Life Rebalanced Live 2023

THE PATH TO DIAGNOSIS & INITIATING TREATMENT

This transcript may contain errors.

[Danielle Tolman, DPT] Welcome and thank you for joining the Vestibular Disorders Association for our third annual virtual conference Life Rebalance Live. I am Dr. Danielle Tolman and I'll be your host alongside my partner Dr. Abbie Ross. We are Vestibular therapists, and self proclaimed vestibulo-holics!

[Abbie Ross, PT, DPT, NCS] And we had such a good first day shout out to Dr. Rizk for talking about the vestibular journey. Today's topic will be the path to diagnosis and initiating treatment. Before we begin, we would like to thank donors, volunteers, and VeDA staff in helping to put this together. The live portion is at no cost to our attendees -- however, if you would like lifetime access to the transcripts, they will be available after the live event for just $55. All proceeds support the wonderful programs and their continued missions to spread Vestibular awareness.

[Danielle Tolman, DPT] Before we start, let's give a shout out to our sponsor this week, the James D and Linda B. Hainlen Discovery Fund and the University of Minnesota Department of Otolaryngology. Jim 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. On another note, if you have questions you would like to ask feel free to put them into the Q&A tab.

[Abbie Ross, PT, DPT, NCS] Keep your questions coming in. Again, today's topic is the path to diagnosis and initiating treatment. Dizziness, Vertigo, imbalance, we want to determine what is causing the symptoms to best identify the treatment that works for you. So the $1,000,000 question is, how do you get an accurate diagnosis?

What Vestibular tests might you expect to be done and what information does your provider glean from those tests? Today's speakers will identify not only those questions, but many more.

[Danielle Tolman, DPT] So without further ado, we'd like to introduce you to today's speakers, Dr. Tehrani and Dr. Hullar. Dr. Tehrani is an associate professor of neurology at Johns Hopkins. He is board certified in the American

Board of Psychiatry and Neurology with subspecialty training in vascular neurology, neuro ophthalmology and vestibular neurology. Dr. Hullar graduated from Harvard Medical School in 1996, and completed a residency and fellowship in otolaryngology Head and Neck Surgery at Johns Hopkins in 2003. He currently works as a full time otologist and federally funded researcher at the Portland Oregon Veterans Administration Health Care System. Thank you, both of you for joining us today. We're very excited to have you here.

[Abbie Ross, PT, DPT, NCS] Thank you both. We will kick off the discussion with a question. It is not the $1,000,000 question, but part of it, who diagnoses Vestibular Disorders?

[Timothy E Hullar, MD] Well, I guess several different types of people. We could talk about individual practitioners who see patients with imbalance, and then we talk about teams who are involved in that diagnosis, and in some cases there are practitioners who diagnose people with dizziness but don't necessarily diagnosed Vestibular Disorders. So I'm an Otolaryngologist, I should put myself last, I guess, out of politeness. But I'll start with a group that I know the best. I think about Otolaryngologist as being good at diagnosing diseases of the peripheral Vestibular system.

We tend to see people as a referral in the offices, we tend not to be frontline people like emergency room doctors or even neurologists who come to the emergency room as consultants to help diagnose people with imbalance. I think the reason for that is we are not good at diagnosing central problems, that is to say the blood vessels going into the brain. So one of my jobs not only is to not only diagnose peripheral Vestibular problems, but also to figure out who's most likely to fit in that general category . So in my best estimates, I tried to get some people who are referred to my clinic from neurology, I tried to get some people over to physical therapy, and people often think of physical therapists as doing a prescribed set of things that maybe someone else told them to do or taught them to do, but one of the major roles of physical therapists is to make diagnoses, so I sometimes see patients or talk to them on the telephone if they have a hard time making it into the clinic, and by the end of the conversation it is clear that the best place for them to go would be a Physical therapist. They don't need to wait to see a surgeon which I am trained as, to take care of a BPPV condition that may be taking care of this Physical therapist, and is probably more comfortable than by me they maybe have other assistants in their clinic and more convenient and comfortable equipment and exam tables that I might in my surgical exam rooms. Other people who diagnose dizziness or imbalance but not really necessarily Vestibular Disorders except to exclude them, I think about cardiologists who work on people who have come up. Let's say come up low blood pressure or high blood pressure or other causes for dizziness or imbalance.

I think about psychiatrists who take care of people who have anxiety that is contributing either to Dizziness or to making Dizziness worse, so that is an incomplete list, but just start off with a response to your question.

