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
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 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 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 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.
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.

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.

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.

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, 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.

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
- 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
Every Step Is A Step-2-Balance
By Amanda Rodríguez

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 through it, but eventually, I had to see a doctor. And then another doctor. In total, I visited 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.

Through it, but eventually, I had to see a doctor. And then another doctor. In total, I visited 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.

ABOVE: AMANDA’S FAITHFUL COMPANION KEEPS HER ACTIVE.

“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

WE STEWARD YOUR GIFTS WISELY

YOUR GIFTS IN ACTION

WHERE YOUR DONATIONS GO

OUR COMMUNITY IS GROWING!
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

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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!

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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 (PPPDD) 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

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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.”