



 ON THE LEVEL
NEWSLETTER

SUMMER 2018

VESTIBULAR IMPLANT GIVES HOPE

RICK BATTLES BILATERAL VESTIBULAR
LOSS AND COMES OUT RUNNING

VEDA

A QUARTERLY NEWSLETTER
OF THE VESTIBULAR
DISORDERS ASSOCIATION

VEDA

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DR. CHARLEY'S HOPE TEAM



Vestibular Implant Gives Hope

By Cynthia Ryan, MBA

Rick Stephens has always been active. He attended college on an athletic scholarship. He went to the gym every day. He worked with a martial arts instructor twice a week, and at the age of 58 he trained with the Marine Corps Martial Arts Program (McMAP), competing with 20-year old Marines. Being physically fit was part of his identity. Then, one day, he found himself with an incurable illness that made it difficult to stand. He thought his running days were over.

In December, 2012 Rick was training for a triathlon, when an accident fractured his left foot. He spent 17 days in the hospital and received 14 gentamicin injections to prevent infection. Toward the end of his hospital stay he started to feel a bit dizzy.

After he was discharged, he began physical therapy for his foot, but had trouble standing. Since he couldn't do the exercises needed to recuperate from his surgery, he asked the therapist to help him with his balance issues. The therapist gave him a test for vertigo but found nothing wrong.

Next Rick visited his primary care doctor, who gave him motion sickness drugs, but his dizziness and lack of balance continued. He went to an ENT, who gave him a battery of tests for vertigo, but they were all negative. The doctor knew he'd been in the hospital recently, so he checked Rick's records and noticed that he'd received multiple gentamicin injections. "Rick," he said, "I have some bad news. Gentamicin is an ototoxic drug, which means it can damage the balance centers in your inner ear. I want you to see a vestibular specialist."

A referral to an otolaryngologist who specializes in vestibular disorders confirmed the first ENT's suspicions - 100% bilateral vestibular loss.

Although he was thankful for an explanation, Rick could not accept the finality of his prognosis. So he visited Dr. Fred Telischi at the University of Miami, who ran a two-day battery of tests. Unfortunately, the tests only confirmed his worst fears.



ABOVE: IT WAS THE HIGHLIGHT OF RICK'S HOSPITAL STAY TO WALK AROUND AND CHEER UP OTHER PATIENTS (PICTURED WITH HIS WIFE AND DAUGHTER).

"There are two types of pain," says Rick, "physical pain and emotional pain." When Rick was told that his condition would be permanent, that there was no cure, and that it could worsen with age, it put him in a very dark place. He knew he had to find some way to cope. "You put it behind you and do the best you can," he says.

Every time Rick moved, he felt like his brain was sloshing around inside his skull. "It's not



a physically painful experience," he says, "but it feels awful nonetheless." Rick got to the point that he didn't move much to avoid this strange and disquieting sensation. He became stagnant, a couch potato. This was not Rick the athlete. He was becoming someone he no longer recognized.

At first, Rick's balance was so bad he had to use a wheelchair. Eventually he graduated to a walker, and finally to a cane.

Rick has fallen many times. Once he was standing by the copier at his office and,

Rick get where he needed to go.

Initially, Rick's wife, Susan, took over all household chores. "It's harder on the spouse than the patient," says Rick. For a long time Rick couldn't be left alone, so his wife quit her job to take care of him. She was later able to get a more flexible part-time job, but still, Rick hated feeling like a burden.

"One of the biggest fears of ototoxic people is darkness," Rick explains. He dreads it getting dark, because he is reliant on visual cues to maintain his balance. Once, when he was home alone, darkness came on so quickly that he didn't notice until it was too dark for him to walk, so he had to climb on his hands and knees to reach the light switch. They have since installed motion-sensor lights.

Several years went by, and Rick learned to cope. At the suggestion of several doctor friends, Rick started reaching out to teaching hospitals to see if there was any research being done to cure this condition. Eventually he heard about Dr. Charley Della Santina at Johns Hopkins and his research on a vestibular implant. Rick sent Dr. Della Santina an email. "All I'm looking for is hope," he told him. Thirty minutes later, Dr.