[Danielle Tolman, DPT] it. Sounds like the broader range of symptoms and causes, the patients might experience receiving a diagnosis from a multitude of people within the field. Dr. Tehrani, you specialize more in neurology, so what about those people in that central realm of interacting with diagnosis?

[Ali Shabahang Saber Tehrani, MD] Thank you again for the opportunity. There are different types of neurologists from general neurologists or vascular neurologists who end up seeing patients for Dizziness.

They each have their own subspecialty. And knowledge of the complex cases where you diagnosed and delve into the complexities of dizziness, so those are the typical types of people that you see on the neurology side. And you know, it is very important to differentiate between peripheral and central causes, and sometimes that is the challenge whether you are dealing with something working from the ear or something from within the brain, perhaps the substrate of the brain or another disease process, so these are the challenges that neurologists see.

[Timothy E Hullar, MD] I think One of the challenges as a patient is to get to anybody in that network of providers who is well experienced, because I think once you satisfy the criteria of being a good or experienced clinician, then one of your primary jobs is to sort out the specialists who can give you detailed evaluations.

But One of the things that patients can that appropriate set of referrals, a source of acute study that this is right now is how to get people onto the right path. I am anticipating a future question right now, but the key is to find anybody in one of the fields that we just listed who can quarterback your entry into this system, which is otherwise very frustrating.

[Abbie Ross, PT, DPT, NCS] Absolutely, you really led into the next question, which is what problems might people have in finding good provider? Not everyone is fully trained in all things Vestibular, and certainly we have our specialties, so to include multiple disciplines where necessary.

But as a patient, how do you help patients to find the providers outside of your own network? So I am sure you get patients from all over looking for help, and how do you refer them to people within their own network?

[Ali Shabahang Saber Tehrani, MD] Please go ahead.

[Timothy E Hullar, MD] I'm in an unusual situation. But my posting is in the VA, so it's a good thing. And a bad thing because it means that people who are not veterans or eligible for those benefits cannot be helped by me directly. I still know a lot of providers around Oregon, and in academic practice.

Yeah it was relatively easy to find a qualified practitioner simply through word of mouth from colleagues or patients either at the university or in the area. At the VA it's a little harder because sometimes there are longer distances to travel. We are able to refer people out to practitioners in the community but I think the real issue is outside of major academic centers or the equivalent, it is pretty hard to get into a qualified group or set of people who can really take care of these patients with these difficulties. I think for a lot of us, the practitioners simply know each other from around the area.

I have a list of physical therapy practices that I can refer to say in the state of Oregon which is very big and very rural come back practices outside of the metropolitan Portland area where I feel like the patient can go. I am a little reluctant to have them go to the corner PT even though maybe that person will do a good job, but in any case, it needs experience. But just talking to senior colleagues with more experience.

[Ali Shabahang Saber Tehrani, MD] Access to care is an issue in the United states. I think on the public health level, connecting primary care physicians to the right specialists would be of paramount importance, but it is a question of, you know, since Dizziness is so complex, how do we direct patients to the right sub specialties whether EMT or Vestibular Neurologist, there aren't that many ENT specialists or neurovestibular specialists in the United States, so that can be a challenge, but I think the biggest thing is connecting databases or connecting with primary care physicians.

That is a paramount step.

[Danielle Tolman, DPT] I know that for a lot of patients when they have an acute onset of Vestibular dysfunction, they end up in the emergency room. What does triage in the emergency room look like, and what is the goal of triaging?

[Ali Shabahang Saber Tehrani, MD] Well, it depends upon the type of emergency room. Sometimes there are nurses or nurse practitioners who triage, sometimes physicians, and there are sub specialized emergency rooms Harvard has their own specialized emergency room where triage is done by ENT specialists. So depending on the institution, the triage is done differently.

But most often it's done by a nurse or a physician. The goal of triage is to put the patient on the correct pathway, so if you feel that Dizziness is due to something cardiac in nature, a cardiac cause, you might be referred to a cardiologist to have your heart checked. If it is more likely to be a stroke, which coincides with other neurologic symptoms, you want the patient to be seen by a stroke Neurologist as soon as possible. And then there are different pathways depending upon the periphery triage process, and patients are directed to the correct area.

[Timothy E Hullar, MD] It's kind of funny.

And the emergency room. I so rarely see patients who are dizzy, and I think that's because what the ER doctors are trying to do is to decide what is an emergency. Neurologists can really help with that, but there are very few things in the ear that are that say central problem, if the patient is having a stroke then the Neurologist has to be involved in diagnosing that.

