Life Rebalanced Live 2023

THE VESTIBULAR JOURNEY

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[Danielle Tolman, DPT] Welcome and thank you for joining the Vestibular Disorders Associations for our third annual virtual conference, Life Rebalanced Live. I'm Dr. Danielle Tolman and I will be your host alongside my partner, Doctor Abbie Ross. We are vestibular physical therapists with Balancing Act Rehab, members of VeDA's Board of Directors, and self-proclaimed Vestibular-holics.

[Abbie Ross, PT, DPT, NCS] And we are so excited to bring you an all-star lineup of expert speakers on the vestibular system as well as patients who be sharing their stories. We would like to thank VeDA's donors, staff, and volunteers for their countless hours in putting together this great event. With their contributions, we are able to put the live version of the conference on at no cost to our attendees. If you wish to gain lifetime access to the presentation following the live event, we will have them available for purchase. You'll get the entire week of presentations including the transcripts of each session for just $55. Your purchase directly supports the programs and the continued mission of spreading Vestibular awareness.

[Danielle Tolman, DPT] Before we start, let's give a shoutout to our sponsor this week, the James D. and Linda B. Hainlen Discovery Fund and the University of Minnesota Department of Otolaryngology. Jim Hainlen was the inspiration for this conference, having hosted his own in person conference for patients with vestibular dysfunction in 2018 and 2019. We very much appreciate his continued support.

And on another note, if you have questions that you would like to ask during the live event, feel free to type them into the Q&A tab.

[Abbie Ross, PT, DPT, NCS] Our topic for day one is the Vestibular journey. The term is unfamiliar to many, so it may be daunting when symptoms first develop. Who do you see? What do you do next? We would love to open the virtual conference with an overview of what a vestibular journey might look like, what symptoms might develop, how to find a qualified provider, and anticipated roadblocks or challenges that may come up along the way. And, of course, many more.

[Danielle Tolman, DPT] We would like to introduce our first Speaker, Dr. Habib Rizk. He is the director of the vestibular program at MUSC, which is the Medical University of South Carolina, where he developed a multidisciplinary dizziness, evaluation and management program for the Department of Otolaryngology. Dr. Rizk, thank you so much for joining us. We are so excited to have you here.

[Habib Rizk, MD, MSc] Thank you for having me.

[Abbie Ross, PT, DPT, NCS] We will be jumping right into questions. Throughout the show if you have questions come up please put them in the Q&A, we will address them toward the initial show. So let's begin. What are some of the more common symptoms that people may experience with vestibular dysfunction?

[Habib Rizk, MD, MSc] Patients usually present with ongoing business that can be a spinning Dizziness or in delusion of movement, or more of a light headed type of dizziness or more likely imbalance, unsteadiness, gait disturbances.

As we talk more about this, some vestibular problems lead to vagal reactions, so it's quite common to have a mismatch of symptoms that are for some parts related to the vestibular dysfunction, for another part they may be related to a vagal reaction to a vestibular problem like nausea, vomiting, sweating, passing out. But the typical ones are spinning, an imbalance.

[Danielle Tolman, DPT] And everyone experiences those symptoms differently, correct? Somebody might experience symptoms a little bit less more frequently than someone else with a particular diagnosis.

[Habib Rizk, MD, MSc] Correct. And I would add to that that there are other things to look out for as providers. If the symptoms are spontaneous, if they show up on their own or are triggered by weather changes or by dietary problems, there are also components that we are discovering more and more patients with vestibular dysfunction coming and using words to describe their symptoms such as being in a brain fog, or I feel like my head is detached from my body or I am walking on a cloud. All of those symptoms in the past, we used to assume they had psychogenic issues, but now we know they are related to vestibular dysfunction but they are much more difficult to express or explain.

[Danielle Tolman, DPT] So it sounds like finding the right provider to listen to what the patient is saying is very important. Going from provider to provider is very common, people with vestibular dysfunction have this experience. Can you touch on the typical or ideal path of ideal diagnosis and treatment or what type of provider to start with or who they might be pressing through?

[Habib Rizk, MD, MSc] Sure. The main problem that patients encounter is a lack of training in the providers they end up seeing. That's why they end up seeing so many providers. It's about finding the person who is trained or sees enough Vestibular patients to start the diagnostic process. So, this provider is usually a diagnostician, so ideally is an MD, or should be an MD or DO that is trained in vestibular disorders whether it’s a neurologist or an ENT/neurotologist, these are two big classes of medical doctors who see these types of patients.

Physical therapists are an important asset to the vestibular patient. Unfortunately because of the lack of enough trained diagnosticians, physical therapists are ending up being the diagnostician, which is awesome in the very well trained individual who guides patients where they need to go, but at the end of the day sometimes patients encounter a physical therapist who is not very well trained, and they are trying to do their best for the patient and maybe they lead them down the wrong path and that leads to the wrong diagnosis, so ideally, you have a diagnosis or label of the dysfunction by a diagnostician, preferably a doctor, followed by ancillary management with an appropriate of clinicians, including vestibular therapists and audiologists who can guide or refine the diagnosis, and give us an idea of the vestibular system and how it is functioning, how it is interacting with other systems.

[Abbie Ross, PT, DPT, NCS] I want to put in a great plug for a feature that VeDA has on this website. It can be hard to find a diagnostician well versed and vestibular dysfunction, but on the website there is actually a tab that says find a clinician. You can sort through clinicians in your state or your city by what type of clinician they are to help you start your process, so that is a very good place to look, if you are in the beginning of your birch or if you are any new provider. But with that, one of the key roadblocks with patients is finding the provider. Can you touch on other roadblocks or challenges that patients may face in their journey?

[Habib Rizk, MD, MSc] So first of all, it's finding the appropriate team to take care of you. That is a very important part of it. Second of all, the other roadblock which I touched on earlier is that symptoms can intermingle with other symptoms that lead patients or doctors on a goose chase to rule out cardiovascular disorders or things that are not necessarily the heart of the problem. And that leads to significant delays. Third -- and I think it's the most important double a vestibular dysfunction is an invisible dysfunction, it's not like you have a broken arm and you are in a cast. It leads to minimal visible finding if you are doing a summary exam, if you're not doing a detailed functional exam, and those patients often feel like they’re being dismissed -- or worse, they feel like it's in their head. They start to doubt their symptoms. And that's something that I have seen over and over again where an easy fix has been delayed for months or even years as the patient literally says, I thought I was crazy.

Another roadblock is, sometimes the patients will have the opposite side. The patients are demanding treatment, but they are not understanding that they need to put in the effort. If we talk about vestibular treatment, it requires a lot of buy in from the patient. It's not always fixed with medication or one session of physical therapy. Sometimes it is a long term rehab, sometimes it's a deep overhaul of their lifestyle, and if they are not willing to put in the effort that's not going to happen, so part of the challenge is also the patient facing choices that they need to make at. Those are the main roadblocks in my opinion.

[Danielle Tolman, DPT] Sometimes, you are the first person in line to interact with this patient and listen to their symptoms, and it is very important to build a team of people in the area and know who to refer to and when it is appropriate to perform certain interventions. So as you had mentioned earlier, sometimes you have someone who's getting started with maybe the wrong approach first, which could delay treatment or they are not getting to the right providers. So certainly as a patient, doing more research and knowing who specializes in this type of dysfunction is important, and also for clinicians know we refer if it's not necessarily in your wheelhouse, per se.

So, the multidisciplinary approach is something that you are a champion of. It is very much preferred for the management of this vestibular dysfunction. Can you talk about what that type of approach is and why it is so great for our vestibular patients?

[Habib Rizk, MD, MSc] I would like to preface that not every single time will a patient need to see a therapist. But if you are treating vestibular disorders in volume and seeing a lot of patients, then you need to build that team around you. There aren't a lot of vestibular physical therapists to go around, they are a very rare breed of physical therapists but they are the workhorse of any vestibular center.

For example, what we did in South Carolina and other clinics, not only did we set up the diagnostic lab with audiology and open the door to see more patients, we also reached out to physical therapists across the state of South Carolina. Not all of them are vestibular therapists, we train them virtually or on a case-by-case basis. And not all of them are our vestibular therapists. For example, someone lives three hours away, I send them for physical therapy, and make sure that the therapist has resources to guide the treatment plan. That is the only way to build a multidisciplinary team on a spread out surface to affect as many patients as you can, because there are areas everywhere, whether there are PT deserts or medical deserts.