Della Santina called Rick back. I wanted to tell you - there is hope," he said.

Dr. Charley, as his patients call him, explained to Rick that he had just received FDA approval to conduct a clinical trial on a multi-channel vestibular implant, which could help restore some of Rick's balance.

Two years ago, Rick applied to participate in Dr. Charley's clinical trial, and was the first person in the world to receive a vestibular implant designed to restore sensation continuously. When asked why he wanted to



ABOVE: AFTER BEING IN A WHEELCHAIR, RICK GRADUATED TO A WALKER, THEN A CANE, AND FINALLY A WALKING STICK.

bam! He fell against the wall, like someone had pushed him. A fall at the gym caused a 7-inch gash in his leg.

Rick's oscillopsia (an effect of vestibular loss) caused everything in his visual field to move about 12 inches side-to-side when he walked or did any other activity that causes movement. He gave up driving, but continued his job as an employee benefits counselor. That meant he was reliant on others for transportation. His wife, friends, family and colleagues all took turns helping

participate in the trial he said, "Having no hope is a horrible feeling." The possibility that it would improve his quality of life even just a little was worth the risk.

Rick estimates he is 70% better since his surgery, and improving. He has better balance and reduced oscillopsia (objects only move 2-inches side-to-side now!). He can control this remaining oscillopsia by walking more slowly.

Rick works out an hour and a half, 5-days a week. "By strengthening your core, you can control your balance better," he says. His goal was to be able to run again.

"BY STRENGTHENING YOUR CORE, YOU CAN CONTROL YOUR BALANCE BETTER."

After his implant, he accomplished this by running a 5K. His oscillopsia as greater when running, but he mentally told himself that he had to keep going.

This past May, Rick participated in VeDA's Steps-2-Balance event, joining Dr. Charley's Hope Team in raising over \$4,400 to support vestibular patients on their road to recovery.

Six years ago Rick's outlook was bleak. He'd almost lost hope. Today, Rick wants to share that hope with other vestibular patients. "You just can't give up," he says.

Julius Schnapp Leaves His Legacy

VeDA would like to honor the memory of Marjorie Schnapp, a long-time member who recently passed away. Marjorie's late husband, Julius, ensured her care through a charitable remainder trust, a portion of which was bequeathed to VeDA.

Born and raised in Connecticut, Mr. Schnapp was a Lt. Colonel and Navigator in the U.S. Air Force. He was diagnosed with Meniere's in the 1940s and left the military as a result of his condition.

But Meniere's disease never deterred Julius. His active life included sailing to such far-away places as Fiji and Ireland. Marjorie accompanied Julius, and even made covers for his hearing aids to prevent them from getting wet at sea!

Julius was always researching his condition, and VeDA was able to help him understand his dizziness and hearing loss, giving some comfort. He decided to give the majority of his assets to charities like VeDA while providing an income for Marjorie after his

death. A charitable remainder trust was the perfect vehicle to accomplish his goal.

To learn how you can include VeDA in your estate planning, contact us at (800) 837-8428 or email info@vestibular.org.



Vestibular Implant Research Study Recruitment

For tens of thousands of people who suffer from severe loss of inner ear sensation due to gentamicin ototoxicity, genetic defects, other drug reactions, Ménière's disease, infection or other inner ear diseases, a new experimental implant based on technology developed in the Johns Hopkins Vestibular NeuroEngineering Lab may alleviate symptoms of the balance disorder, including chronic disequilibrium and difficulty seeing while walking or driving.

The Multichannel Vestibular Implant is like a cochlear implant except that it is designed to sense motion rather than sound and to stimulate a different part of the inner ear.

To find out if you are eligible to participate in this study, visit: www.jhu.edu/vnel or contact Study Coordinators Kelly Lane and Desi Schoo, MD at vestibularimplant@jhmi.edu.

