watches videos and on migraine days she listens to the soothing audios or reads printed articles.

Randi now feels happy and at ease. She is returning to normal life with confidence.

"I am not a 'science-girl,'" says Randi, "but now I finally understand the neuroplasticity process and can use these tools at home to recover from my symptoms."

You can view a video of Randi telling her story in her own words at <https://www.seekingbalance.com.au/case-studies>.



# VEDA

5018 NE 15TH AVE, PORTLAND, OR 97211, USA  
800.837.8428 | INFO@VESTIBULAR.ORG | VESTIBULAR.ORG

CHANGE SERVICE REQUESTED

NONPROFIT ORG  
U.S. POSTAGE  
PAID  
PONTIAC, IL  
PERMIT NO. 592