

# ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION



INFORMATION

SUPPORT

AWARENESS

ADVOCACY



## My “Trifecta Squared” Diagnosis

By Theresa G.

My name is Theresa and I have been diagnosed with a vestibular disorder and convergence insufficiency, as well as post-concussion syndrome. It all started with a bicycling accident that resulted in trauma to my head, neck and left shoulder. My past medical history was unremarkable, with the exception of a neurological condition resulting from a fall in 2004 that involved a blow to the head. It took from December 2013 until February 2016 to be properly diagnosed, after multiple consultations with various medical providers from several different specialties.

Before this began I enjoyed a full life with many interests and activities. I loved being outdoors and on the go. I am an accomplished professional in the HIV community and a published author, lecturer and consultant. I have extensive experience in multidisciplinary grant program management and development, and I am an ardent advocate and activist.

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TOP LEFT: THERESA BEING INTERVIEWED ABOUT HER WORK WITH HIV ADVOCACY  
BOTTOM LEFT: THERESA ENJOYING THE OUTDOORS BEFORE SHE BECAME SICK  
BOTTOM RIGHT: THERESA USING HER BROCK STRING FOR VISION THERAPY

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TRIFECTA SQUARED...CONTINUED FROM PAGE 1:

Athletic by nature, I was a runner, bicyclist and a gym rat up until the day I fell sick with vertigo. I love the arts, dabble in photography, and play guitar. Life was good. Then, suddenly it all came to a screeching halt. My life went from normal to *Kafkaesque* in one spin of the room.

It was December 16, 2013. The morning had started with some dizziness, associated nausea, and a headache. I thought I was coming down with some sort of a bug. This had also been preceded by three months of pulsating tinnitus.

I was sitting at my desk when all of a sudden the computer screen appeared to jump out at me. I pulled back in my chair, turned away from the screen and thought to myself, "That was odd." Then the room started spinning. It seemed to pass and I remember thinking to myself, "boy that was trippy," but within minutes it began again, this time even faster and more furious. I tried to call my boss, but while I was on the phone with her it started again. Someone called 911. In the 17 minutes it took for the ambulance to get there I had about seven severe episodes. I thought I was either having a heart attack or stroke. It was by far the scariest experience I have ever had.

I was taken by ambulance to a local hospital and diagnosed with severe episodic vertigo. After many hours of observation, with hydration and medication to calm the nausea and vertigo, I was discharged. While in the hospital there was discussion of having a CAT scan, but the doctors dissuaded me from doing so. They said it was likely the kind of vertigo that would self-resolve. This turned out to be the first in several medical mistakes that occurred while unraveling the mystery of what would become a complex of three distinct diagnoses.

The ER doctor suggested that I follow up with an ENT. However, the ENT could find nothing wrong with my ears. He sent me for neck imaging to rule out a possible blood clot, which came back benign/normal. The ENT said that vertigo was pretty common, that it could originate from the ear, neck or brain, and that I would likely have another episode within a week or two. He added that in most cases it would go away on its own in two weeks to two months, but he also recommended that I see a neurologist.

After extensive neurological testing the diagnosis of vertigo was confirmed. Although my neurological exam was essentially normal, except for an unsteady gait, I was still feeling dizzy and just generally "off."

Despite her findings, the neurologist ordered an MRI. The results

suggested possible migraine, prior inflammation, or cerebrovascular risk. The neurologist referred me to a neuro-otologist for additional testing. He was the best that New York City could provide.

At this point my working diagnosis was vertigo, labyrinthine dysfunction and vestibular neuronitis. The cause was still unknown. He repeated audiology tests re-confirming that my hearing was normal. I went back to the regular neurologist, who referred me to vestibular rehab.

During this time I felt horrible. I had problems moving about and eating and I was exhausted all the time. On the few occasions that I went out of the house, my symptoms got worse as soon as I hit the street. I came to understand that it was simply too much stimulation; my eyes, my vestibular system and my brain just couldn't deal.