Out of the Mouths of Babes

By Kelsey Flint



ABOVE: KELSEY SPORTING HER DESIGNER CANE

I went to a phone store looking at getting a newer model of my iPhone. Going into stores and establishments with fluorescent lights, which nowadays is a commonality, I typically use a cane even though I am only twenty-one years old. A grandmother with her two granddaughters walked in, one older and one younger. The youngest was about four years old. They were playing around the store and the youngest came and looked up at me and said, "Why do you have a cane? You aren't as old as my grandma." I laughed and got a bit embarrassed. I explained to her my vestibular condition in a way she could understand, and told her not only do grandparents need a cane but so do vestibular migraine patients like me, to help us balance. She seemed amazed at the fact that a "headache" could do so much. Then she told me she liked the floral pattern on my cane, and said she hopes I "get well soon." It was cute even though I will not simply "get well soon" and she didn't understand completely.

It's important to not only educate our peers and family members about our vestibular conditions, but strangers as well. Living with a chronic invisible illness is confusing and often causes the person experiencing the condition to feel embarrassed. Hopefully, one day we will fight the stigma of our invisible illness and teach everyone about vestibular disorders, young and old alike.

GRAVITY IS A STRONG BEAST

By Susan Barthel

Gravity is a strong beast
Grasping, shaking
Gulliver's Lilliputians at work

I hug the floor
Harder than Sisyphus
the struggle to stand, walk, push

Crazy eyes. Bright lights.
I hate neon, the sun, leaves, wind
And... fear myself

Like the Zeppelin
I float, crash and burn
Again and again.

Slowly learn to walk, think, sit,
rest, wear stripes
look at people

This other me
bound to the ground hovering
at the same time

Releases the original
to kick down walls
everywhere





BALANCE AWARENESS WEEK

SEPT 16-20, 2018

Balance Awareness Week is an annual weeklong event focused on balance-related and vestibular community. We rally cry for public awareness so patients can receive empathetic care. Together, we can move forward positively.

HOW DOES IT WORK?

- Put Balance Awareness Week on your calendar for September 16-22, 2018
- Set a personal fundraising goal to support VeDA and vestibular research
- Register your Peer-2-Peer Fundraising Page on VeDA's website at Vestibular.org/BAW
- Share your Life Rebalanced story to help inform and inspire people
- Take a selfie with a VeDA flat flamingo and share on social media (using hashtag #BalanceAwarenessWeek2018)
- Invite friends & family to LIKE VeDA on Facebook to learn more about vestibular disorders

WHERE DOES BAW TAKE PLACE?

Balance Awareness Week is a series of virtual events, both online and in communities around the world. Check vestibular.org for opportunities to participate, lend your voice, and take action!



Balance Awareness Week (BAW) is the Vestibular Disorder Association (VeDA's) annual campaign to broaden the awareness and understanding of vestibular conditions. This September, VeDA is calling for the community far-and-wide to come together and amplify a collective voice of support. The goal is to make "vestibular" a household word, so that those affected can be more rapidly diagnosed, effectively treated, and gain the support they need from friends, family, and co-workers. And by working together, we can advance the funding, research, and policymaking needed to impact the lives of thousands living life without balance.



WHO CAN PARTICIPATE?

Anyone who is living with, or supports someone with, a vestibular condition. Our goal is to grow the community of support by making vestibular more broadly understood. Inviting friends, family, co-workers, and other connections to participate will help spread the word. Additionally, healthcare professionals across a range of balance-related fields are encouraged to promote Balance Awareness Week at their office, hospital, within their community, and online. It takes a village, so let's make our village even larger and more diverse.

WHY CONSIDER SUPPORTING BAW?

For most of us, until you're afflicted with a balance-related condition, the word vestibular is completely unknown. We want to change that. We believe if more people are aware of and understand the complexities of imbalance, we will not only reduce accurate diagnosis times, but also reinforce a culture of greater understanding, empathy, and support. And by helping to raise funds, you'll further VeDA's mission, advance research, and grow the community of support!

Balance Awareness Week Ambassador: The Dizzy Cook



ABOVE: ALICA WOLF, BAW AMBASSADOR

Hey y'all! I'm Alicia and I was diagnosed with vestibular migraine in 2017, a diagnosis that changed my life. I went from being a fun-loving, world-traveling 30 year old to never leaving my house. I was newly married and thought my life was over. It took a few months for me to find the right neuro-otologist and the right treatment plan for me, but in the past two years I've become stronger than I could have ever imagined. Through the Heal Your Headache diet, vestibular therapy (VRT), key supplements, and ballet, I'm back to living life to its fullest. I started The Dizzy Cook (the dizzycook.com), a diet and lifestyle website for those with migraine and vestibular disorders, as well as their family and friends. I share the recipes and tips that have helped me get my life back in the hope that it will help others in some small (or BIG) way! I've also joined VeDA as an Ambassador, and I call new members to welcome them into our Community of Support. I hope you will join me in supporting VeDA and raising awareness about vestibular disorders by participating in Balance Awareness Week!