So in terms of the multidisciplinary approach, first comes the limitation of having one team to see everybody. That leads to some of my patients coming to see me, and they expect that I will do the full testing every single time. That is not how I work, and that is not how we should work with vestibular evaluation. Again, the multidisciplinary approach means I have a team that can rely on to fine tune my diagnosis, the functional level of the patient, and treatment plan. But it doesn't necessarily mean that a patient needs to see 15 different providers for their condition every single time.

As we talk about multidisciplinary approaches come up the way I would like to compare it is that vestibular patient, as you said, can present with so many symptoms that crisscross in involve multiple organ systems in the body, but when you map the system, it's also widespread in the brain in the same way that it's spread there, we have to understand that dysfunction can affect multiple aspects of the patient's health, and there is no one provider who can tell you that they can take care of all of it. Mental health is a big problem in those cases and having the necessary support group lists, partnerships with the psychiatrist or psychiatry department, that is important.

Having a good relationship through the primary care physicians and internists is extremely important because there are a lot of times we may need to prescribe something that interferes with other drugs, so again, what I would give as advice is not going to the dizziness clinic and necessarily expecting that this is going to fix everything at that specific point in time -- you have to think about a vestibular disorder as a journey that might require other factors along the way.

[Abbie Ross, PT, DPT, NCS] I want to dig a little bit deeper into who makes up the multidisciplinary teams. Let's say that I am a patient. And I have a feeling based on my research on Doctor Google that I have BPPV or I have migraine. Is there a certain MD that I should be looking for first?

[Habib Rizk, MD, MSc] So whenever you hear migraine, people think migraine headache. And sure if you have a lot of headaches, a Neurologist is the main person you should be seeing. But in the past, in the past nine years since the creation of the awareness criteria for vestibular migraine, our conception of migraine has shifted tremendously. We as ENT ended up seeing a large portion of vestibular migraine patients who were dizzy without having a migraine.

So the short answer to the question you ask is, a Neurologist or otologist would be a great way to start. BPPV in someone has never diagnosed, if they see a well trained physical therapist then they can get the diagnosis straight away, but if we were talking about the ideal path and not what is usually or necessarily happening in the US health system, in an ideal path you try to get a diagnosis with a provider, usually a neurologist or ENT, and then you go from there. Again, sometimes I trust vestibular therapists more than other doctors, to tell you the truth, because they are very well trained at the oddities. But again, we are talking about typical pathways, ideal pathways of what it should look like: it's trying to get a diagnosis first.

vDanielle Tolman, DPT] Just as a sidebar come up. We have a question where a patient was told that Vestibular dysfunction would normally disappear between 8-12 months. They're coming up on one year of symptoms. Is this something you would typically hear in this situation?

[Habib Rizk, MD, MSc] Actually I do. A lot of patients are told there is nothing to be done, it will go away on its own, as it relates to vestibular neuritis. And sometimes it does go away on its own, but not if you are an older patient. If they don't improve on their own, those patients end up in limbo.

Appropriate education of the true history of the sentence is important. So even if you actually recover from vestibular dysfunction, it is typically with you lifelong. It may manifest at a later date in a different form, so patients need to be well educated about that.

So that specific person was asking if symptoms had persisted, then they need to be evaluated medically, but also functionally by a physical therapist to see what is the vestibular dysfunction, or rather how is it affecting all of the metrics of function to basically quantify the impact on balance and daily activities.

[Abbie Ross, PT, DPT, NCS] Right, and when we think about providers, whether a vestibular physical therapist, a Neurologist, ENT, what qualities does it take? Because I think there are specific qualities for this patient population to make you a really good provider. One that I think of off the top of my head is that you have to have empathy and understanding for patients, especially as we touched on earlier when they are coming to you explaining things that sound different than people are used to hearing. To us we hear it every day, I feel like I am walking on clouds, but what does it take in a provider to really provide quality care for this patient?

[Habib Rizk, MD, MSc] I would definitely say empathy, but with vestibular disorders it is an invisible injury and the symptoms do sound weird when patients come in and say, I feel like my head is detached from my body. At the end of the way. It's just another way of saying I am spatially disoriented. The other important aspect is having good training and good exposure, and not having tunnel vision. Tunnel vision is unfortunately, on both ends of the spectrum for medical doctors as well as physical therapists.

From a medical doctor standpoint, neurologists hear things like neurologists don't believe in vestibular migraines. It's kind of, it moves science into a field of dogma and not true science. So a neurologists says “OK, you don't have a headache so you don't have a migraine.” You have events on the other end of the spectrum saying this is not a surgical problem. So I'm not wasting my time evaluating it. 40% of referrals to our clinic come from the general ENT. Within the past decade there has been a big shift in the way we train our residents, our ENT residents.

This is something where unless you're never going to see any visitations come up, they are not going to see you. So not having the appropriate exposure and not fleeing from the exposure is important. From the physical therapy standpoint, you have superb physical therapists who are very well trained, and you have therapists who want to help their patients. But the scope of practice is limited to BPPV. And they end up treating everybody because they are not used to seeing anything other than that, which sometimes may lead to worsening symptoms or a delay in diagnosis. So, any provider who is interfacing with the Vestibular patient needs to have enough background information, needs to no limits, and needs to know when to appropriately refer in my opinion.

[Danielle Tolman, DPT] This is where we can encourage patients to continue to be advocates for themselves. See where a lot of them have to be able to navigate this journey, but do your research. You can call ahead to offices and ask if the doctor the physician has been comfortable with treating these kinds of conditions, you can ask what type of technology or testing they do for these patients just to see if you will land in the right place. Some ENT, you know, they specialize in throat issues or vocal cord issues, and there are other ENTs who focus more on the sinuses, so you want to ask around and see if there is an ENT who does more with the inner ear or dizziness just to help to focus what you are trying to get to the bottom of.

We had another really great question in the Q&A, we are talking about here. Somebody asked, do you have suggestions for combating old medical records full of missed diagnosis? I find it impossible to get the information corrected. I am not a hypochondriac. Are there ways to combat that? As you know, some people have two, 3, 4, 5 diagnosis added at a time. How does someone go about weeding those out?

[Habib Rizk, MD, MSc] It's not uncommon to have more than one diagnosis and vestibular world. You can have BPPV and vestibular migraine, you can have many years disease and vestibular migraine, they're not mutually exclusive. But the question that this person is asking is important, because it leads me to how the patient needs to be implicated in their own care.

I think the most difficult part of the encounter with the patient is when I ask a question and they say it is all my records. I end up telling the patient, if it was that easy. We wouldn't have been waiting for years for a diagnosis. So the best way to combat errors is to be able to sit down, and even though it is frustrating, except the fact that you are going to ask a lot of the same questions. We aren't trying to trip you up or second guess you, well it's because I want a better understanding of what you are going through, and the best way is how you describe your symptoms. That's my launching pad for any diagnostic investigation. I also would like to say that old records are great to know what medications you are on, these are important to know.

In our clinic, we instituted a sheet of paper that the pharmacists delivered to the patient. So that I can get a good idea of what medications they are on here that's just one part of the medical records that I find valuable or important to have on hand when you come to a doctor's appointment. It's important that I know on the spot what you’re on. So basically, the main issue about combating errors is being sure to obtain a fresh perspective, which requires you to answer a lot of the same questions. I don't agree with repeating the investigations and I rarely actually do full investigations on Vestibular patients, probably around 30% of them get the full evaluation.

Because a lot of times we don't need to do the full vestibular lab workup to arrive to a diagnosis and treatment plan. Did I answer that question? I feel like I went into a sidebar.

[Abbie Ross, PT, DPT, NCS] It's easy to do that. There is so much to cover, but I wanted to go back to something to look for or consider as a provider, and it relates to tunnel vision. But I think it is slightly different. I cannot tell you how many patients I've had to switch gears with, meaning being open to going down a different path of intervention if one intervention is not working whether medication-related from your end, or exercise-related from our end, or lifestyle modifications. I think it's big in this population because everyone presents so differently. And then on top of that, expectations. Patients want to know when they are going to get better, is this going to happen again and I want to hear your take on how you set up patients for success in terms of managing expectations.

[Habib Rizk, MD, MSc] That's a great question. And I think, in the chronic Vestibular Disorders, that's the most important thing to address during a visit. It's more important than finding a label for their illness. What I would say is that it depends upon the diagnosis. There are diagnoses that are straightforward, like positional vertigo, you may have a 10% chance that this happening again - 10% per year. So likelihood that this will happen again, is high, but we can teach you how to be autonomous, how to recognize the symptoms, and which reduces a lot of the anxiety. In other diagnosis, and usually on a first visit I tell patients that I don't have a clear label or diagnosis for them, but they need to be comfortable with a trial and error approach because we do sometimes have to switch gears because new information came to light or initial medications.