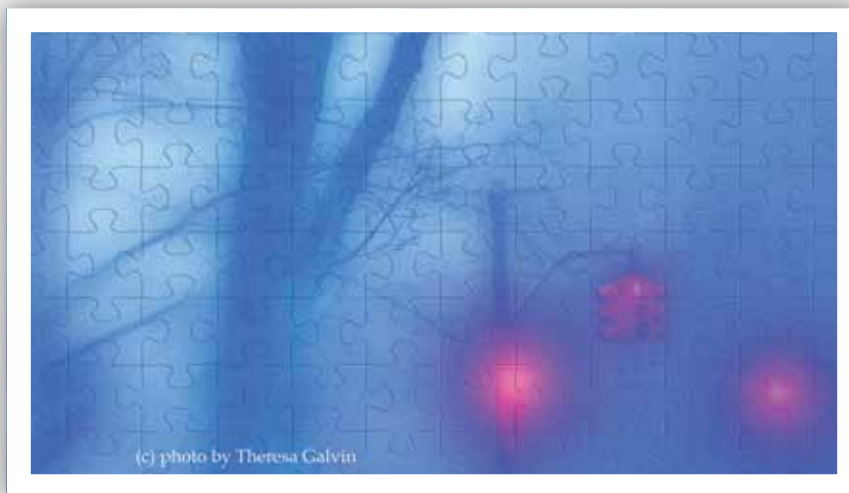
Three months into this ordeal I started vestibular therapy. Although I immediately loved my therapist, I detested the testing and consequent therapy. I went once a week for about six months and each time I felt ill, sometimes with "residuals" lasting 1-2 days after my therapy. It seemed counterintuitive to me that the therapy for this condition would make me feel worse before I could feel better! Nevertheless, I did it every week, as well as home exercises three times a day. My therapists repeatedly pushed me, explaining that the exercises would deliberately invoke the symptoms in order to desensitize the brain. It has been by far the most difficult therapy I have experienced.

To make matters worse, my partner was not at all supportive of my situation. In the end, we split up – not in a nice way. I came to realize that because

vestibular disorders are invisible, those who are not afflicted can't comprehend what it feels like, making it easy to discount our journey. Sick and struggling, now I had to find a new place to live.

During this time, a job I had held for 20 years came to a close. With my FMLA leave over, and not cleared to return to work, I was notified that my position would no longer be held. That same day I was profiled nationally as being an "HIV/AIDS Hero." It was a day filled with both devastation and jubilation.

Concurrently, my mother suddenly became sick, and within two months had passed away. I was traumatized and devastated. This loss was profound and made life feel almost unbearable.



TERESA EXPRESSES HOW SHE FEELS THROUGH PHOTOGRAPHY. THIS PHOTO IS ABOUT WONDERING WHAT THE MISSING PIECE OF THE PUZZLE WAS IN HER RECOVERY, WHICH TURNED OUT TO BE GETTING DIAGNOSED WITH POST-CONCUSSION SYNDROME, CONVERGENCE INSUFFICIENCY, AND VERTIGINOUS MIGRAINES - HER "TRIFECTA."

In a six-month follow-up with my neurologist I was told, "There is nothing else I can do for you." I decided to seek a second opinion at the NYU Rusk Institute. The neurologist there paid attention to everything I said and asked probing questions. One of the first things she said to me was, "Have you ever

been asked if you have migraines?" I said no, but I had noticed that since the start of the vertigo I had been having daily headaches. The next question she asked me was if I had ever hit my head. I reported two instances, one in 2004 and the second occurring with the bicycling accident in 2013. She suspected that I had a concussion and made a presumptive additional diagnosis of vertiginous migraine, prescribing high doses of vitamin B2 and magnesium. Things were starting to make sense, pointing her clinical assessment and treatment of me in a completely different direction.

CONTINUED ON PAGE 4:

She referred me for an evaluation at the NYU Rusk Department of Neuropsychology. Three days of testing revealed findings remarkably consistent with post-concussion syndrome. The neuropsychologist also concluded that my vestibular disorder was likely related to that, and additionally, the tests suggested there were problems with visual tracking and acuity. This resulted in a referral to SUNY College of Optometry for an assessment of my eyes, explaining my problems with reading and focus. However, for three months I had no health insurance. In February 2016 my medical insurance and therefore medical journey and services resumed. I was first seen by an Occupational Therapist who specialized in vision therapy at NYU Rusk. She did testing that was consistent with a concussion and confirmed my visual problems.

**“HAVING A CHRONIC  
AND POORLY  
UNDERSTOOD ILLNESS  
IS ISOLATING.”**

At SUNY, I spent two days of comprehensive testing in the head trauma unit, where they diagnosed me with severe Convergence Insufficiency. My trifecta was confirmed: Post-concussion Syndrome, Convergence Insufficiency and Vestibular Disorder. NYU Rusk’s interdisciplinary team approach has been extraordinarily effective. I am so lucky to be in

the capable hands of these specialists. It is the only place I feel one hundred percent understood, which is tantamount to the healing process.

During this illness my photography really started to take off! I am working on a series entitled, “Patient Behind the Lens,” which was born of my desire to capture via an image what a symptom or diagnosis looks like. This series was driven by my own frustration of having inadequate language in which to explain to people how I am feeling at any given moment.