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TO FIND OUT HOW YOU CAN BECOME A BALANCE AWARENESS WEEK SPONSOR, CONTACT MICHELLE EYRES AT (800) 837-8428 OR MICHELLE.EYRES@VESTIBULAR.ORG.

Best Charitable Gifts to Make in 2018

With the recent tax code changes, you may be looking at your finances and wondering how you will be impacted. Good news for your charitable giving: you have many ways to support vestibular patients on their journey back to balance and still personally enjoy possible financial benefits.

Here are just a few of the tax-smart ways to be charitable in 2018:

- Donate appreciated stock and eliminate capital gains tax.
- Name VeDA as a beneficiary of retirement plan assets, which are not taxed when given to a nonprofit.
- Give from your IRA (if you are age 70 1/2 or older) to help you fulfill your required minimum distribution.

Questions? Contact Michelle Eyres at michelle.eyres@vestibular.org or by calling (800) 837-8428.



Balance Benefactors and B.E.S.T. Donors - Watch for your Special Report

Balance Benefactors and Balance and Equilibrium Society Trustees (B.E.S.T.) will be receiving their mid-year report after July 1. Watch your mailbox for an up-to-date snapshot of where VeDA is half way through the year and what our next projects will be as we race toward 2019.

Balance Benefactors have given a one-time gift of \$250 or more in the last three years. B.E.S.T. donors have given \$5,000 or more in their lifetime. Wondering how close you are to joining these giving circles? Give Michelle Eyres, Development Manager, a call (80.837.8428) or email (Michelle.Eyres@vestibular.org).

Welcome to new Balance Benefactor members: David Watts and Agnes De Vries.

"I found VeDA in 1994 to help me cope with a vestibular disorder caused by a perforated membrane in my middle ear. It left me unable to walk due to the vertigo and in bed for months and months. Using the information provided by VeDA, I was able to get diagnosed by the correct specialist and undergo surgery to repair the membrane. VeDA's information about recovery continued to help me stay focused and patient throughout the process and give me hope that I would indeed recover." - Louise Geib, B.E.S.T. donor.



ABOVE: LOUISE GEIB, B.E.S.T. DONOR

MalaDIO - A Different Kind of Research

By Andrew Hickey

Before I began suffering from vestibular problems in 2016, I was blissfully unaware of the anguish caused by vestibular migraine. Since then, I've discovered that a large part of the anguish is not caused by the symptoms themselves, but by the confusion and hopelessness surrounding every aspect of the condition, from triggers to treatments.

I was first exposed to this suffering in the many Facebook support groups dedicated to vestibular issues. The pages were full of exasperations from people at their wits' end, having seemingly tried everything and made little progress in diagnosing and treating their symptoms. It quickly became clear that there are a range of symptoms, reported triggers, and effectiveness of treatments, even within those given the designation of 'vestibular migraine.'

Some came to the groups for moral support and understanding from those with the same issues. This purpose the support groups fulfilled well. Other people, like me, came for answers. I didn't expect the answers to be instant. I wanted to get a better understanding of the underlying mechanisms of the condition and navigate my way to better treatment, utilizing the collective knowledge of those 'in the trenches.' I didn't expect the answers to be instant, but I expected they would come. They didn't.

What I quickly discovered was that there was little value in polling group members about any aspect of their vestibular issues. There was simply too much variation in responses, and the method failed to take account of age, symptoms, general health, diagnosis, or any one of many factors that I figured would have a massive bearing on results. It was simply too blunt and unsophisticated an instrument, prone to every type of bias.

I was simultaneously humbled by the wealth of experience and supportive spirit found in the groups, and equally frustrated by the inability to mobilize this invaluable resource. This is when I

started to conceive MalaDIO.

