

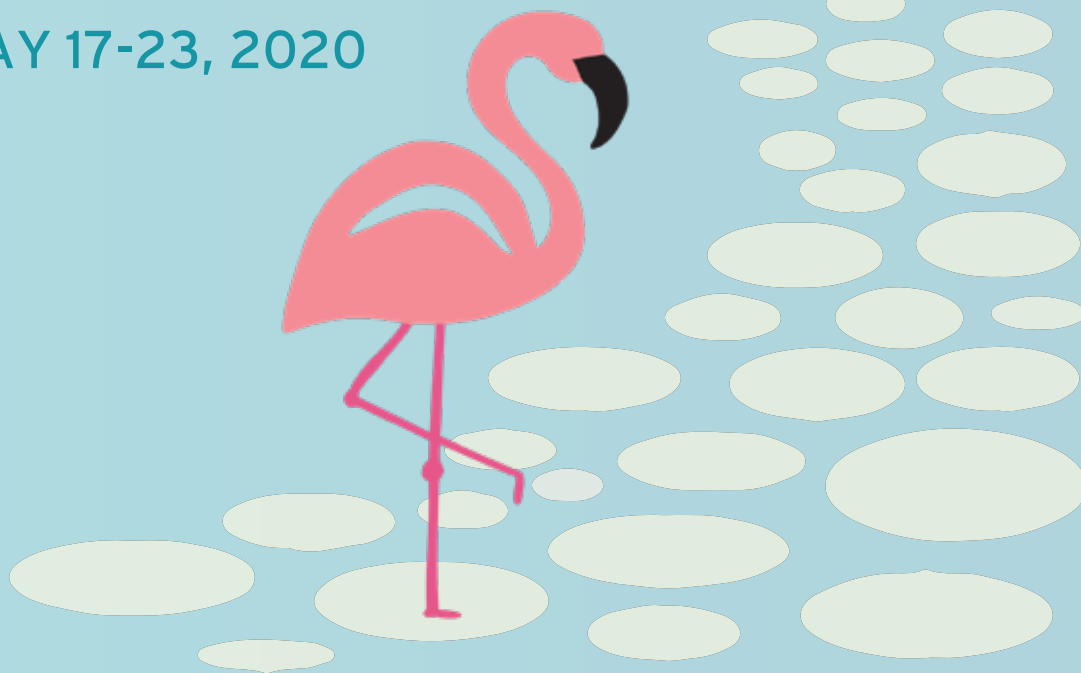
SPRING 2020

KEVIN ROUX

TAKES A STEP
FORWARD IN
HIS RECOVERY
DURING

STEPS-2-BALANCE

MAY 17-23, 2020



VEDA

A QUARTERLY NEWSLETTER
OF THE VESTIBULAR
DISORDERS ASSOCIATION

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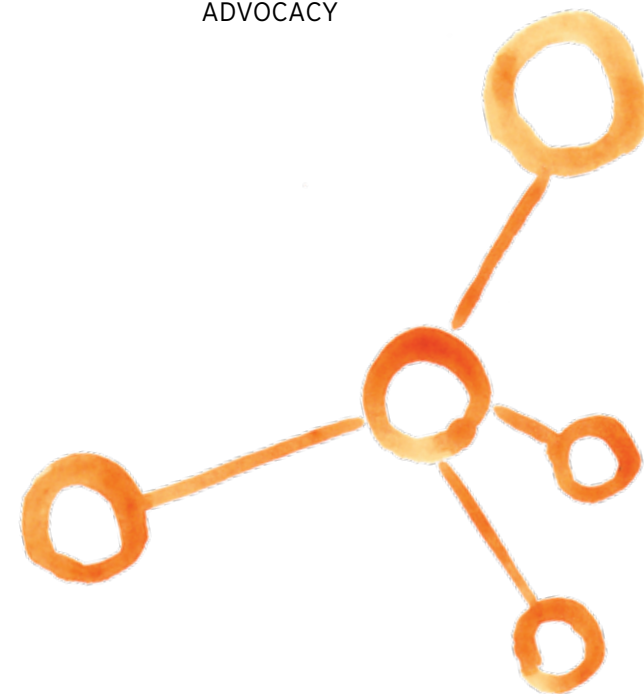
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Football Changed My Life Forever

By Kevin Roux

2005 was the year my life would change in a way I could have never foreseen or imagined.