The most challenging population for those with chronic symptoms, and depending on where I ended up labeling them, I usually encourage them to get in touch with a peer support group. We do have one locally, and I do direct patients to it. Not anyone patient is similar to the other. But if you look at the collective of individuals going through similar Disorders, it might give you an idea of what to expect, better than what a medical doctor sometimes can give you advice wise, I think the peer support group is the best way to get a better idea of expectations in those chronic disorders.

[Danielle Tolman, DPT] Speaking of chronic disorders, I am scrolling through the Q&A here and people are worried are worried about this is something they will have to live with forever. Is this something that, if they've had chronic dizziness they just have to kind of buckle down and wait it out? Or is this something you can experience improvement from, eventually getting back to some aspect of a better quality of life and do the things you want to do?

[Habib Rizk, MD, MSc] The majority of patients actually improve. You know, you always have the patients who don't respond to a lot of things. And, you know, that's reality, but they're not the majority of patients. Majority of patients who are well accompanied and with peer support groups and are well informed and have a good education of what the diagnosis is, its primordial. A lot of patients don't understand how important it is to make those lifestyle changes. I'm going to give you a small example. Meniere's disease. We have patients who say I have tried the low salt diet, but it has to be ongoing.

They have to go through a four week screening period where they are really restricted on salt and. A lot of patients who came in miserable supposedly having followed a low salt diet did double effort because they thought they had chance of getting into the trial, they were not doing it right here back. They did not have that motivation. Sometimes the motivation is hard to find, and sometimes it sucks to have a vestibular disorder. But when a majority of patients put in the effort, and trust is not something to impose on somebody, but if you are trusting the treatment of your therapeutic team and you follow their recommendations knowing that there might be some curves along the way where the treatment is fine tuned, the majority of patients get to a better quality of life.

I tell patients that this is not cancer, we are not looking to get to 0% cancer cells. We are getting you down to a level of symptoms that is functional enough that it does not affect the quality of life. And when you measure of the outcome with this lens, a lot of patients achieve success in doing what they want to do.

[Abbie Ross, PT, DPT, NCS] I like that. There's so much actually within a patient's control with the right education, and compliance to the program or recommendations provided. But there are also things that are outside of a patients control, external stressors, for example, a death in the family or a hard time at work -- how might that impact the Vestibular journey?

[Habib Rizk, MD, MSc] I don't want patients to come away from the lecture thinking that it's all on that. I am trying to convey a message of empowerment, and there are a lot of things that you can do that is in your control. Yes our stressors that we cannot control.

The main thing is the financial insecurity that stems from Vestibular disorder. A lot of studies show how much absenteeism there is in the workforce with Vestibular Disorders, and how much there is presenteeism - like you are at the at your desk, but you're not productive. And there's a study out of Europe that shows 12% of disability claims are related to dizziness. So it is a big factor in that regard. But it depends on which country you live in at the end of the day. And how much social support. We do our best to help patients. In a lot of cases, my patients have insurance for disability. A lot of states in the US they have rehab programs that can retrain them and help them find a job with less stressors, but managing the stress is very important.

In Charleston we have a lot of factories, Volvo, Boeing, a lot of people working in industry with loud noises and fluorescent lights, a lot of movement. So if they have a Vestibular migraine patients may quit their job or change jobs, and that is something that unfortunately sometimes has to happen, otherwise you risk injury on the job. But apart from those specific examples we can work with the patient to reduce the burden that this presents on their work, but not everybody achieves success using that metric.

Other stressors that is important to know about is sleep deprivation. We are a culture that is chronically sleep deprived anyway, and in Vestibular Disorders it rings very true. For example, and here I am talking only from my expert standpoint but I have had vestibular neuritis myself.

So from a patient's perspective too, so if you go on a stretch of sleep deprivation it's not uncommon to develop unsteadiness or Vestibular neuritis symptoms. Vestibular migraine patients are usually very sensitive to sleep deprivation. That's something to take into account. Even though these are external factors, and can still have some control over it. One factor you have no control over is weather. I have patients who work in different states, and on the west coast they are fine, but the minute they hit Charleston all of their woes come back. These are things that you cannot really tackle head on, but you can start recognizing them and reducing the other triggers that you have identified along the way that may help manage them better.

[Danielle Tolman, DPT] How about commorbidities and how they affect vestibular diagnosis? There are a lot of questions in the Q&A in regards to things like AFib or vagal nerve issues, even very high diagnosed anxiety. How do these comorbidities impact Vestibular journey?

[Habib Rizk, MD, MSc] Sometimes the symptoms of vestibular dysfunction can interfere with vagal reactions that may cloud the picture. So it’s not uncommon for Vestibular patients to have high rates of anxiety or comorbid depression. It has been well studied in a multitude of Vestibular Disorders.

We will start with this, which is kind of the elephant in the room -- anxiety and depression. They are a significant modifier of treatment and successful treatment. Anxious people are less likely to participate fully in a rehab plan, or are less likely to give time for the treatment because every treatment does not work immediately come you have to give it time to work. Anxious patients or patients who have depression are usually on medications, and a lot of the medications that we use for vestibular disorders are off label and are antidepressants that may affect what they are already on. I am not treating anxiety or distress pression but the Vestibular problem, and those drugs work like that. So you know, a lot of the comorbidities you cited, they interfere from a symptom standpoint which clouds the picture. So these are my Vestibular migraine patients who are also vagal and are sent for a heart monitor or they go down that road and everything comes back normal. Or from a treatment perspective because of the medications they are on, it may interfere with some of the medications that I would like to put them on.

Other comorbidities to think about is POTS. this is something I see slightly more in migraine patients. And it could be because it sets the stage, or there's a similar population. POTS effects women, young women as well as post-menopausal women, so there are overlapping diagnosis, but not necessarily a pathogenetic correlation. It could just happen in the same patient population.

[Abbie Ross, PT, DPT, NCS] Also touched on multiple Vestibular diagnosis occurring at the same time. How does that impact prognosis and overall journey? For example, neuritis and BPPV. Or we mentioned Meniere’s and migraine or even PPPD.

[Habib Rizk, MD, MSc] We are sometimes guilty of tunnel vision as practitioners. In a patient who presents with typical vestibular migraine symptoms and I am sure of the diagnosis. I make it a point to lean them back and a Dix Hall pike maneuver to make sure they don't have on top of it Benign Paroxysmal Positional Vertigo, because they may have both, and that could explain some of their symptoms. And that one is an easy fix and the rest you can treat it differently. The opposite unfortunately happens more often. These are patients who have vestibular migraine and they have BPPV they end up being treated for BPPV solely with maneuvers for PT that leads them to be more motion sick, that leads them to be aversive of physical therapy and of doctors and you know that that's the way it could also go completely the opposite way. So accepting that you may have more than one diagnosis, sometimes you have more than one. And that may be true with PPPD. PPPD was coined in 2017, and basically labeled as a type of dizziness going on for more than three months. They have symptoms, they have a non-spinning dizziness, so it's not a sensation of movement necessarily. They could have a sensation of rocking on a boat that is aggravated when they move, or when there's visual motion like going into a supermarket. 25% of those patients also have vestibular migraine. About 2/3 had another problem, whether neuritis or something else that put them on the path.

Mind you I am not saying that neuritis that is not treated well leads to PPPD, I am saying that a lot of them with PPPD usually have started with the different diagnosis, where the brain is no longer interpreting motional signals accurately and they developed that sensation. One way I explain it to patients, so that they understand what I am trying to say, you have to think of patients who feel like they are rocking all the time, it's like the brain is trying to figure out where the center of gravity is. And it's like trying to put a key in a keyhole and you finally find the center and you put it in.

So those are patients who suffer Vestibular problems in the past, they may have recovered from it. But then the brain is having issues with the calibration. This is where PPPD patient needs to understand that you may have more than one label, more than One diagnosis, and they need to be treated.

[Danielle Tolman, DPT] You have questions related to central Vestibular Disorders or Disorders coming from the brain rather than the inner ear itself, and we do have a whole other day set aside for this, but I would love to hear the difference between peripheral and central journeys for the patient. Is a central issue treatable? Is it going to get better? What does that look like?