Having a chronic and poorly understood illness is isolating. The sounds of isolation can be deafening at times. I guess it all comes

down to not begrudging your life and making lemonade out of lemons. Easier said than done – I have to remind myself of this every single day.

*This story was able to be told by the grace of an extensive deadline, extraordinary effort by Theresa and countless symptomatic days, assistive devices, a very good friend who did most of the editing and organization, and VEDA for additional editing and pulling it all together. Theresa’s full story can be found at [vestibular.org/theresag](http://vestibular.org/theresag).*

## What To Do With Your IRA’s Required Minimum Distribution

By Doug Nielsen, CPA

Individuals age 70 ½ and older must take Required Minimum Distributions (RMDs) from their IRA each year, which can have tax implications. Did you know that you can donate up to \$100,000/year from your IRA to a charitable organization tax free? A direct contribution to VEDA from your IRA can satisfy the RMD without having to report additional income on your personal tax return.

Everyone’s tax situation is different. If you are considering a charitable contribution to VEDA from your IRA, it is a good idea to consult a tax advisor.





# 3rd Annual VEDA Champion of Vestibular Medicine Awards

CHAMPIONS OF VESTIBULAR MEDICINE ARE MEDICAL PROFESSIONALS WHOSE WORK HAS HAD SIGNIFICANT IMPACT ON INCREASING AWARENESS OF VESTIBULAR DISORDERS AND/OR CONTRIBUTING TO REDUCED DIAGNOSIS TIMES AND/OR INCREASED TREATMENT EFFECTIVENESS.

## KIM GOTTSBALL, PT, ATC, PHD



Dr. Gottshall has spent over twenty years treating vestibular disorders in the U.S. Military. She and her collaborators established the first military vestibular rehabilitation program over two decades ago. Since that time, Dr. Gottshall has treated thousands of active duty, retirees, and military dependents with vestibular disorders, many of whom were injured in war. Dr. Gottshall is a superb clinician and has done cutting edge research in this area for two decades. *[No photo available.]*

## JENNIFER DEREBERY, MD



Dr. Derebery is an otologist at the House Clinic in Los Angeles, California, where she specializes in the diagnosis and treatment of allergy-related hearing loss and vestibular disorders. Dr. Derebery also serves as a Clinical Professor of Otolaryngology at the Keck School of Medicine, University of California, Los Angeles, and is the author and co-author of numerous papers on otolaryngology and allergy, particularly as relates to otologic conditions.

## NEIL SHEPARD, PHD



Dr. Shepard is a professor of audiology at the Mayo Clinic in Rochester, Minnesota. His research activities include the clinical assessment and management of persons with dizziness and balance difficulties. For the past five years he has focused on postural control issues and investigating tools to assist in the risk for falls. Dr. Shepard has a passion that is contagious. He is a pillar in the vestibular community, and a valuable resource to his many students and colleagues.

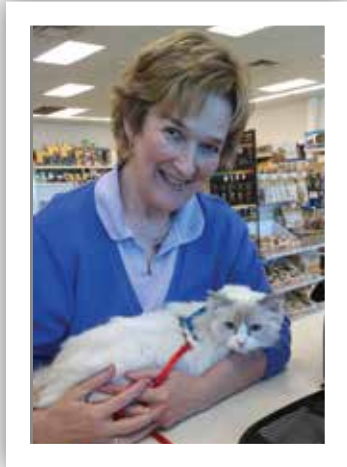
## HAMISH MACDOUGALL, PHD



Dr. MacDougall is the Director of the Vestibular Lab at The University of Sydney, Australia. He has been involved in over 100 vestibular related publications, and is one of the lead researchers to develop a new saccadic indicator of vestibular function called the aVOR. The aVOR is a teaching, training and testing tool for the vestibulo-ocular reflex (VOR). It demonstrates saccadic eye movements, including those caused by canalithiasis (free-floating particles in the canals) and both functioning and dysfunctional VOR, showing how BPPV is caused and treated.

# Relationship Management - Finding the Right Gear

By Sherron Laurrell, vestibular patient



SHERRON WITH HER OFFICE ASSISTANT, SPENCER

Ever since I developed vestibular dizziness in 2013, I have wondered why some relationships survive while others collapse when one partner is diagnosed with a vestibular disorder. I sought to answer this question by interviewing a successful "post-vestibular" couple, as well as a patient whose relationship deteriorated soon after

her symptoms began, and seeking advice from a professional psychologist.

Katie and John Mahoney have been together for 13 years, four as a married couple. Thirteen months after their wedding in 2012, Katie became ill with vestibular neuritis, extreme fatigue and motion issues. Three years later she still struggles daily with her limitations. Katie and John continue to enjoy their lives together, along with their beloved doggie-daughter Heidi, despite the significant pressures illness has placed on them.