At the time, I was sixteen years old and in great health. I was in high school and dreamed of studying music in college. I was practicing guitar three to four hours a day, and I loved every minute of it.

I have also always loved sports. Growing up, I played baseball, soccer and basketball. In middle school and high school I was heavily involved in football. After school my afternoons were spent at the gym and my evenings going to practice. Weekends were all about the game. Apart from the injuries you might expect from a sixteen year old boy who loved sports, health was never something I had to worry about. On October 29, 2005, all that changed.

I was playing the last football game of the season. During the last play before half time I remember laying at the bottom of a pile and seeing another player falling towards me. As if in slow motion, we slammed together, helmet to helmet. I could tell right away that I had a concussion.

Sitting in the locker room at half time, I can remember having a splitting headache and feeling like I was going to throw up. I even said to myself, "I have a concussion." I also remember thinking, "It's the last game of the season, and I'll have plenty of time to recover."

I continued to play in the game, and continued to sustain hits to the head. The culture of football is "pain is food," so I pushed on. Eventually, at the beginning of the fourth quarter, I ran full speed to block another player running full speed at me. Once again, we collided helmet to helmet. At

this point, I started to see multiple football fields and I felt so dizzy I could barely stand. The next day I went to a neurologist, and, surprise, surprise, I received an official diagnosis of "concussion."

For the next few days I felt extreme dizziness, vertigo, imbalance, migraines,



ABOVE: KEVIN (#90) ALWAYS LED THE CHARGE, ALONG WITH HIS TWIN BROTHER, STEVEN (#65).

brain fog, short term memory loss, nausea, slurred speech, and was unable to sleep, despite feeling tired. I kept thinking I would eventually get better. When I did not get better, the neurosurgeon diagnosed me with post-concussion syndrome, and said there was nothing more he could do other than send me to a specialist to learn how to cope with the symptoms.

Days turned into weeks. Weeks turned into months. Months turned into years. I never



expected this concussion to become a fifteen year battle and the hardest thing I've ever endured.

Within the first year I started noticing new symptoms, such as body pain, muscle tension, and food sensitivities, as well as anxiety and depression. Everyday life, and especially school, was very difficult. I missed most of my senior year of high school, and my college plans were drastically altered. It took me three years of community college and four more years at Winthrop University to finally get my undergraduate degree.



ABOVE: KEVIN FOUND HIS WORK AND HIS PASSION AT BETTER BRAIN & BODY.

One of the most difficult aspects of a vestibular disorder is how invisible it is. On the outside I looked fine. On the inside I was miserable. This wasn't how I was before. My friends and college professors, even some of my family members and doctors, accused me of making up my symptoms, or at least over-exaggerating them. Most people never truly understood the level of pain and discomfort I was in 24/7. I always wished I could show people the real struggle and what I was capable of before my injury.

Over the course of ten years I went to countless doctors and specialists trying to find answers. I had many different experiences with doctors. Most healthcare providers were cordial and genuinely tried to help. Others were not so compassionate. I had one doctor yell at me because I stopped taking a medication that made me feel worse. I also had a doctor, whom I had put a lot of hope in, say, "Most people get better when the settlement comes through."

In the end, the outcome was almost always the same: the doctors were able to confirm my diagnosis but unable to "fix" me. I was put on so many medications, which usually made me feel worse. I tried treatments such as physical therapy, hyperbaric oxygen chamber and IV infusions. Some of the treatments provided temporary relief from one or two symptoms but nothing ever "cured" me. I started to give up hope.

After college I was unable to find work, so I moved back in with my parents. My family and my faith have been my rock through this whole experience. Without them, I would be in a very different place. Moving back home with a college degree but no job and feeling trapped in my body increased my depression to a level I had not experienced before. My mom couldn't take seeing me in pain anymore. She was determined to find a treatment that would work.

After a lot of research, she discovered the field of Functional Neurology. At that time, Cerebrum Health Center in Atlanta had a team of doctors whose only goal was to treat patients like me who suffered with daily, debilitating symptoms from brain injury and other neurological issues. After an extensive exam, for the first time ever, this team of doctors was able to explain how my brain and vestibular system were affected, and create a treatment program specifically for me.