[Habib Rizk, MD, MSc] So a peripheral vestibular disorder usually presents in a harmonious way, not only in the history but one side, one ear. That means it's the inner ear and the organ that is a problem. Central Vestibular Disorders are a bit more complex because the Vestibular system in the brain is widespread in the brain. For example, the part of the brain that controls vision is in the occipital lobe. And that's only where you have the main issue. In the Vestibular system. It's from the brain stem to the cerebellum.

And then projects throughout the area of the cortex of the brain, so with that, it means that there is a lot more variability in presentation of those Disorders. We're not talking about tumors or strokes of the cerebellum, these are pretty straightforward to diagnose and they have a significant impact on prognosis. Vestibular migraines, those are central Vestibular Disorders. Although I may be waiting into muddy waters, it's not happening in the inner ear necessarily, maybe more along the brainstem. And again, some central Vestibular Disorders are very easy to treat. But they require recognition of the diagnosis, appropriate treatment planning, and not necessarily from the get go, trial and error or medications.

You just take it from there and. One point that I would like to stress enough to crystallize the idea of appropriate diagnosis and treatment plans, is that Vestibular migraine patients typically should not get regular Vestibular physical from the get go. It's actually preferred not to have them do physical therapy because they are extremely motion-sensitive. If some of My patients are watching this, from the outset when you are not able to continue a session with clear communication of the physical therapist, it's not just necessarily. That's why it's important to diagnose accurately. So the short answer is, central Vestibular Disorders can, yes.

[Abbie Ross, PT, DPT, NCS] And I want to touch on something you just said. So many people don't want to move because the movement makes them feel worse. How do you explain to a patient that movement is what you are recommending?

[Habib Rizk, MD, MSc] That's tough. sometimes we cannot get through to the patient that this is what happens, usually the way we overcome this is by repeated advice and counseling, and there are patients who are particularly distressed by that. And I encourage them to connect with support groups. The only way you will be convinced is to see people who have gone through it before you, so I truly encourage patients to reach out.

Happening to them has happened to other patients, make it feel like an isolating experience. But I have patients who refuse to even let me lay them down. They need to overcome that fear and go through it. Yes, it might not feel great, but we have strategies or medications.

[Danielle Tolman, DPT] Have a lot of questions in the Q&A about traveling. So if you have someone affected by travel, whether by train or plane or tunnels or altitudes come up what strategies do you give them to reduce symptoms?

[Habib Rizk, MD, MSc] Most of them are migraine patients who are triggered by light.

Almost all of my Vestibular migraine patients, I encourage them to get blue light blockers. An easy intervention that produces one important trigger, all of my patients why follow have the Vestibular first aid kit, which is, I don't let them travel without a short course of steroids on hand, a short amount of valium and phenergan on hand . And I tell patients that even though there's not a way to predict if you're going to have an attack, the longer you go without the attack, the less likely you will -- if you can identify your triggers and manage the symptoms, a lot of the patients travel safely, uneventfully, even going on cruises.

They email me very happy that this happened. But if they have an episode, they just have to remember OK, it's just one episode. And we have the tools to treat it. Kind of like when you have one headache and you take something for it. If it happens. Of course, this doesn't apply to MdDS which require an hour on their own of talking about it, but it's a very obscure central Vestibular disorder where the rocking sensation is triggered . Unfortunately, those are the hardest patients to treat, if I am being honest. We can reduce the symptoms, we can teach them strategies to reduce the symptoms of rocking. But Mal de debarquement Introduce significant problems with travel. You cannot fly from here to Peru. And then take a bus for Three hours and visit machu picchu all in three days. And that happened. That's the patient where that actually happened. You just need to make smarter choices and accommodate yourself here.

[Danielle Tolman, DPT] I think that speaks to the point that different people may react differently. So we do have some questions about what someone can do if they are sensitive to medication. I think you alluded to the fact that there are other approaches that we can take to help reduce symptoms, especially where medication is not the route.

[Habib Rizk, MD, MSc] They also tell patients early on that there is virtually no medical treatment that is free of side effects. But also, the majority of side effects that they encounter are typically temporary, and yes, I do have patients who cannot tolerate this in spite of medications at smaller does this. We might have a sub-optimal outcome, but there is usually a risk versus benefit when they need medications. Some Disorders don't need medication.

[Abbie Ross, PT, DPT, NCS] Touched a little bit on light sensitivity. Do you have other suggestions on patients who have light sensitivity, especially this particular question, which asks about night time driving or headlights.

[Habib Rizk, MD, MSc] Is a tough one. New cars have the night vision on the mirror, but other than putting on blue light blockers, which can be difficult when you are driving at night, there is no good answer here. A lot of patients have extreme sensitivity to light. And they have uncontrollable Vestibular migraines or headaches. Treating the brain, calming that down, usually reduces the and I encounter it every now and then and that specific one on its own isolated, there isn't much you can do other than blue light blockers where feasible.

[Danielle Tolman, DPT] What about driving in general for Vestibular patients? What do you advise for your patience when it comes to driving?

[Habib Rizk, MD, MSc] That's a broad question. Very few studies have been done to analyze that question. Order to do it you need to have, you know, some centers have the test driving cars see if you are fit to drive, but it's a difficult study to perform or achieve. Mac rule of thumb: if you are driving a school bus and you are actively having an attack, I would ask you not to drive. I tell patients who are not driving for a job, like when they are driving their own car especially early on to reduce exposure to fast lanes or highways as we work through the burden of reducing symptoms.

And I rely a lot on the physical therapist from a functional standpoint. They can rely on how to keep focus while moving the head, they can give me a lot of information on safety during driving. But again, the rule of thumb of thumb is, reduce exposure to difficult terrain and fast speeding lanes to reduce the injury. Unless you are driving a school bus or something like that, I would never bench you or write a letter to the DMV that you are not allowed to do something.

[Abbie Ross, PT, DPT, NCS] You know that multiple Vestibular Disorders can exist together.

Is it common to develop them simultaneously or is it more likely that you get diagnosed with neuritis and then later on down the line another diagnosis comes into play?

[Habib Rizk, MD, MSc] That’s usually the case. For example, 30-40% of people who have Superior neuronitis will present with PPPD. The caveat to that point is that if the patient presents with a short-lived neuronitis, if they were initially diagnosed as having neuronitis then we're told it was not likely to happen again. But two years later, they had another attack, at that time, diagnosis can be revised from neuronitis to potentially migraine or Meniere's Disease.

there wasn't enough element to label you as having a migraine or Meniere's. it's not that that disease developed because of neuronitis but rather because the nature of the inner ear is such that you had Vertigo that resulted in then a couple of years later, you lost the hearing on top of the Vertigo. hope that makes sense.

[Danielle Tolman, DPT] Have a general question that a lot of people watching this may have been prescribed this this medication once throughout their journey, is meclizine. Can you talk a little bit about this?

[Habib Rizk, MD, MSc] I'm not meclizine's friend. If you have episodes of vertigo, the same way you take Advil for a headache or imitrex for a migraine you can take Meclizine for a Vertigo attack.

That's fine. it. Becomes a problem when you think Meclizine is treating the problem, come up, which it's not. Or if I see you are taking Meclizine more than once a week, that means we need to do something else about what you are going through rather than just sitting around and waiting to pop a Meclizine. It is in a class Vestibular sedatives, and as the name implies, it's the dates the Vestibular system. It inhibits the ability of the brain to compensate There in a good fashion following an episode. So it grogs do a little bit and takes away the necessary mechanisms or triggers needed to recover or bounce back, so it's not my favorite drug and if you have a neuronitis it's OK, we to take it for a few days to get over the nauseating symptoms, but then you have to make peace with the fact that you're a physician is going to tell you that you need to wean off it.

That's a difficult conversation to have with patients. Same thing goes with valium -- I know that some doctors prescribe it go. in certain cases, but I don't like it because it is habit item forming. When you are 80 it has multiple implications to safety. So again, they are not preventative medications.

[Abbie Ross, PT, DPT, NCS] Other question in terms of journey as we wrap up our crime shortly, what can one expect for follow up? So obviously patient-specific, it obviously depends upon diagnosis, but in general, how often are patients returning to MDs?

[Habib Rizk, MD, MSc] I sometimes see patients and then they follow up in six months. That's not rational reasonable. A good rule of thumb for practice, if I prescribe the medication, I want to see the patient back after 6-8 weeks to see how they did. They can see me or a PA who does that, Laura so I think for every new intervention for Vestibular patient. You have to have a follow up between six weeks and 12 weeks, So 2-3 months. We'll see if that strategy has worked, if you need to change it or tweak it, otherwise, I don't think that we are doing any favors to the patient. And that goes back into the ideal setup is that there is not enough, you know, doctors and clinicians to go around that have the capacity to absorb the volume of dizzy patients.