[Danielle Tolman, DPT] Just as a quick sidebar, I would say that it seems like -- and I would love your input on this -- but it seems there is more training being provided for residents in quick bedside testing in the emergency room whether it is positional testing or a quick hints exam.

Has there been an increase in training for that?

[Timothy E Hullar, MD] Sometimes I have been in the emergency room, it's across the hall. So I will chat with doctors sometimes or see the residents and I am heartened by the testing developed at Hopkins, HINT testing, which is his transformative in the ability of doctors to evaluate patients who are having a stroke. I am surprised because I see it all time in the notes notes, and I'm really grateful. I'm not sure how well they perform it sometimes, but I will take it on face value that they are at least thinking about it and come up related to your question, that they recognize the value of it.

[Ali Shabahang Saber Tehrani, MD] I second that. It is amazing how well the curricula has been updated, examination techniques relative to neurovestibular assessment, Nystagmus, deviation, and so on. To be fair, these techniques are fairly complex, and while our physicians are amazing in the emergency department, accurate recognition of these findings are challenging. So there's so much that you can learn on the family. No way that you will Be as good as Dr. Hullar and recognizing Nystagmus, and so on. But looking at that pathologies, we can have ways to objectively measure normal eye movement, think the neo goggles or phones to help our Ed physicians.

[Abbie Ross, PT, DPT, NCS] I would like to delineate a little bit between what to expect in an emergency setting versus an outpatient setting in terms of diagnostic tests. So we spoke about HINT in the emergency room, but what else might have patient expect when presenting with Vertigo versus say come up later on when there is -- what can they expect from the outpatient setting?

[Ali Shabahang Saber Tehrani, MD] In the ED, the biggest job, and an ED position may be able to comment more eloquently on this, but the number one job is to stabilize the patient, to make sure that they are ruling out anything that can kill a patient.

So something that we can fix and treat, so something like a stroke, you need to fix that. If there is something that while it is causing discomfort, something like a Vestibular migraine, it cannot be fully treated or may not be fully diagnosed in the emergency room, but since this is not going to permanently disable a patient, the right approach is to stabilize the patient, make sure the patient is fine, is safe, and then discharge and arrange follow up in the outpatient setting. So the biggest thing for the ED is to rule out the dangerous causes, say stroke.

And then there is the additional idea of patient safety, for example BPPV. It feels bad, it's very disabling, you have major problems with balance. While it's not going to kill the patient. It is horrible to be in that situation. The key is to help the patient to prevent The future fall at home, for example, so in terms of the number one priority that's what it is. And I will let Dr. Hullar comment more.

[Timothy E Hullar, MD] I see patients almost exclusively in the outpatient setting. We will get some sent over from the emergency department with uncertain diagnosis, or with -- for example, a lot of patients say the provider has tried to do a Canal repositioning maneuver, but they will send them to us just in case it did not work or if the patient needs a second treatment, so that's one way we can take care of patients who come to us. I think a lot of times we actually, maybe they get an evaluation in the emergency department, but really the patient is still left with a lot of questions. And so in essence, they're sending the patient over saying we've ruled out, you know, the patient is stable, can you take it from here?

Restart the whole process? And I think that's frustrating for some patients, especially if they need to wait to get into the clinic, but really, it is important for each of us when we see a patient at any point to step back and say, I'm a fresh set of eyes. And this is a tertiary or quaternary medical center. One of the things that can be very good in that process is if some important studies can be done before I see that.

So if I get a referral from the emergency room. I am almost always going to ask the patient to get an audiogram. And sometimes the patient says, but my hearings not not a problem for me. And I would say, well, it might be because you don't, a lot of times you don't know if it is you don't have a great frame of reference. And, and the other thing is maybe there's subtleties in there that I'm looking for that you can't really tell me about just saying like, well, I can still hear my wife or something like that.

But in my practice, I typically -- and I think most sophisticated practitioners don't do a lot of this testing before I have the chance to really start from baseline, and the patient -- it doesn't help me if the patients going through a multi $1000 workup and I tell them that they have BPPV that could have been taken care of in 5 minutes. So I really want some tests and I don't want other tests.

[Danielle Tolman, DPT] That's question, which is, it sounds like testing is great for people with Vestibular dysfunction. We want testing done, but at what point? It sounds like it varies from person to person and from case to case.

[Timothy E Hullar, MD] I hope I'm getting this number right, but the literature shows that among the major diagnosis that we make in neurology is that very few require laboratory testing. So the top diagnoses that we say, vestibular migraine or BPPV, they aren't diagnosed by way of lab testing.