I asked John how he deals with the changes in his life since Katie fell ill. He explained that "Katie is still Katie." John sometimes allows little things to turn into big deals and Katie describes herself as a "control freak." That combo could lead to relationship strain, but fortunately, that is not their reality. John never allows Katie's limitations to discourage him. "I hope I am someone she can rely on when it really counts," says John. Katie's biggest source of guilt is that her severe fatigue, especially on days that she has to work, robs the couple of together time. She is often

in bed by 5pm, leaving John to spend the evening alone.

She tells a poignant story of a garden wall they had planned on building together – one of their special home projects. "We love to do things together. Watching him build that wall by himself was very difficult for me," says Katie. John reminds her: "We are both doing the best we can and that is all we can do."

Katie's advice: "Don't let this illness destroy your happiness. Relationships require work and effort. Don't take things out on your partner. Remember that this isn't only about you." John's advice for spouses: "Be patient. You can find a new gear to make it through together. Do not give up hope."

Theresa G. represents the other side of the story, showing what happens in a relationship when the person you believe loves you simply walks away during your illness.

Theresa and her partner had been leading a full and exciting life in New York City, when she was diagnosed with post-concussion syndrome, convergence insufficiency and vestibular neuritis (see her story on page 1 of this issue).



KATIE AND JOHN MAHONEY ON THEIR JUNE 2012 WEDDING DAY, ONE YEAR BEFORE SHE WAS DIAGNOSED WITH VESTIBULAR NEURITIS. THEIR RELATIONSHIP IS STILL GOING STRONG!



HERESIA'S RELATIONSHIP ENDED SOON AFTER HER VESTIBULAR SYMPTOMS BEGAN HAVING AN IMPACT ON HER LIFE.

A successful HIV / AIDS author, lecturer and nutritional consultant, Theresa lost her health, career, partner, and very tragically her mother, all within 9 months.

She believed, and her partner had reinforced, that they were "set for life."

But during her illness, when she became homebound, afraid, lost and in need of support, her partner withdrew, becoming indifferent. She exhibited what Theresa's doctors described as "an almost willful ignorance" to Theresa's plight.

It became clear that although Theresa was predisposed to care taking because of her upbringing and HIV work, her partner did not embrace that role. As Theresa became more in need of help, her partner became more distant and detached and, in the end, abandoned her.

"I realize now that my partner did not have my back and she would never have been able to accompany me on this journey. It takes a special soulmate to traverse the more difficult path."

For insight on why some relationships of the chronically ill work and some fail I turned to Dr. Laurie Appel, PsyD, a practicing Psychologist in Swedesboro, NJ.

## WHAT INFLUENCES WHETHER RELATIONSHIPS WILL SURVIVE OR FAIL?

It depends on several mitigating factors, such as the strength of the relationship before illness hits, the degree to which the illness affects the patient's lifestyle, and the degree to which the partner can

tolerate the patient's limitations and empathize.

## WHAT PRE-EXISTING CONDITIONS CONTRIBUTE TO RELATIONSHIP SURVIVAL?

The ability to communicate feelings, and relationships that have a strong friendship base. Couples may not be able to have the same activities or sex life as they did before the illness, but a solid friendship relies more on a meeting of the minds rather than physical activities.

## WHAT FACTORS PREDISPOSE A PERSON TO RESILIENCE IN DEALING WITH CHRONIC ILLNESS?

Resiliency is a combination of nature and nurture. Some people are born seeing the sunny side of life. Others struggle to see the positives. A family can nurture resiliency by modeling good coping skills, honest communications, good conflict resolution, a habit of self-care, and asking for help when needed.

## WHAT ADVICE WOULD YOU GIVE A PATIENT ABOUT THEIR RELATIONSHIP?

Educate your partner about your illness. When people can't see your illness, it is harder to understand. It is important for the chronically ill person to focus on educating and not defending. Have several people you can reach out to. Allow your caretakers to take breaks.

## WHAT ADVICE WOULD YOU GIVE THE CARETAKERS?

Take care of yourself. Take breaks to replenish. Caretaking is not the same as being ill, but it can be draining. Ask others to help you help your loved one. Don't let exhaustion and resentment build up or your relationship will deteriorate.

## WHAT OTHER ADVICE DO YOU HAVE FOR COUPLES DEALING WITH CHRONIC ILLNESS?

If a couple is struggling, it is so important to get help early rather than later, when resentment, hurt and misunderstandings have already developed. Couples counseling can help.



# Balance Awareness Week 2016

## FLAT FLAMINGO PHOTO CONTEST



THE TEAM AT ELEMENT PHYSICAL THERAPY HELPED TO FLOOD THE INTERNET WITH FLAMINGOS!