I think that was a wonderful snapshot into a broader picture of what the Vestibular journey looked like. Thank you so much joining us joining, I think you are it the perfect person to help us jumpstart this week and I know all of the comments in the Q&A. And our chats definitely verify the feeling. So thank you so, so much, we really appreciate it. We are going to bring in Laura. Happy Life Rebalance Live.

[Laura Cala] Amazing opportunity to come together here.

[Danielle Tolman, DPT] I'm excited to be here Abbie and I are going to sign off and we are going to pass it on to you

[Laura Cala] You're just bringing in our panelists now for those who have not met me I am Laura, based over in Australia. My diagnosis is Vestibular migraine and I'm lucky to be your patient moderator for the life rebalance live 2023. I'm going to hand it over to the stars of this session here. And we're lucky to be joined by Rachelle, Kevin and Rishi. I'm going to hand over to each of them we're going to kick off straight into their symptoms and if you do have questions please pop them up in the Q&A and we will start chatting.

I might pass over to you first Kevin. Can you tell us a little bit about yourself and the initial symptoms for you?

[Kevin Thomas] I live in San Antonio, I was in management for a museum and had two departments under me and my first symptoms history, I originally had classic migraine with aura but all that dissipated and then I developed another issue 1 morning. I woke up out of bed and literally hit the floor. The night before, I did notice that when I went out and about, ran to the store, things like that. And I noticed the lighting was wrong.

Things were too bright, I was thinking double and triple of everything. Everything was going wrong. So I went to bed. And I said, the next morning. I woke up and I fell to one side here. It was not full of Vertigo but it was very close. Very heavy Dizziness which I've been having off and on this particular time it did not go away for a few days. Eventually, I took benadryl or something it went away. Flash forward, that feeling never went away completely, always just kind of there. Went through a life change maybe a month later.

Was waiting at the airport to fly out to Mexico where I have been for Six months. And I collapsed at the gate boarding the flight. From that point forward the symptoms just hung with me, dizziness, nausea, no balance whatsoever here. And had no clue what was going on you're getting on a bus and going to the border of the united states and Mexico, so I was on the US side. And I said well I will stay here, regroup maybe take some durmamine or something like that because something was off here.

I arrived that Thursday. That Friday I got up. I had a full Vertigo attack. The room flipped, everything starts spinning here I was terrified. I went in the ER, doc said it's BPPV, gave me Meclizine, they were just talking about Meclizine, went back and I started doing the different positions you can do. And it wasn't helping. This went on, I was literally staying in a hotel 4 and 1/2 months alone, not having any idea what was going on. Paying for ENTs, some which had no idea what was going on. One finally asked me about a little family history. I told him my grandmother had been diagnosed with Meniere's disease here I end up doing some tests and I did not have any hearing loss. Moments of hearing loss but it was not for hearing loss.

From that point to now, I've been dealing with that. I have other medical conditions but compared to where I was in the summer of 2021 to now, there's been a difference. Things have helped, become better, but I'm still very episodic so when they were just talking with doctor Habib of Meclizine, I am on Meclizine, not even the full dose I will do a small amount, I say take the edge off. I'm sure we will discuss later. I don't have providers, and I haven't not been on a particular medication for it.

I've done my own therapy, just walking. Going up stairs, cleaning the house, just kept going even though I was kind of messed up. I will leave it there and let the other ones go.

[Laura Cala] I will move to Rochelle next here. I think for everyone else. It's watching it even for yourself. I'm literally nodding along the whole time. As you explained you have those two weeks and you just had no idea what was going on here. The world was going around and no one was able to really provide you with an explanation on what on earth was going on here for context, how many years did that sort of span over initially?

[Kevin Thomas] That was the summer of 2021 we are now going to 2023.

Luckily, I did have some ENTs that knew nothing -- I ended up moving from San Antonio to north Texas and the ENT that I could afford at the time really broke things down. And that's what we came up with Vestibular migraine and triple PPPD only because my symptoms lasted more than a period of time here Ménière's disease isn't off the table. Because of the history with my grandmother and other family members with Ménière's disease so it's still there.

[Laura Cala] I will move across to Rachelle I can see people in the chat who have said they've experienced similar. Rachelle tell us a little about your initial Vestibular symptoms.

[Rachelle Alford] Mine were pretty straightforward. I was working as an ER nurse, very busy mom of three.

Kind of a stressful job obviously. And my youngest son actually has a lot of health issues as well here. So juggling all of that is just kind of a stressful time in my life. I decided to go with some coworkers on a cruise in January of 2019 and my whole life was flipped upside down from that cruise. It was my first cruise. I did really well. I'm usually prone to motion sickness but I didn't get motion sick until the very last day when we pulled into court -- pulled into port and the ship stopped moving here.

I got violently ill here that whole night. I can pinpoint I believe the exact moment something flipped, like a switch was flipped in my brain. I was standing on the deck and my whole body just kind of moved back like a wave hit me. But no one else moved there. I was just like, whoa did you guys feel that. And everyone was like, no, you must have had a little bit too much to drink here after that, I got really sick and I spent the whole night really violently ill. Debarking the ship the next day I pretty much had to be carried off of it.

The minute that my feet hit solid ground it felt like someone had grabbed my hair and was like pulling me down sideways and backwards at the same time, I would say probably for about six months I could not even hold my head even upright on my shoulders here. I felt like I was being violently thrown around, backwards, forward, side to side, all at the same time. I was bed bound for the first week. And I started googling post cruise Vertigo here the First thing that came up was MdDS. I was very scared it says some people get better, some don't. And sometimes it goes away. In a few weeks weeks a few months, sometimes it doesn’t.

Then they thought that I had a stroke. So they admitted me. Could not figure out what was wrong. So they discharged me and add me follow up with an ENT and the ENT had asked was there anything different that you did prior to these symptoms and I said Yeah I went on a cruise. Really that's when everything got really bad. And she said, I think you have MdDS and it will probably go away in a few weeks. After a few weeks had passed, I went back in and I did the Vestibular testing and the tech was like, they could not even do all of the testing on me because I could not hold my head up here I was put on a slew of medications, sent to a slew of different doctors.

I started Vestibular therapy and my vestibular therapist was an absolute godsend. I couldn't walk unassisted. I used a cane, walker, wheelchair. And he spent about eight months working with me and he taught me how to ground myself and stuff like that, how to trick my brain here. So I hold up a lot of walls when I get really unsteady. He taught me to press my spine and my bed against the wall and it kind of tells you you're Vestibular system that that you're OK. He kind of came to a plateau with me. And he suggested that I start dancing again before I was an ER nurse I was a professional dancer of like all the different kinds.

He said he started studies about people with Parkinson's disease and how they would be very we tactic and I was very ataxic as well. And they would begin to dance and their tremors and everything would go away. He said, I think you need dance therapy. So I got ahold of the studio, asking them if I could rent the studio, and they said, no, you can have a key and come anytime you want. I've been rehabbing now for about 3 1/2 years or so with dance therapy. I also did go to mount Sinai in New York City and did the doctor Nai protocol with the strike therapy hearing.

I did develop vestibular migraines within a few months of the MdDS, which is why I was so debilitated to the point where I couldn't walk because I was fighting two things at the same time, you're going to new York City really helped with the MdDS side of things. It didn’t take it away. But I got about, I went in there on a Monday on a wheelchair and left walking unassisted on Friday. So it was life changing for me. It got me about 50% better, to the point where now looking at me you can't really tell unless I'm triggered, when I get triggered I go back to being thrown around and I can't walk and really can't function. The Vestibular migraines sometimes it's hard to differentiate between the two. I don't know which monster. I'm fighting some days. I definitely struggle. I have not been able to return back to work. I do volunteer at the dance studio as a teacher, a few days a week. I volunteer at a couple other organizations so I found my purpose again. I had lost that in the midst of all of that. Where I'm at now is my world is very small. I go to the studio, I order my groceries in because public places are very triggering for me. I'm very sensitive to lights especially fluorescent lighting and stuff like that so I'm still limited. But I've found purpose, and I found so much joy and I'm living and I'm thriving in the midst of this battle now for four years.