Sure, we do at bedside or may do other things to rule out other things. But fundamentally for most of those we can diagnose over the telephone, and in fact, I would say most of the time that I do diagnose over the telephone because I have patients who are coming from. So far away and they would rather not drive across the mountains to see me. I think that the data show that about 80% of people can be diagnosed without any sort of laboratory testing if they end up with those diagnosis. My residents will do this too, but one of the things that we try to train our residents and other practitioners and other trainees is if you're going to order a test, you need to know why you're ordering it.

And you see this all the time in, in in not just in Dizzy patients, but everywhere in the everywhere in the field. People might just automatically get a cat scan. So many times the patient comes in and says look, I wasn't having a stroke. And I was like, number one, we knew you weren't having a stroke based on your history, but also that CT scan isn't really a very valuable test to tell me if you are having a stroke. So let's say look for superior canal dehiscence, I'm the one who has to order this because otherwise, the radiologists don't know the right protocol that they and I have specifically worked out over the years. So yeah, I think when I get a patient referred to me, even from a private party from a regular provider or from an ENT, and they've done a bunch of vestibular testing, the first thing I think is this person doesn't know what they're doing.

It might not be fair, but so often it's true. One exception to that is an audiogram, and the reason I do that is because so many of my patients are older. And if they don't have a recent audiogram anyway. They probably should and in any case, I'm taking care of their hearing loss and not their imbalance with that test. A lot of patients resist it but I am pretty insistent on it.

[Ali Shabahang Saber Tehrani, MD] I second that. Tests really need to be tailored to the patient. It's not a one-size-fits-all type of thing. We need to figure out what is the question that needs to be answered or what the appropriate testing might be.

[Abbie Ross, PT, DPT, NCS] Can we tease that out to talking a little bit more about ruling out other causes? What about medication-oriented side effect or another cardiac issue or even orthostatic hypotension, how do we know it's a Vestibular issue and not something else? I will start by saying that One of the most important things, I think, in a Vestibular evaluation is the history. So much of what path you are going to take comes from the patient communication to you initially.

[Timothy E Hullar, MD] I might have it easy in this regard, because as an ENT, this is a certain extent is to say, is this a peripheral balance problem?

If it is not who do I send them to? If the patient does not have Benign positional vertigo and is still dizzy in certain positions, well it's probably not an inner ear problem. It might be vascular or intracranial hypertension, it could be POTS. What I can do with a clean conscience, maybe is to send patient to a different practitioner. And that's where I think the Vestibular testing is actually very useful, because when I give up, to me that's an indication for doing Vestibular testing because then I turn the patient over to a neurologist. And I can say look, I've done the best that I can. And I have ruled out everything in my court. And I need some help. But I think it's sending a patient over to another practitioner without doing that evaluation or to exclude peripheral pathologies is a mistake on my part. So that's kind of my role.

[Ali Shabahang Saber Tehrani, MD] History and the physical examinations, objective findings, those are major factors. Going from there, we would just do the appropriate test.

[Danielle Tolman, DPT] Could you guys maybe just just lightly touch on some of the tests that vestibular patients might be ordered? So we talked about an audiogram, which is like a hearing test? I sure a lot of people who are watching are familiar with a VNG. Somebody already put in the comments asking if there were any other new tests with the emerging technologies, so they don't have to do a VNG again. You know, can you just touch on some of the things that people might experience with this vestibular testing?

[Timothy E Hullar, MD] So I can talk about new technologies. What should I talk about first?

[Danielle Tolman, DPT] Just what are some tests names and different tests that patients might experience currently, if they're getting a vestibular workup?

[Timothy E Hullar, MD] This goes back to your first question about how you know who to send someone to. We look at certain prescribed exercises, looking to the left, looking to the right, from target to target. But the keystone historically has been caloric testing. It's traumatic to patients because the intention is to make you very dizzy, and if you are not dizzy you fail the test.

But that test is... not falling out of favor, but I think they may be relying on it less and less. It’s being replaced, at least to a large extent, by video head impulse testing. The advantage of video head impulse testing is that you can test all three semicircular canals. So you can test a large part of the inner ear balance system on each side. So one of the jobs of the neurologist or ENT is to figure out where the problem is, and then we can go from there. So impulse testing is much better than the others to figure that out. The other thing is, with a caloric, they make sure you don't have wax or fluid behind the eardrum and they make sure we don't have an outer ear infection or something like that, whereas Vestibular head impulse testing is kind of A one-size-fits-all testing, as long as you can let your neck be moved to relatively short distance, that test can be completed. So to me, that's the Keystone test to be done.