## SOCIAL MEDIA

33 FACEBOOK POSTS REACHED ALMOST 300,000 PEOPLE.



YOUR LIKES AND SHARES HELP US RAISE AWARENESS!

## DIZZY DASH



THE BALTUS FAMILY, AND MANY OTHERS, WALKED 5K TO DEFEAT DIZZINESS!

## PRESS RELEASES

TWO PRESS RELEASES FOR A TOTAL OF 390 MEDIA IMPRESSIONS WITH A COMBINED REACH OF OVER 362 MILLION

## WORLD HEALTH ORGANIZATION PETITION



PATIENTS INITIATED A PETITION THAT GARNERED OVER 1,300 SIGNATURES

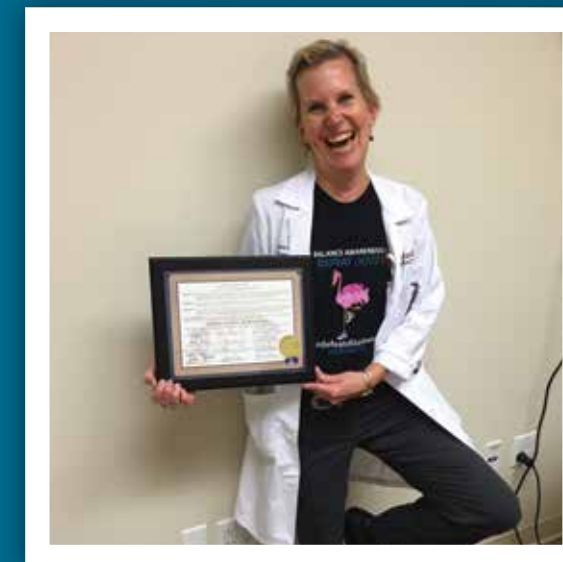
## FUNDRAISING

TOTAL RAISED: \$67,773

### TOP FUNDRAISERS:

- SANDRA ROBERTS: \$5,538
- GARY BREITBORD: \$4,314
- JANIT GREENWOOD: \$2,836
- LOUISE GEIB: \$2,015

## GOVERNMENT PROCLAMATIONS



JOYCE CHADDERDON, PT ACCEPTS A PROCLAMATION FROM THE CITY OF SAN JOSE, CALIFORNIA



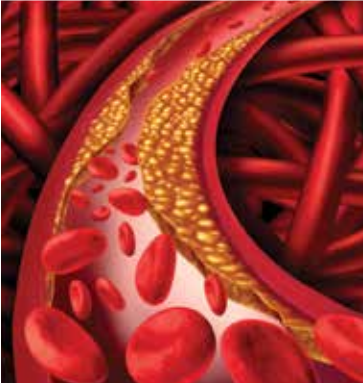
Thanks to you, millions of people learned about the impacts of vestibular disorders!



# Research Corner



## CAROTID PLAQUE IS A NEW RISK FACTOR FOR PERIPHERAL VESTIBULAR DISORDER



Although carotid plaque development is linked to atherosclerosis (a disease in which plaque builds up inside your arteries), it is unclear whether such plaques can lead to the development of peripheral vestibular disorder (PVD). A study was conducted to investigate the presence of an association between carotid plaque and new PVD events. Carotid plaque presence was measured with high-resolution ultrasonography, with PVD events recorded during the 1-year follow up period. Among the 393 patients there were 76 new PVD events; patients with carotid plaque had a greater risk of such events (crude HR: 3.25; 95% CI: 1.62-6.52) compared to those without carotid plaque. This risk was even higher after adjusting for traditional risk factors for atherosclerosis. Researchers concluded that carotid plaques are associated with an increased risk of new PVD events.

*Medicine (Baltimore). 2016 Aug;95(31):e4510. doi: 10.1097/MD.0000000000004510.*

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## Impact of Diabetic Complications on Balance & Falls

By Kelsey Hatton, Au.D., CCC-A

A fundamental issue in diabetes is that the body creates abnormal chemical byproducts from sugar and proteins, which build up in sensory tissues. Abnormal treatment of proteins can also impair the transportation of certain substances across cell membranes, required for proper blood vessel function. Abnormal protein channel use can create oxidative stress, which directly damages the structure of protein, and can affect normal cell signaling mechanisms. This can lead to impaired blood transport to capillaries with poor delivery of oxygen or nutrients and damage to the myelin, or nerve cover, slowing transmission of information and excess waste deposits in sensory tissues that impair tissue function.