[Laura Cala] Thank you so much for sharing. Even as panelists on here. Now we are all not along and feeling for you People commenting on the chat as well. So thank you so much for sharing that here. I want to hear more. But we will come across to Rishi, over to you.

[Rishi Bhosale] Thank you. Can you hear me properly?

I'm sorry to hear about Kevin and Rachelle's stories. It seems most of the things are pretty similar. It started this started in March of 2020 when I was sick with the flu and I was bedridden for three or four days. I was get up and go out and get a walk and some fresh air clear point on the streets of new York. And after walking a couple of blocks something hit me like a storm where I was just walking and everything started spinning so bad. And then there was a post box nearby, I just held to it for like 3040 seconds, and then it stopped. That gave me such a terrible panic attack. Like what happened and I mean, you guys can relate to it pretty well.

I immediately went into emergency room. But march 2020 was COVID beginning. So everything was -- only COVID was taken into priority. Obviously there was need of the hour. But then doctor said that you might have a BPPV here sent me home. I slept, got up in the morning there was no spinning. But I realized that I'm not able to walk straight here. It's like I'm walking on some sponge or bouncy house or something here scared me again, like what's happening. Why am I unable to walk straight or not be the person I was yesterday. Tried to make a lot of appointments with my specialist because the first thing which strikes my head is something wrong with my brain because like it's a neurological disorder or I'm not able to work properly. Call my general physician, he said like, just go and speak to neurologist, no appointments, because of COVID.

So I stayed home and I lived alone in a studio. 3 or four months. I was by myself in the studio and ordered in food and groceries, tried to make it through. Luckily in June, I got an appointment with a neurologist here she told me you don't have PPPD but you might have something else. So she sent me to a specialist who diagnosed me with Vestibular neuritis. They did all the testing for me at NYU. And it came out to be 20% damage in my right ear of my Vestibular nerve, which was causing the issue come out the spinning, the unsteadiness pure the best part was, I met my amazing therapist who gave me exercises and told me keep on going and tell your brain that this is the new normal. So do not stop all the activities. Keep on doing it. He gave me a lot of access to the checkerboard. I don't know if you guys have done that or not but a checkerboard and you just move your head side by side. All those things, standing on the sponge while you're brushing your teeth, wearing some foam issues, going out for a walk. Slowly and gradually by January of 2021 I was able to walk and jog for a longer time. And I kept on going and One of the biggest helps for me was yoga. I started doing balancing exercises with yoga and that was a shift for me. I had never stopped it. And I am a professional cricketer so I play cricket.

I said this thing is not going to stop me. So I started training here. I learned that as I go ahead and tell my brain that this is something new for you, something normal for you, even if you are unsteady. I started to go through it, learn through it. And today I would say I have episodes, if the weather is changing. I think that is one trigger for me and screens are a big trigger for me. That’s why I wear these glasses. I work in finance with my job is computers. So I have to keep them with me all the time.

But now weather, lights, like a lot of lights, and computer screen, these are my current triggers which gives me some episodes. I would say just keep on going and that helped me a lot.

[Laura Cala] I think it's so interesting and looking back to doctor Habib's speech previously, isn't it running all the symptoms we describe are so scary. And you don't know how to best describe them. And that is sometimes what stops us from getting the answers. It sort of pigeonholes yourself where you want to sort of lock yourself away and try to get through that survival, but it's so interesting hearing doctor Habib's take on that.

I think it is just so interesting hearing everyone's different perceptions of what's happened here. They have these names, but we never come across them before in everyday life because we don't learn them. A question following that is someone has asked what tests specifically diagnosed the 20% neuritis damage?

[Rishi Bhosale] There was a rotating chair test to see if I was misdiagnosed and so that was number one, the important test was the pumping the hot and cold air in your ears and seeing the response through your eardrums I guess.

[Laura Cala] Another question that's just come in before we go into our next stages, does anyone have trouble in the low light settings.

And I think I've seen that coming because in the chat people are talking about the high lights, fluorescent lights here. I know myself walking into a shopping center back in 2016 I just could not do it here. I would order my shopping, get it sent to the door. I would almost be sent into an anxiety whirlwind. Does anyone have experience with low light?

[Kevin Thomas] Rishi, I wanted to say something quick to you. You're one of the people who got me inspired you really did help me a lot. As far as low light, I have light issues.

And I was a big Walker and I would walk day or night. I can't walk at night anymore. It's because the light that's there. But it's also the darkness, it throws my balance off. Even in the room. I'm with my family now in the room, I need to get a light for the room because if I wake up in the middle of the night and want to go to the restroom or something it totally throws me off. Any light issues, bright or dark.

[Rishi Bhosale] I did a lot of study why does this happen in dark light and basically one of the senses for us, seeing, perception and touch which help with balance. Since our Vestibular system is damaged we already have taken a toll on our balancing. Light if it is not there, it takes more toll.

It happened to me a lot in the initial phases where I had to grab something, switch on the light. And then I could go. When the light was on the symptoms were 50% less and when the light was off, where am I? I don’t know in what part of the universe I am walking here. So yes, it happens. But then the remediation for that, which I did and I don't know if you want to speak it up right now is whenever I practiced my best simulate the therapists standing on the sponge, just close your eyes for one set of iteration that turns your brain again that this is again a new normal.

[Rachelle Alford] A couple of things with that for me, I struggle with being able to focus my eyes here. So being in low light makes it even harder for me to focus. And then I was told as well.

When I went to New York City that I am very highly visually dependent. With the visual dependency like you guys are saying if there's no light for my eyes to be able to see where I'm at, I'm all over the place. So definitely the bright lights and the low lights affect well dash

[Kevin Thomas] One of the reasons why I have not been to the movie theater the brightness of the light. But the darkness before, not playing that game.

[Laura Cala] That's so funny that you mentioned that because I don't drive at night time. But I had not considered that as low light period.

I'm sort of at that stage now I'm a diagnosed back in 2020 and 2023 here I am at the other stage of my medication, but I always got -- I think I thought it was the bright lights with the cars that are flashing by because that used to almost speed me into an anxiety because the lights were flashing but I have not been into a movie theater for a long time either, Kevin. I think it's that overwhelmingness of how much white is going to come from that screen. And that is what would have me concerned as well.

You can talk to other people and think I don't have that symptom. But then you are like, hang on a minute. Yes I do have that symptom. Something that's so often happens with other Vestibular warriors you come across. And then you learn how to explain symptoms better as well, let's move on to what does a day in the life of your Vestibular journey look like now, whether that is -- Kevin did share offline with us that he's actually having I Vestibular day at the moment so how do you manage your Vestibular symptoms on a day to day basis?

I will go to Kevin first.

[Kevin Thomas] It's really strange sometimes I won't know that it's actually happening. I have another major physical disorder and recently dealing with mental health also. At first I knew every time I was having a Vestibular episode or whatever. And every day was just 24/7. It's just not good. And I adjusted, I pushed myself, go to the grocery store, I don't care if you fall out when you get there, go to Kohl's I'm on the floor leave me alone I'll be OK. And then over time, it did get better.

My problem was learning when it was happening. I'm here in north Texas right now with my brother and his family, the weather is up and down like crazy. There's one person, she passed through here not long ago. And she lives somewhere. And she came through here and she said “how do you do this” because the pressure is going up or it's plummeting. So my thing is catching it. But those days I will just ride it out here. I take other medications and some of those will help stabilize me. I dealt with anxiety and depression before this happened, then you add this on, you're going to see the psychiatrist now.

I don't immediately grab her medications period. I only have Meclizine . I don't have doctors or whatever I will start putting myself through my own therapy. Get up. Go shower. Showering is terrifying for me. If there's no one in the house, the kids are in school. My brother is there, if I'm showering I will leave the door open out of if I collapse, that way the paramedics can come and get me. I did it this morning. I will start moving around the house. My family, they really want me to sit down. I need to do things I need to stretch and, bend, move, do this do that because that is my of therapy therapy.

There are times when it's really overwhelming, that's when I will grab a Meclizine. Actually getting ready to start a new medication from my mental health that I think is actually going to help with my Vestibular disorder. It's really antihistamine which in the Vestibular community. We know antihistamines help. I will be doing that a few days a week here. I just live, keep going. And I will cut short because I will talk a little bit more. I had to start being honest with people around me. How are you doing Kevin, I'm great even though I'm literally falling, wearing C bands.