I traveled back and forth to Atlanta that first year three different times to be treated, each time staying as long as a month. I was overwhelmed to realize that these treatments were actually improving my symptoms.

One of the moments that stands out the most is the day my dizziness calmed down. I remember standing up after a repositioning maneuver session with Dr. Jerome Lubbe (now at Thrive Neuro Health). Feeling the ground under my feet again, I realized my vision was clear. That was the first time in twelve years that I felt like I was not spinning or falling over!

During one of my visits in Atlanta, one of the doctors told me there was a Functional Neurologist in Charlotte, NC where I live, Dr. Alicia Brown at Better Brain & Body. I was elated to learn of a doctor near me where I could continue my treatment. After receiving the planned treatment, I am happy to say that most of my symptoms are completely healed!

In January 2019, after being a patient for almost four years at Better Brain & Body, Dr. Brown hired me as an assistant. Following a training and a certification process, I am now assisting patients through the same process I have been through myself. It is incredibly rewarding and humbling to share in others' experiences and help them in the way I was helped.

Throughout my treatment, one thing that kept me going was talking with other patients who were struggling with the same symptoms I was. I'd felt so alone for so long, it was like a release, a validation, to find others going through the same experience.

This motivated me to start the Charlotte Area Vestibular Support group (CAVES). It has been incredible to hear people's stories, and to share ideas on treatments and ways to cope. The Vestibular Disorders Association (VeDA) has been instrumental in getting this group going, providing me with support group guidelines, meeting topic outlines, and administrative tools. I wish I had found these resources earlier in my journey.

It's amazing to have an organization that shines light on these invisible but debilitating illnesses. My injury has truly been the hardest thing I have ever been through, but at the same time, I find myself incredibly grateful for where I am in life because of it.

I know there are many people going through similar issues that may feel hopeless and alone. I just want to say: you are not alone; never give up! You never know where your life will take you and who you might positively impact because of your injury or disorder.




ABOVE: KEVIN (LEFT) AND HIS BROTHER, STEVEN CELEBRATE BALANCE AWARENESS WEEK 2019 DURING A SUPPORT GROUP MEETING.

Kevin is now leading the charge as VeDA's Steps-2-Balance Ambassador.

Learn more about Steps-2-Balance at vestibular.org/S2B.

TAKE A STEP FORWARD

IN YOUR RECOVERY



COVID19
affects all of us.
Share your story!

HOW TO PARTICIPATE

1. Register
2. Share on social media
3. Hold a virtual event
4. Ask for support
5. Purchase a "Vestibular Warrior" t-shirt



STEPS-2- BALANCE

MAY 17-23, 2020

REGISTER AT
[VESTIBULAR.ORG/S2BP2P](https://vestibular.org/s2bp2p)

HOST A VIRTUAL EVENT

WHAT BETTER WAY TO HONOR SOCIAL DISTANCING AND SHELTER IN PLACE GUIDELINES AND STILL PARTICIPATE IN STEPS-2-BALANCE?

Dance Party

Put on your favorite music and boogie!

Happy hour

Mix yourself a cocktail (or mocktail) and donate the cost of your drink.

Wine tasting

Pour yourself a glass of wine (or sparkling cider) and donate the cost of a fancy wine tasting.

Coffee/Tea Meetup

Brew a cuppa and donate the cost of your coffee, tea and/or pastry (yum!).

Stay-at-home hair salon

Is your hair getting too long? Are your roots showing? Share what tips you've discovered for dealing with your unruly locks, and donate what you saved by skipping a haircut and/or color.

Self-Massage

Talk about ways you've been pampering and donate the cost of a spa treatment.

Facial Party

Dig out that blue clay mask and proudly display your beautiful face! Donate what you saved by having a virtual facial.

Mani/Pedi Party

Soak your feet, and use that glitter polish you've been hoarding! It's a great opportunity to catch up with friends. Donate the cost of your virtual manicure and/or pedicure.

Window Shopping

What's your favorite new online shopping website? Get together (virtually) with friends to share your recent splurge, and donate what you would have spent on gas to get to the mall.