Blood, nerve, and tissue impairment can lead to degeneration of the vestibular organs. Studies on animals with diabetes show abnormal deposits blocking nutrients from entering and waste from exiting connective tissue of organs used to detect linear acceleration (i.e. the utricle and saccule). This damages the sensory hair cells imbedded in the connective tissue, especially in the organ called the saccule. Another study noted animals with diabetes had poorer myelin covering the vestibular and hearing nerve, along with smaller nerve diameter. These changes limit the speed and quality of information traveling from ear organs to the brain.

In humans, the saccule uses insulin receptors and protein channels to balance fluid and electrical charge in the inner ear. Damage to saccular tissues can also lead to calcium particles imbedded in the membrane to break loose, typically yielding positional vertigo. A post-mortem study of ears of patients with diabetes revealed many patients had loose calcium particles, even when they had not complained of positional vertigo during their lifetime.

Damage to the vestibular organs can lead to a higher occurrence of positional vertigo, poor gaze stabilization, poor eye tracking of moving targets, delayed signals from the ears which help direct eye movements (delayed VOR phase), or reduced information from the vestibular system (reduced caloric response). These problems are observed more often in patients with diabetes. Taken in combination with other diabetes-related findings of slower gait speed, lower physical function, variable stride length when walking, and more postural sway when standing, it is not surprising that older patients with diabetes are more likely to fall recurrently and have more serious injuries secondary to falling.

Potential assessments that may help determine risk of falling for patients with diabetes include: vestibular testing, questionnaires measuring impact of unsteadiness on daily life, gaze stability evaluation, postural sway testing, determining gait speed, and evaluating consistency of stride. Measures shown to help patients with falls risk includes: gaze stabilization exercises, treatment of positional vertigo, obtaining proper footwear, training with assistive devices, and a combination of aerobic and resistance training. A varied exercise program has been shown to reduce falls risk by improving glycemic stability, increasing physical function, improving overall balance, and improving gait speed in patients with diabetes.

### Reference:

D'Silva LJ, Lin J, Staecker H, Whitney SL, & Kluding PM. Impact of Diabetic Complications on Balance and Falls: Contribution of the Vestibular System. *Phys Ther.* 2016; 96 (3): 400-409.



# Coordinated Care Results in Better Outcomes

By Dr. Kimberly Fox, Asheville Balance & Vestibular Center

Vestibular disorders do not belong to one healthcare specialty, but require a multi-disciplinary approach to ensure that patients are accurately diagnosed and effectively treated.

Often patients are referred by their primary care provider to several different healthcare specialists, who may or may not communicate with each other to ensure that the patient receives coordinated care. For optimal results, vestibular patients should be treated by a team of healthcare providers who have additional training in vestibular disorders, working together for the patient's overall well-being.

An example of an integrated balance center that provides easy access to a variety of specialized providers under one roof is the Asheville Balance and Vestibular Center (ABVC) in Asheville, North Carolina. Their providers include physicians, physical therapists, audiologists, a dietician & nutritionist, and a mental health counselor. Each provider has received additional training in balance and vestibular disorders.

"The center was born out of a vision and a need to enhance the quality of care for vertiginous patients," says ABVC founder and owner, Dr. Kimberly Fox, PT, DPT.

"The concept of ABVC is not new," says Fox. "Select hospitals have vestibular centers with a multi-disciplinary approach, but it is not as common for an independent clinic to bring together an integrated team with a focus on the care of vestibular patients."

It is important to determine which specialist each patient needs to see at what point in their evaluation and treatment. At ABVC, initial evaluations are typically performed by the physical therapists. Direct communication between patients and providers is also important. A proper evaluation may require longer than normal session times to ensure that a thorough assessment either leads to an accurate diagnosis or a referral to the appropriate specialist(s), eliminating the need to see multiple

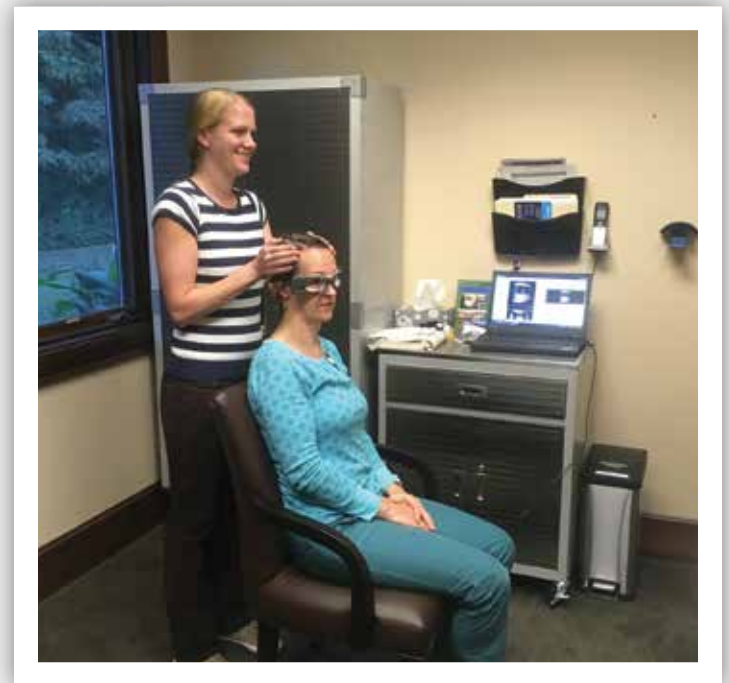
providers and many months of waiting.