And I know the other day my sister in law came in and said, how are you doing. And I said, I'm not doing good. And she said, I'm sorry. That was fine. I had to stop telling that story you're a little harder with my nieces and nephews because their active, they're going. But it's like, they'll see me a few days. I'm great. But then I'll have those two or three days where I'm just like, Yeah, I can't do anything. And you're like, why are you always sick? I literally sat down two or three times to explain vestibular disorder. This one, that one, you know, Unc, is old and he's going. I think they're starting to get it now.

[Laura Cala] I think it's what you said, having confidence in knowing that that is the diagnosis. And I feel like for me, it's been a matter of hang on a minute. I know that I'm not going to drop dead tomorrow. So I just need to have that confidence, and I'm the same if I do nothing. I feel worse. Sometimes I have to keep going and people will say slow down. You don't need to go that fast. Sometimes you do here. It's that retraining of the brain. And I think initially when I look back, I was told I had generalized anxiety disorder, I certainly had anxiety but I had anxiety because I had no idea what was going on.

And I think that is often a misconception here can I hand over to you Rachelle?

[Kevin Thomas] Really quick what you just said, I just lost to the point you just said it. I'll come back here

[Laura Cala] Jump again, when you. You got it here

[Rachelle Alford] Every day is different. I live in Florida. Like Kevin was talking about the pressure changes, summers are hell on me because we have storms, big storms that roll in quickly and leave quickly. And those quick changes and pressures really messed me up. On a good day when -- I'm never symptom free. I would say my biggest complaint there's a weird sensations because you kind of get used to that after a while. But it's the brain fog and the depersonalization and I'm constantly fighting to feel connected to my body and my surroundings here that's an all day everyday battle that I fight and it's really hard on people who are control freaks. It makes it even harder. On a good day when that's just kind of at the back of my mind, I try to do some chores and make sure I make a decent dinner for my family.

And then I will go to the studio and do some dance therapy you're on a bad day. Remember there's days when I will get up for a couple of hours. And then I have to go back to bed and I sleep four or five hours and then I get up and try to start over again. And sometimes I can and it's OK. And there's some days where I just can't. I've had to learn to give myself grace for those days. And not beat myself up about it. It's hard as a perfectionist kind of person to give yourself grace and not to have super high expectations every single day for yourself.

So it's been a learning curve. I have good days. And I have bad days.

[Laura Cala] But I think that's a win all in itself, though. Like, it's a win saying to yourself, Well, today, I just need to rest and I need to do the best thing for me. And that's, that's a decision that you make. So no, I think that's wonderful.

[Kevin Thomas] I remember what it was when you made the comment about basically, I've been through this before. I'm not going to die -- people newly coming into this dealing with new onset, the anxiety, the fear because you don't know what's going on. Especially coming right after the pandemic and you did not know what was going on.

And that is the one thing that to this day - that comment you made - is what keeps me at this point because I will have days that are horrible where everything will go wrong not just this and I have to go back. Remember in 2021 when you were alone , you are still here and you just take a little Meclizine you will be OK here that is the point I wanted to bring up for any new people you will be OK. You should still go to the doctor because Vestibular could be one issue you could have other physical stuff going on.

[Laura Cala] I think even now my symptoms onset 2016, I look back and I think, how on earth did I survive and you look at all the things that come across in your journey now and actually every day is 1 big massive fist pump here what we go through , each and everyone of you are amazing.

You are how many people could say that is what every day looked like. And you still managed to kick things off your to do list? Juggling symptoms, just now it's not like before because you know what's going on. I think it's, my heart fills with so much gratitude and love. We have to celebrate ourselves and what we go through because it is amazing. You explain your symptoms to people and they think you're crazy. For us, that's what we just have to get on with really in order to survive.

[Rishi Bhosale] I mean, first of all, am I gonna die? Am I having a heart attack? Or am I having a brain stroke was like initially for six months was the same. And every time it was the same, because I didn't know anything what's happening. And again, we're celebrating that war. And now we know how to deal with it. So anyone who is new with this stay strong, there's nothing to worry about.

And I go about my day today, I mean, for now it has been much better because my first rule is don't stop. I think I've myself that challenge that you don't have any options to stop. I'm a single guy, living by myself working in finance. If you stop, there's no backup where I can rest and take care. Break here. I do take a break my employers I've told them about the condition. I have, showing them the videos and they understand what’s wrong with me, but I make sure that is not the hurdle for me.

And that's what my mindset is with this disorder here. I tell myself get up early, make yourself breakfast, go to the office, come back, work out, make yourself dinner and do your life and sleep well. Big thing I would like to comment is sleep, if I have a bad day of sleep, if I go out for a happy hour suppose with my company and I come out late and if I sleep well, that next day is terrible for me here. The whole day my head is hurting and unsteady you're not able to focus on screening.

And so sleeping is one of the medications. I don't take any medications at all. But I make sure that I also push myself out of bed, do the workout and do all the stuff even if I'm feeling low that day. That when you challenge your brain to understand this is the new normal here creating your brain and training. It this is the new normal.

[Laura Cala] I've got some questions that have come in here one for you Rachelle. Could you quickly repeat what therapy you received in New York?

[Rachelle Alford] It's called the doctor Dau protocol, D.A.I. although Dr. Dye has passed on. So Dr. Sergei has taken over that treatment. And basically, they use the optic kinetic stripe therapies. So it's really interesting, it's this round room, that they put you in the middle of in a chair and the chair moves, it'll go, it'll spin around, or it'll like rock side to side. And then you stare at a black.on the wall while he's projecting stripes going different directions around you, while they're playing a metronome. And he's standing behind you rocking your head back and forth. It's a trip. So crazy, but it took him about three days to figure out the perfect combination for my brain. I mean, it goes down to, like, the brightness of the stripes and the direction. And it's, it's very scientific, but um, I mean, it definitely made a difference for me. So yeah, it's called the Dr. Dai protocol. It's at Mount Sinai Hospital in Manhattan in New York City. I did five days of treatment there. And he actually wanted me to stay longer. But we hadn't planned for that. And you kind of have to plan to stay an extra week in New York.

[Laura Cala] Thank you for sharing that. Going through all of that is scary, but it provides sometimes those additional answers here. I'm going to hand the question over to Rishi here someone has asked about the glasses you and Kevin are wearing are you able to provide an overview about how you got onto the glasses and how they help with your everyday life.

[Rishi Bhosale] Yeah, sure. So this was again recommended to me by my vestibular therapist in NYU, that they told me to use blue light filter glasses. And I ordered a couple of them I had like, five or six pairs ordered. I used them like every class for a week or so to test it out which one is working best for me. And then I landed upon these which are 90% Blue, like what are you like filter blocker? They're called Terra specs. And then I have another pair for called axon optics. These are the two glasses which they work wonders for me. But it's not just the glasses and doing the work. I also have turned my screen one on laptop. So no bright lights, a warmer screen and dark mode for like emails excels or, or Word documents where you have five screens in the background. So once you dim the lights of your screen and use these I guess they're working wonders for me.

[Laura Cala] Yeah, perfect. Kevin, I'll hand the question over to you. So someone has asked about losing balance and the unsteadiness with your eyes closed. I know for me, I remember when I initially got diagnosed, I remember waking up one morning and it felt like I wasn't laying on my bed. And that was with my I remember opening my eyes and closing my eyes. Have you had any experiences where you feel unbalanced with your eyes closed and open?

[Kevin Thomas] One of the things that used to really scare me when this first happened, people talk about drop attacks. One of the things... I would go to sleep at night, because originally, they thought I had meniere's, so I was doing the diuretics the low salt diet and all that.

I would lay down and go to sleep and close my eyes and I would immediately fall off the bed. Just laying there. And it kept happening. Eventually it stopped. And I was like "am I having drop attacks in bed with my eyes closed?" So I had those issues here. I don't have the drop attacks. But I have other eye problems here. I have ankylosing spondylitis until a week ago, I could not see out of this eye I had to have surgery on it. That along with Vestibular, and I use it in anyway because of my spinal condition. So I'm just a wonderful, happy person off balance all the time.

[Laura Cala] I just think you're amazing. You're you are all amazing. I continue to be in so much awe. That is interesting about the drop attacks. I am conscious that we are onto our last 15 minutes and we have questions coming in here. I will hand over to Rachelle. The person has asked how is flying or traveling on a plane? For me this was one took me a long time to be very brave to get back on a plane because I had experiences in the midst where it literally felt like I was just floating in the middle of the earth. So I don't Rochelle is can you relate to relate to that yet? I'll let you go for it.