As a technologist, I'm interested in the way networked technology has improved the lives of people through the sharing of information. I wondered if there might be a way for people to devise their own studies into whatever condition they had, and get fellow sufferers to take part remotely through the use of mobile applications. A Facebook poll of 10 people on the relationship of dairy and vestibular problems was utterly insignificant. A poll of 1000 people, controlling for variation, with the ability to interrogate the data in detail, I thought, would yield interesting findings.

THE VESTIBULAR DISORDERS SUBJECT SURVEY

I documented the concept of this research tool on a blog, and sought input from those within the online groups. I devised an online survey to seek the opinions of those living with vestibular conditions. It asked questions about their frustrations, their hopes for the future, and what kind of additional information would be most useful to them. The responses can be found here: <https://www.maladio.com/research-data>.

Bolstered by the confirmation that there was demand for a tool that could help shed light on vestibular conditions, the next step was to conduct a focussed survey on vestibular migraine. The survey would serve as a proof-of-concept, showing how detailed polling of patients could help draw out patterns that might be useful in improving outcomes. The survey asked some demographic questions, along with questions about symptoms, triggers, treatments and other conditions. When the responses were in, I examined the data and published the results at <https://www.maladio.com/vmsurvey>.

WHAT'S NEXT FOR MALADIO

I've been in talks with VeDA about partnering

to conduct further studies into vestibular conditions. Seeking the input from VeDA members about what aspects of the condition they want investigated, we'll work with clinical experts towards devising a study focused on providing the answers members need.

This study will be the first to use the MalaDIO suite of tools.

MALADIO SUITE

The Platform: The platform will be the interface we'll use to design the study and onboard participants. The platform will store the responses from respondents.

The App: All people participating in the study will do so through the use of a mobile application. The application will prompt them to answer questions throughout the study period.

The Hub: When all of the data is in, the Hub will provide access to the collected data for all, allowing users to filter and sort data as they wish in order to draw out responses that are most relevant to them.

THE BIG PICTURE

MalaDIO will seek to be nothing less than a revolution in the way health research is devised and conducted. It will remove the barriers to entry that currently exist, and put the power of serious empirical research into the hands of patient groups. It will allow them to choose what they want to

investigate and how they do it. The days of waiting for public health bodies and pharmaceutical companies to generate the data are over.

A SOPHISTICATED TOOL FOR COMPLEX CONDITIONS

In bringing MalaDIO to life, there are issues to be addressed around research ethics, data integrity, and privacy, among other things. I will be seeking the input of specialist condition groups such as VeDA, clinicians, medical research experts, regulatory bodies and statisticians to address every aspect of the project required to make it a success.

WHAT CAN YOU DO?

If you'd just like to know more about the project and read about the details of the planned system, visit <https://www.maladio.com>. If you'd like to keep up-to-date with developments, we have a mailing list. If you have any question or comments, you can use our contact form

at <https://www.maladio.com/contact>. As MalaDIO will be user-driven, we welcome all type of input.

I'm hoping that many of you will support MalaDIO, and take part in research conducted with VeDA. It's my hope that the tool is useful in bridging gaps in the knowledge we have about vestibular and other chronic conditions.

MALADIO IS AN INITIATIVE TO CREATE A PUBLIC HEALTH RESEARCH PLATFORM DIRECTED AND DRIVEN BY PEOPLE LIVING WITH CHRONIC HEALTH CONDITIONS LIKE VESTIBULAR MIGRAINE.



MalaDIO Insights

48%

said that onset of symptoms was preceded by a period of high stress

35%

had a confirmed or suspected digestive disorder

77%

reported they received some or great value from their neurologist

8 in 10

reported "brain fog" as a symptom, most said it was severe

72%

reported alcohol as a trigger

79%

reported stress reduction as the most beneficial lifestyle change

**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 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 this newsletter and other membership benefits.

Dr. Charley's Hope Team

By Betty Cress

I am a vestibular implant recipient and member of Dr. Charley's Hope Team. Last month we celebrated the success of our surgeries by participating in VeDA's Steps-2-Balance event (S2B).