"The goal is to get patients better as quickly as possible," says Fox. "Every provider on our team always remembers that the patient comes first."

In addition, at ABVC, each provider spends time observing and cross training to better understand the role the other providers play in this collaborative environment.

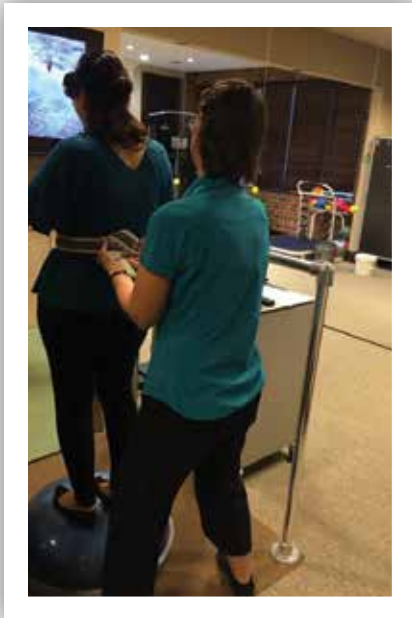
ABVC physical therapists are referred to as *vestibular providers* because they have dedicated their efforts exclusively to balance and vestibular disorders and have extensive training in evaluating and treating vestibular patients. Each has a Doctorate degree in Physical Therapy (DPT) and has also undergone extensive coursework and additional training to become specialized and proficient, well beyond routine vestibular training.

Testing and treatment is a collaborative effort. In addition to VNG testing, the physical therapists at ABVC use infra-red video goggles, caloric testing, a computerized balance platform, Video Head Impulse



VESTIBULAR SPECIALISTS AT ABVC USE UP-TO-DATE TECHNOLOGY TO EVALUATE VESTIBULAR PATIENTS.





VESTIBULAR REHABILITATION AT ABVC  
MADE FUN WITH GAMING

Testing (vHIT), and Suppression Head Impulse Testing (SHIMP). A new ceiling mounted harness track will allow higher level challenges without compromising patient or therapist safety, and in the near future they will also include Vestibular Evoked Myogenic Potential (VEMP) testing.

Audiometry and Auditory Brainstem Response (ABR)

testing is performed by ABVC audiologists.

Test results are sent to a physician, who works with the rest of the team to formulate a working diagnosis, then refers the patient for appropriate

treatment.

Many patients undergo vestibular rehabilitation therapy. The rehabilitation gym has an array of equipment, from low tech to high tech, for the purpose of enhancing strength, balance, and conditioning and to promote recovery. The number one goal is for patients to maximize their potential, but ABVC's therapists also try to elevate the fun factor!

Learning to live with a vestibular disorder can be challenging. Mental health counselors can help patients learn coping strategies, while also finding acceptance for their physical and cognitive limitations.

Part of building an integrated balance center is starting with a knowledgeable team who share a common passion for the treatment of vestibular patients.

"Some providers love working with and helping this patient population," says Fox. "I am certainly one of them."

## VEDA Publishes Patient Registry Data in Medical Journal

By Cynthia Ryan, MBA - Executive Director

In 2014, VEDA created a patient registry to collect data on the vestibular patient experience when engaging healthcare providers in the search for an accurate diagnosis and effective treatment. Data related to diagnostics, treatment, quality of life, and healthcare costs was collected.

This year, in collaboration with Dr. Michael Schubert from Johns Hopkins University, we published a white paper on our findings in the Journal of Otology and Neurotology.

This is a MAJOR accomplishment, and we couldn't have done it without YOU and all the patients who participated in our patient registry.

An analysis of this data validates many subjective claims we have heard from patients like you over the years, including long diagnosis times, multiple specialists referrals, and over use of certain tests

some of which are not typically useful in diagnosing vestibular disorders.

While the paper itself is copyrighted by the journal, I am working on an article that will explain its findings, as well as introduce a more in depth analysis of the data. Stay tuned for more updates!



# Tools to Diagnose Head Trauma, Concussions, Balance Disorders

By Marie Cosgrove, CEO - *balanceback*

We hear it in the daily news. We read it in the daily paper—another concussion due to sports injury.