[Rachelle Alford] Definitely your travel is definitely a scary thing. But I got to a point in my life where it had already stolen. So much from me that I refused to let it steal anymore experiences. I want to go back to what you guys were talking about earlier, those attacks like in the beginning it's absolutely terrifying and the anxiety makes it so much worse. You're there's times where I have episodes where I'm like this two will pass here. It's always passed before, I will wake up tomorrow and it will be a new day here I kind of take that mentality when I travel first of all, I have some cheats for traveling here I take advantage of the wheelchair service that is an amazing free service. I call it baked potato mode here I just kind of sit there and drool on myself because I don't know like I can't process anything. The wheelchair service is amazing, especially if you have to travel alone. And you get disoriented in the attacks that way. I don't have to worry about finding my gate and stuff like that. I highly recommend for everybody to get that struggles with Vestibular and has the neurosensory -- neuroma sensitivities. Flying with earplanes which are these ear plugs that help. The way Doctor Sergei explained, you won't relapse if you take one of the equations out that contribute to the Vestibular so the vision, the ears, the Vestibular system, those two things. By using the earplanes that takes the equation of the ears out.

So it helps you not revert back to square one. I also do premedicate with valium when I travel and then elevators are a huge trigger for me. They will put me out for a whole day after I arrived one. So I try, we try to get rooms that are more on the ground level or just a few floors up where I can take the stairs versus the elevator. Sometimes you can't avoid it but those are kind of like my travel tips.

[Rishi Bhosale] Same thing happened to me, which was being scared to travel. It’s not whats going to happen in the air, but that the change in weather is going to hurt so bad. I just want to tell you patients who are at least like Vestibular neuritis, or migraine, which I am suffering through last year, 2021. I worked on myself did all of the exercises, and I decided - Enough of not traveling. I started traveling internationally and I traveled to 8 countries last year. It’s like, just like take the flight with the airplanes, that's very helpful here. If you have valium to support it if you feel like an attack is coming. Or meclizine. But again, it’s just habit building. The first plane I took was not good for me kind of Second was OK, but then it started becoming better and better. I think our brain is a powerful machine. You tell it that it's OK. And it's fine it's going to act that way. I came here yesterday from London, the travel is part of my life, because I'm also traveling for work now.

[Kevin Thomas] Don't feel guilty if you won't come on the plane because I still will not fly. My doctors asked me not to for awhile because one thing that happened before the Vestibular, I had to fly very often from my previous career. I was having serious problems with the bad ear you get the pressure, the pain come up mine would stay for a day or two here still some work to be done there. But if you still are scared of it. Don't feel guilty, it will come to you I will get on the train and even that has its issues .

A friend invited me to California for a couple of weeks. I'm going to be on the train for a week because I’m not getting on the plane. So don't feel bad if you can't do it, just yet. It will come in time or you could be like me and just never fly ever again here I was just presenting another mindset of it. Another view of it if you think about it, you can do it your [Kevin Thomas] I would like to take a flight from here in Dallas to San Antonio which is like a 30 minute flight just to see how I would do.

And if I do good on that -- I still have not gone up in an elevator yet. Everybody is at different levels.

[Laura Cala] Setting different goal posts to I remember in the midst of my journey. I could not walk down to the end of the driveway at one point. When I was at the beginning of my recovery, walking to the end of the driveway at the end of the day was a big fist pump for me. I added to my goals each time, I'm nailing this now I'm going to start trying to walk around the block here it was setting those gold posts. The next question is probably one of my favorite questions that asked about favorite forums to go in and ask questions and have conversations.

I remember being diagnosed with vestibular migraine I remember saying to my therapist. What on earth is that. I remember getting a sheet of paper that gave me the migraine diet. And I went home and googled everything Vestibular and I came across David's group, our ambassador who does so many things for us. And he has his group on Facebook, which I love. And I'm sure Cynthia will share the link. From there. I made beautiful friends with other ambassadors and now I sort of embrace the Instagram Vestibular community here can everyone share their favorite forum, a group, I will start with you Kevin.

[Kevin Thomas] There's so many and I lean right now toward podcasts and my favorite... well I just forgot it here. She's actually going to be on. I love those a lot because I constantly hear from various people whether they have Ménière's or Vestibular neuritis there's quite a few. And I can't name them all. One of my things is a lot of brain fog. Sorry.

[Laura Cala] You're good. You're good. Rachel how about yourself?

[Rachelle Alford] Shortly after I got sick. I started sharing my experiences on YouTube, which I haven't for a few years here that kind of led into starting a support group on Facebook for Vestibular disorders and that's my go to.

I have almost 600, a little over 600 members now. And it's a pretty open dialogue group. So as far as forums that one. And I also found an amazing community called the unfixed community with Kimberly Warner and that was incredibly healing. I'm so thankful that I was able to participate in that. That kept the hope alive for me there in the beginning because I was like, I've been given these cards. I don't want it to go to waste here, I want to do something with that. And I was able to do that with Kimberly .

I'm really one of the only Vestibular people represented in the unfixed community but there are so many people dealing with so many other things. And it -- chronic illness is universal. So you learn from, I've learned so much from every person's journey that was a part of that. And what she's doing even after that, moving forward has been incredible to watch that and be a part of it.

[Rishi Bhosale] So I was fortunate enough to work with Kimberly also or the Life Rebalanced Chronicles docuseries. I was One of the Vestibular warriors in the series. That helped us the second is David's group on Facebook.

That group is amazing. I'm also working myself with David as an ambassador, connecting people in India who can be helped and connecting doctors over there. So that is One of the ways I'm trying to help the community. I also have a few other followers. I help them by their Instagram. But VeDA is one of the biggest supports from here. These are the roots and from here, we are spreading.

[Kevin Thomas] It was Ménière's muse and there's a new one. And they're going to kill me because I cannot find it, Marissa and joy, I love you I'm sorry. I'm just having a foggy day.

[Laura Cala] They do that amazing YouTube.

[Kevin Thomas] As Rishi just alluded to, a new cast of Life Rebalanced so I will be there filming and I'm doing B roll trying to get that down. I'm loving it. And it was funny because they kept saying, because I was really going through some things, do you not want to do it, I said I need to do it. It will keep me active here. I did see Marissa comment in the chat earlier. So if you want to maybe share a couple of the links to what you have done. I'm sure many of the others watching would love to see it as well.

Before we wrap up. I'm going to hand across some final words here. Sorry if we have not come back to your Q&A. But I'm hoping with the panelists last words it gives you support and comfort. A few people have asked patient panelists details. So what we will do before closing is if you want to give your message of hope to those that are at the beginning of their journeys embarking on something that's really difficult I'd love to hear whether it be a sentence or a statement that would be fabulous, and if you would like to share your instagrams or pages people can reach out to you on, I certainly encourage that.

I will hand across to Kevin first.

[Kevin Thomas] For me, I would say this too shall pass here you will come out the other end. I know it's terrifying, so scary. You're going to run with a lot of different doctors, it will get better your check the VeDA website to get some good practitioners in your area. Much love.

[Rachelle Alford] I agree with Kevin obviously here fear is your biggest enemy, fear and anxiety, when it comes to Vestibular Disorders up here. I see a therapist on a regular basis here. I think everyone should have one.

It's incredibly healing and it's OK to not be OK. And you need to give yourself grace would not compare yourself to other people or compare yourself to who you were prior to this. Surround yourself with people that are supportive and loving and talk about it, don't bottle it up to try to hide behind and people will assume that you're OK. It's OK to not be OK. And good luck. It does get better. Time is a healer. There is purpose for your life. That purpose has not changed just because he's not sick it's just changed direction.

There's purpose in the pain and there's always a way to use that for the greater good. And not let it destroy you

[Laura Cala] I love that.

[Rishi Bhosale] You have a new purpose to help others who are also suffering from this. So whatever experience you get and whatever information, pass it on to people who might not be able to access this. You are stronger than this. No disorder is going to stop you if you determined you're going to win.

[Laura Cala] Will Life Rebalanced Live, day one, just amazing. Well done to the panelists, I want to do a thank you to James D and Linda B from the Hainlen Discovery Fund and the University of Minnesota department of Otolaryngology for sponsoring conference.

You can purchase lifetime access to the recordings and transcripts of the entire conference at vestibular.org/lrl-recordings and you can make sure the valuable information is presented at this event remains free to everyone by making a donation. I'm sure Cynthia will post the link, but it is vestibular.org/lrl-donate.

Thank you for joining us today here. So much love to each and everyone of you, can't wait to continue following your journey. And I will see everyone tomorrow.