Clean your closet

It's time for spring cleaning! Take a page from Marie Kondo and put aside anything that doesn't give you joy. Donate what you would have paid a professional organizer to do it for you.

Involve the kids

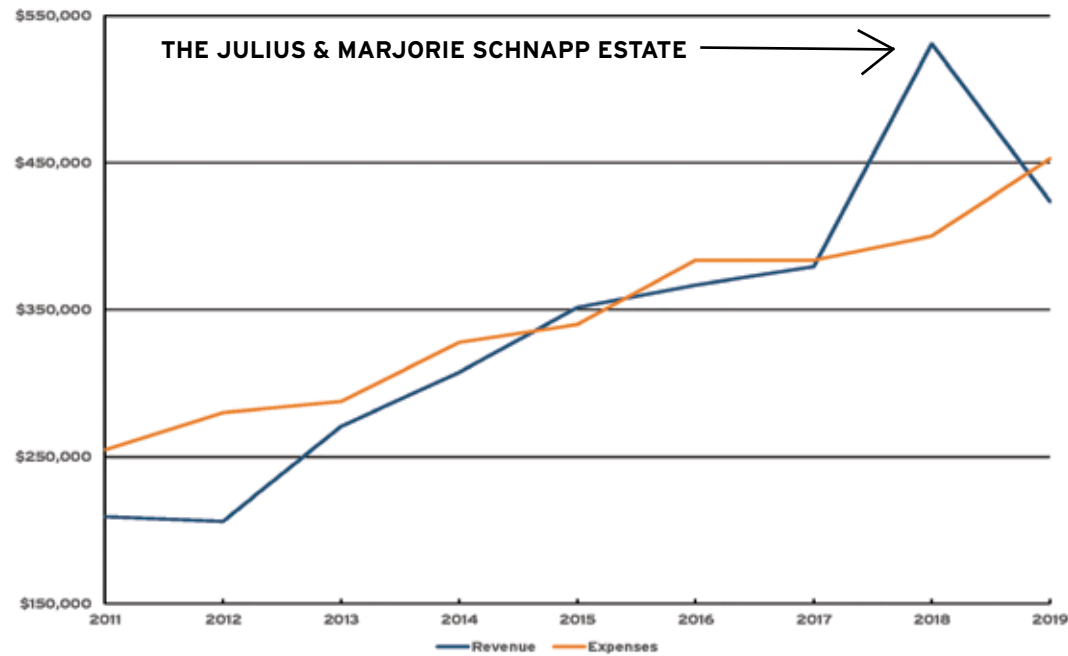
Hold a virtual kids' dance party, drawing contest (best flamingo?), charades, Pictionary or trivia game. Ask your kids what they want to do!

PRO TIP

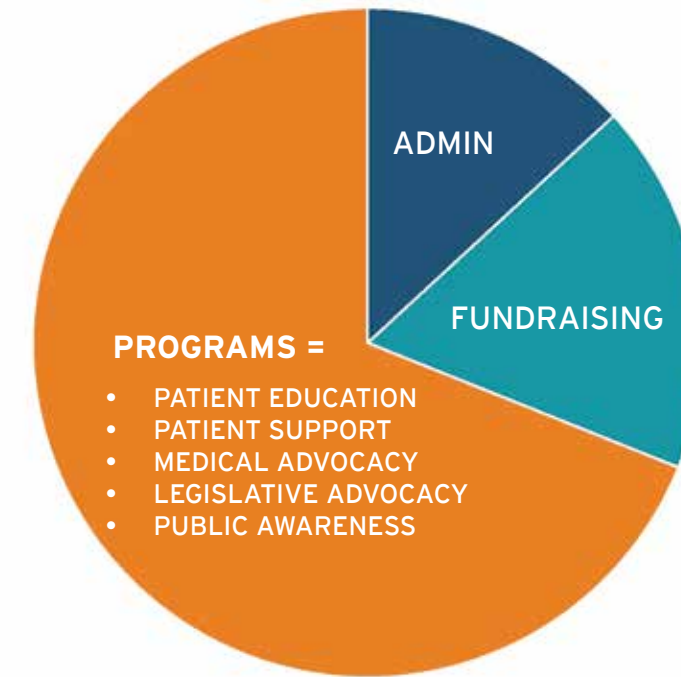
ZOOM, SKYPE, AND GOOGLE HANGOUTS ARE SOME GREAT VIRTUAL MEETING/
GATHERING PLATFORMS. YOU CAN ALSO USE FACETIME, FACEBOOK LIVE, OR
JUST PICK UP THE PHONE!