Dr. Charley's Hope Team - named for Dr. Charley Della Santina, our surgeon and vestibular hero - consisted of four vestibular implant recipients - Rick Stephens, Carla McDowell, Bill Cummings, and me.

Our S2B event was a tremendous success. We completed a three mile walk on Sunday, May 20th. The weather was absolutely perfect: a mixture of sun and clouds with a slight breeze blowing in from the harbor - beautiful.

Bill could not attend our in-person event due to a tornado hitting his town leaving 97% without electricity. We were joined and supported by Dr. Charley, his wife and their sweet smile maker, Pepper (the cutest little black dog), Carla's family (husband, David; daughter, Morri, her husband, Jay, and their eight month old son), Rick's wife, Susie, the MVI (multi-channel vestibular implant) team - Nicolas, Peter and his girlfriend Merlin, Meg, Adrianna, Yoav and his three children, Brian (Dr. Schoo, Mehdi, and Dr. Carey were greatly missed), and last but not least, my husband and "knight in shining armor," Eddie.

Our team raised \$6,117, which is 60% of the total raised to support the work of VeDA. We are deeply grateful to all who contributed to support our team.

To help you visualize the blessing of this weekend, I am going to try to "paint you a word picture." It started back in January of this year. Carla suggested that all of us "implants" meet to get to know each other.

We thought this suggestion was a grand idea, and chose Baltimore as our meeting place - the most appropriate place for this is the city where we all received the most wonderful of blessings, our MVI implant at Johns Hopkins. I suggested the weekend of May 19th to coincide with VeDA's S2B event.

When Carla and I first met, I felt like a kid again. We were silly with joy - like teenagers without a care in the world! We met up with Rick and Susie a little later. I was walking through the lobby with my walking stick and here comes this very tall man with a huge smile on his face. It was like meeting a long lost brother for the first time. We all wanted to talk at the same time, asking each other questions that we'd had in our minds for so long.

Saturday dawned with the predicted rain. We visited the National Aquarium, which was very busy with wide-eyed children showing amazement at the most spectacular water creatures. The subdued lighting and escalators made the tour challenging for us with our vestibular damage, but we did not let the challenge stop us.

Then we visited Dr. Charley, who graciously gave us the most wonderful tour of the Johns Hopkins campus, including the vestibular lab where ground breaking research has occurred. One of Dr. Charley's amazing gifts is the ability to explain the most complicated research in words that we, with non-scientific minds, can understand. After our tour, Nicolas inspected our implant power control units and videoed each of us to ensure proper battery changing technique. Nick has such a keen sense of humor and always keeps us smiling.

Later that evening, Dr. Charley treated us to a lovely dinner. There was much laughter and joy, which comes naturally with this group.



CONTINUED FROM PG. 15

Sunday we held our S2B event. We started our walk at 9am. I so admired Carla and Rick's ability to walk "normal." I want to be able to walk like them. I carried my walking stick for the whole walk and felt the need to hold Eddie's hand for increased steadiness most of the way. Adrianna was beside me when Eddie wasn't, and often had her hand ready if I needed it. This is one of those "subtle things" that happen when you are aware of being beside someone with a balance issue.

The most amazing part of our walk was that Rick, Dr. Charley, Meg, and Nick ran the second half. I have tried to run since all has happened, and I would describe my running as a half-hearted fast walk. My goal is to run, and with Rick setting the example, I will continue to strive for this.

We said our goodbyes with hugs all around, savoring every moment of the wonderful time we'd had together. Dr. Charley and his MVI team have truly given us the hope we thought we'd lost. Life is a very dark place without hope.

Thank you is so small, not adequate to express our feelings for the hope we have been given. THANK YOU, DR. CHARLEY AND YOUR MVI TEAM. Thank you to the Vestibular Disorders Association and the important work you do to bring awareness of the vestibular system and the effects of vestibular damage. Thank you to my family and friends that have journeyed thus far with me in this new normal of vestibular damage, this "new normal of the wobbles."

Visit VeDA's provider directory for more information about Dr. Charley Della DSantina.

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ABOVE: DR. CHARLEY'S HOPE TEAM AND THEIR FAMILIES WALK TO RAISE AWARENESS