Yet, according to the CDC, only 9.8% of head injuries are due to sports injuries while a whopping 90.2% are completely unrelated to sports.

Head injuries may be the result of falls, auto-accidents or work-related.

Sometimes, the head injury may be so minor that it goes initially undetected by physicians or the patient.

Symptoms may later appear as:

- Headaches
- Weakness
- Loss of balance
- Decreased coordination
- Vertigo
- Confusion
- Nausea
- Vomiting
- Slurred Speech

Obtaining a diagnosis as early as possible and seeking treatment and/or rehabilitation is crucial.

Michelle Mras was driving 30 mph when a young woman ran a stop sign traveling at 40 mph and struck Michelle's car—hard enough to total both vehicles. Michelle experienced no 'physical' injuries that were visibly noted. Because they were driving at "slower" speeds, it was thought that the impact was not sufficient to cause any damage physically to Michelle.

However, 12 days post accident, Michelle began to experience dizziness and slurred speech, then lost her ability to perform cognitive functions. When she was well rested she was fine. Both she and her primary care physician felt that because the symptoms were resolved when she was well rested she was going to be fine, and in time all her symptoms would subside.

Eight months later, Michelle was referred to a neurologist after realizing that her symptoms were deteriorating to the point where she was experiencing short term memory loss. The neurologist who tested her discovered what she feared most - she had a traumatic brain injury.

Michelle said, "What I have learned from this experience is: 1) Never underestimate any head injury, 2) seek help immediately, and 3) you, as the injured person, will not always notice the symptoms. I had short term memory loss, yet I didn't realize I was forgetting things."

Captain Joseph Moore, US Navy, M.D., Medical Director of Miramar Sports Medicine and Reconditioning Team (SMART) Center, Former Commanding Officer of the Medical Treatment Facility aboard the Military Sealift Command (MSC) hospital ship USNS Mercy (T-AH 19), emphasizes the importance of seeking immediate clinical care. Dr. Moore, states, "Pushing forward the idea of rehabilitation



IVCR (INTUITIVE VESTIBULAR & CONCUSSION REHAB) SYSTEM CAN HELP DOCTORS ACCURATELY DIAGNOSE BALANCE DISORDERS

CONTINUED ON PAGE 16

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*"I have had unilateral meniere's disease for 10 years. I skeptically started on this product in July, 2015. My disease is at the stage that my attacks are less frequent but the pulsating tinnitus is very uncomfortable, loud and the duration may be up to 6-10 hours. I need to take benzodiazepine to cope.*

*I can honestly say that ingesting 1/4 Cup of spc-flakes three times each day has nearly alleviated the loud pulsating "gong". My head feels better and I have no vertigo regardless of the direction in which I turn my head. This was after 2 weeks of using spc-flakes! I can only imagine how I will feel after a month. Best news is this is a medical food without any side*



and fall prevention, if you have an awareness of your balance (or proprioception) and you train to keep it at its highest peak, like we do with flexibility, strength and endurance, we're going to see a reduction in injuries. I think the intuitive Vestibular and Concussion Rehab System (iVCR™) is a wonderful product. Balance equipment utilizing an unstable platform, such as the iVCR™ system, really is one of the greatest inventions in the 21<sup>st</sup> century. We found that by using the unstable platform we were able to diagnose where (people) are weak, retrain those fibers, and re-teach the body reflexes necessary for proper balance. The equipment is an invaluable tool for aiding proprioception—the body's ability to know where our extremities are, and to keep us balanced. And it allows us to effectively get a person back up to speed faster, ready to go back to full duty."

Christopher Usery, Major USMC, experienced the used of the iVCR system, "The strengthening of my 'core' was what we were trying to accomplish, and while sit-ups were completely out of the question, he walked me over to a device that looked more like a video game than something that was going to keep the surgeon's knife in its sheath. He told me that this piece of equipment would not only teach me how to keep from falling as I struggled to regain my balance while learning to walk again with this horrible painful injury, but that it would also strengthen my core muscles in a 360 degree range of motion."

Maj. Christopher Usrey states, "It's not just the advice and/or direction of competent medical personnel, but just as important, the medical equipment they utilize in the treatment of specific injuries that can mean the difference between a full recovery or a lifetime of chronic pain and limited activities. In addition to the procedures and exercises set forth by my physical therapists, the iVCR was a mainstay in my recovery success. Today, after my successful treatment, I am no longer slouched over and crippled up—I am a standing tall 6 foot 3 in. Marine who is able to carry his sons on his back."

Brought to you by balanceback.



**VESTIBULAR**

DISORDERS ASSOCIATION

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