2019 ANNUAL REPORT

WE STEWARD YOUR GIFTS WISELY



WHERE YOUR DONATIONS GO



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927
Patients received
one-on-one support

195
Volunteers

63
Support Groups

MILESTONES & CHALLENGES*



**4 COLLECTIVE
ADVOCACY ACTIONS**



**96K PEOPLE REACHED
THROUGH ALL CAN FALL
CAMPAIGN**



**275K PEOPLE REACHED
THROUGH DID YOU KNOW?
CAMPAIGN**



**10 NEW/UPDATED PATIENT
EDUCATION RESOURCES**



***MANY DONORS NOT
MOTIVATED TO GIVE BECAUSE
OF TAX LAW CHANGES**



***LIMITED RESOURCES
ALSO LIMITS WHAT WE CAN
ACCOMPLISH**

Long-Term Outcomes in Triple Semicircular Canal Plugging

By Dennis Fitzgerald, MD

INTRODUCTION

Meniere's Disease is an idiopathic (without known cause) disorder of the inner ear. Its four main symptoms are sensorineural (inner ear) hearing loss (often one-sided and fluctuating), tinnitus (noise in the affected ear), fullness or ear pressure, and episodic vertigo (often spinning and accompanied by nausea and vomiting).

BACKGROUND

Many treatments have been used to control the frequency of Meniere's attacks, such as dietary changes, vitamins, and diuretics. For patients whose attacks continued unabated, the next level of treatment has been the use of corticosteroid medicine taken orally or injected into the ear. This is effective in 25-30% of Meniere's patients. Beyond this level of treatment comes non-destructive endolymphatic sac surgery. Finally, destructive interventions include: intratympanic gentamicin (a steroid injection through the eardrum into the middle ear), vestibular nerve section (where the vestibular nerve is cut to eliminate recurrent vertigo attacks), and surgical labyrinthectomy (removal of the labyrinth).

The idea behind single semicircular canal (SCC) plugging began decades ago to control vertigo from persistent benign paroxysmal positional vertigo (BPPV). The paper that I reviewed chronicles the use of canal plugging of all three SCC's (triple semicircular canal plugging or TSCP) to control vertigo in Meniere's patients.

METHODS

Over a six year period, 361 cases were studied. Vertigo control and hearing loss were monitored. Seventy-three patients were treated with intratympanic gentamicin as controls. Three hundred and sixty-one patients were treated with the TSCP. These patients were followed for two years. In the TSCP group, 80% had complete vertigo control and 18% had "substantial" vertigo

control. Hearing loss occurred in 26%. In the gentamicin control group, vertigo control was 63% and "substantial" vertigo control was 20%. Hearing loss occurred in 25%.

DISCUSSION

This TSCP appears to be a novel, and, as yet, unsubstantiated approach to control vertigo attacks in Meniere's patients.

This paper's report of 63% complete control and 20% substantial control of vertigo with gentamicin is in line with a long-term study from the Mayo Clinic, which showed 86% total control (complete + substantial).²

Intratympanic gentamicin can be performed in several protocols. The Mayo Clinic uses a slow approach with an injection on a monthly basis. This reduces the incidence of gentamicin induced hearing loss and still provides excellent vertigo control.

The disadvantage of the TSCP is that it involves a surgical procedure of at least one to two hours under general anesthesia. Unless this procedure is done by experienced surgeons, the 25% incidence of surgical hearing loss could be quite a bit higher. There are other potential complications inherent in inner ear surgery, e.g. vertigo directly due to surgery on the inner ear, postoperative infections, facial nerve injury, bleeding, and pain.

STUDY LIMITATIONS

This seems to be the first reported series of TSCPs and will have to be duplicated by other centers to validate its results.

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- JEANNE O.

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To donate, visit vestibular.org/OTL.

YOUR SUPPORT MATTERS

We are all affected by COVID19. Your gift allows VeDA to continue supporting vestibular patients during these trying times, when symptoms are heightened and healthcare systems are overloaded. STAY SAFE!

Forging the Future: Virtual Vestibular Rehabilitation

By Abbie Ross, PT, DPT, NCS



INTRODUCTION

Telehealth is catapulting to the forefront of healthcare due to the safety measures enacted in response to COVID19. This opinion piece explores the viability of virtual vestibular rehabilitation therapy and discusses the benefits and challenges that accompany the use of telehealth.

We are facing unprecedented times. It is broadcasted every hour of every day and flooded on our social media channels. The COVID19 pandemic is felt all around us. Moreover, it is affecting our jobs, our children's school schedule, and our access to healthcare providers. Talk about stress. It is stressful enough to navigate the vestibular disorder waters alone, now add this virus to the storm and the forecast suddenly appears even gloomier.

However, there is a light shining through the cloudy skies and it goes by the name of telehealth.

While telehealth made its entrance years ago, it now, more than ever, plays a significant role in connecting clinicians to patients.

For most patients, and many clinicians, telehealth is a novel approach to healthcare. As defined by the American Physical Therapy Association, telehealth is "the use of electronic information and telecommunication technologies to remotely provide health care information and services."¹ In simpler terms, telehealth is an alternative delivery mode to provide care. In even simpler terms, telehealth is "physical therapy first, telehealth second."² In other words, your clinician will use the same interview, clinical judgement, and care planning skills whether he/she sees you face-to-face in person or face-to-face over video. The value that a vestibular-trained clinician provides to your health and wellbeing does not change based on the medium used.

Utilizing videoconferencing for physical therapy, and in particular vestibular rehabilitation therapy (VRT), is a new concept for many. Thus, the question of how it is even possible may come to mind. Beyond that, if it is indeed possible, is it quality care? I started my virtual practice for some of the obvious reasons: to provide accessibility to vestibular care for those in areas that lack clinicians trained in this field, to provide VRT for those too symptomatic to commute, and to provide flexibility for those unable to take time off from work to attend in-office appointments. After practicing VRT via live videoconferencing for almost two years now, my list in support of virtual VRT is ever-growing.

WHY TELEHEALTH

- Telehealth may seem intimidating

to some due to the technology piece. Good news: most systems are extremely user-friendly. Connecting to the video is as simple as a click of a link or button - that's it!

- Telehealth means one-on-one care. Due to decreasing reimbursement rates, some physical therapy clinics opt to see more than one patient at a time. While this works for some, VRT truly requires one-on-one individualized care, and telehealth allows for that.
- Telehealth is conducive to education. An important piece to VRT is learning about and understanding the vestibular disorder: what it is, how to treat it, and how to implement lifestyle changes to improve quality of life. A bonus is that learning about these aspects can help to lower the anxiety that often coincides with vestibular symptoms.
- Telehealth can improve accountability and independence. When participating in virtual appointments, care rests entirely in the patient's hands. The patient performs therapeutic interventions at the guidance of the vestibular therapist, but he/she is not relying on the therapist for anything more than his/her knowledge and clinical decision making. This suits VRT particularly well because we know how important the home exercise program is for improved management of symptoms.

TELEHEALTH CHALLENGES

I would be remiss to not discuss some of the challenges of telehealth, which may be the very reasons that have prevented some patients from giving it a try. For various rationales, telehealth is not for every patient or for every clinician.

- The patient does not have access to a smart device to connect to his/her clinician via video.
- The clinician may feel he/she must be hands-on in the patient's care, or the patient is cognitively unable to follow verbal directions and would benefit more from hands-on cueing.
- From a patient safety perspective, if he/she does not have stable vital signs, telehealth may not be the best delivery mode for care.
- The use of videoconferencing does not allow for every test under the sun to be performed, as some require hands-on or special equipment found only in the clinic. However, for many patients

WHY TELEHEALTH?

- USER-FRIENDLY
- ONE-ON-ONE CARE
- EDUCATION
- ACCOUNTABILITY

CHALLENGES:

- LACK OF INTERNET ACCESS
- NEED FOR HANDS-ON CARE
- SAFETY
- LACK OF TESTING EQUIPMENT

with vestibular disorders, the interview alone can lead the clinician to a clear care plan, or, at the very least, the initiation of one.

SUMMARY

For the millions of people practicing social distancing, telehealth allows clinicians and patients to connect without disrupting continuity of care. While time will tell if telehealth again falls into the healthcare world's shadows once we shift back to "business as usual," this time of uncertainty demonstrates telehealth's value. Virtual care for both evaluation and subsequent treatments is a viable option for the future of vestibular rehabilitation.

ABOUT THE AUTHOR

Dr. Abbie Ross is a physical therapist specializing in the evaluation and treatment of patients with vestibular and balance dysfunction. She is a board-certified neurologic clinical specialist, a member of

the American Physical Therapy Association (APTA) and vestibular rehabilitation special interest group, and has completed the Vestibular Competency Course presented by Duke University School of Medicine and the American Physical Therapy Association (APTA) in Atlanta, GA. Dr. Ross began her career at NYU Langone Health in New York City before recognizing the need for a virtual vestibular rehabilitation physical therapy clinic. In 2018, Dr. Ross opened Balancing Act Rehabilitation PLLC to provide care through live videoconferencing.

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My Spin on Vestibular Advocacy in Africa

By Sara Abassbhay, BSc, M.Sc., PhD



the severity of dizziness and vertigo that I witnessed made me realize how little I knew about these invisible problems, and how overlooked these symptoms are in healthcare systems.

I returned to Montreal in 2017, where I had earlier graduated with an MSc Physical Therapy degree from McGill University in 2012, to continue learning about the diverse world of geriatrics and VD. Driven by a desire to travel and exchange knowledge about VRT, I moved to Ghana in 2018. I started my work with Anna Hughton, owner of Accra Physiotherapy and Sports Injury Clinic (APSIC), where I have started the implementation of VRT by bringing awareness amongst the healthcare community.

My main approach is giving short presentations in teaching hospitals and clinics to ENT specialists and nurses, general practitioners, and physiotherapists. I also raise awareness in the general population through different interest groups that I am part of. In February 2019, I facilitated a workshop to train the first cohort of 18 physiotherapists for VRT in collaboration with APSIC and Ghana Physiotherapy Association.

Five years ago I was invited to go through a vestibular rehabilitation therapy (VRT) training program as part of my neurological rotation at Khoo Teck Puat Hospital in Singapore. I never imagined the journey that was waiting for me.

With my work in the acute and emergency care outpatient department, as well as with the elderly population in geriatrics, I discovered a strong interest for vestibular disorders (VD). The spectrum of

SARA LOOKS FOR OPPORTUNITIES TO INCREASE AWARENESS ABOUT VRT ON THE AFRICAN CONTINENT.

The process over the last year has been slow and challenging at times. Nonetheless, we have started getting referrals from ENTs and physiotherapists to treat vestibular patients. In addition, an opportunity to collaborate with the Jackson Clinics Foundation and Kenya Medical Training College will give birth to the first VRT program in Kenya this March. My collaboration with Christine Rogers, another passionate advocate of VD in South Africa, will allow me to be part of the faculty



members teaching at the 4th South African VRT training course at the University of Cape Town in June 2020.

From my experience, inadequate knowledge about dizziness management by healthcare professionals, the over reliance on pharmaceutical intervention, and the limited access to continuing education, can increase the risk of chronicity and reduce quality of life for patients with vestibular-related symptoms. As such, I continue to look for opportunities to bring awareness to and organize trainings about VRT in different countries on the African continent. Implementing VRT in a developing country like Ghana has been and is still challenging, especially as a foreigner. The key element to making it possible and rewarding is to remember to consider the variety of perspectives of those involved in the process and the uniqueness of every system. As a Vestibular Disorders Association (VeDA) Ambassador, I hope that my work will draw more attention to the plight of those living with vestibular disorders, and contribute towards improving global access to better healthcare.



SARA TRAINS HEALTHCARE PROFESSIONALS IN GHANA IN VESTIBULAR REHABILITATION THERAPY, INCREASING ACCESS TO AND QUALITY OF CARE FOR VESTIBULAR PATIENTS IN DEVELOPING NATIONS.

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