And then we're also introducing VEMPS with are vestibular evoked myogenic potentials, and those evaluate not their rotational gyroscopes in the inner ear, but they they evaluate the pendulums and the inner ear, the plumb bobs that are the utricle and the saccule. Those tests are a little harder to do, I think they're less available in other centers. A major problem with these tests is that they cannot be billed to insurance. – its hard to get a test unless the practitioner gets reimbursed for it, which kind of makes sense. I'd like to see us getting reimbursed for more of these tests. But the VEMPS I think in general are not reimbursed. So outside of a dedicated center that's willing to go the essentially the extra mile for the patients it may be hard to get there also require some pretty extensive training in order to do properly and get reliable results.. Historically, another century-old test, rotational chair testing, often creates a lot of motion sickness, claustrophobia. You are turned around in the dark and you have goggles on and your eye movements are measured.

That's sometimes a traumatizing exam, sometimes even more so than caloric exams. And it gives less information than most people think. So having that rotational chair testing, one of the first things is, well, do they really need this? the other test that is maybe not as commonly done. But I think should be done more is Posturography. So I would say in terms of developing technology, there's a lot more we could talk about, we could talk for hours about Vestibular testing.

But switching to the second part of your question, new technology, it's so great to talk to Ali and other people who are really working on this. But some of the technologies that I think are really promising are Vestibular psychophysics, where instead of providing a big stimulus and looking for eye movements. There are reflexes related to inner ear function. Instead, we put people in a chair, let's say we rotate it very slowly, and we say, how slowly can we rotate this before you no longer notice you are turning. So it's like an audiogram, how low can I make this sound before you no longer hear it. It doesn't have much clinical use yet, but people are concentrating heavily on exploring it how it might be used.

It's a relatively patient-friendly test, and I think the biggest risk is boredom. Another thing I'm really interested in is inertial sensors, so wouldn't it be cool if we could strap a little monitor on someone's head and monitor them all day?

[Danielle Tolman, DPT] Some of the more gold standard tests do sound a little like medieval torture devices that we deploy on these patient populations. Are there any other additional tests you might see or Vestibular dysfunction side of things?

[Ali Shabahang Saber Tehrani, MD] We do have a lot of toys to help us diagnose. Videography is helpful. If the goggles are on comfortably, you know, all of the eye movements can be detected in capturing the video of a patient. When we are suspecting a central cause, an MRI is indicated sometimes. Sometimes we need a lumbar puncture. Rarely, other panels are indicated.

[Abbie Ross, PT, DPT, NCS] To add to that, what if we have someone who has a Vestibular diagnosis, but testing is not showing that, right? Something like migraine or PPPD. What are you looking for in order to accurately diagnose those diagnose these?

[Ali Shabahang Saber Tehrani, MD] Go back to what you said earlier, history would be important.

Sometimes what is really helpful is we many times we ask the patients to record a video of their eye movements while they're symptomatic. Sometimes the patients can do that, but sometimes, depending on the quality of the phone that's not the case. Now, hopefully newer apps are coming out that can actually not only take a video, but also quantify objective the eye movements objectively as well. So those are some tricks that you know, history and then getting inside finding object, looking at objective findings, while the patient is actually experiencing the symptoms is very helpful.

[Danielle Tolman, DPT] Looking at our testing, are there things that can affect testing outcomes, for example comorbidities or medications? What are some things that might interfere with that?

[Ali Shabahang Saber Tehrani, MD] Well, there are, I guess there's always the question of what we are dealing with versus what's been going on chronically. I may have had a vestibular neuronitis when I was 13 years old but today when the doctor is examining me he is seeing the effect of what I had 40 years ago. And these question is come up well, what if this is new or what part of this is old ? sometimes if you have difficulty with your neck, that can complicate things. I think things of that nature.

[Abbie Ross, PT, DPT, NCS] Looking at audience questions, I think this is relatable. When it comes to finding a diagnosis, we talked about it taking a long time, whether you've found a provider or not and it takes months. How do you keep the patient optimistic through the process? They may have those psychological impacts from waiting for so long. How do you prep them for the journey ahead? Dr. Hullar?

[Timothy E Hullar, MD] I just counsel them. I try to recognize their frustrations. I think it's going to take care. I think emphasizing that it's going to take a while to get to the right diagnosis in many cases, and saying I feel comfortable that we can get you to someone who can make a good diagnosis and probably make you better. Essentially, we have a plan. That's what providers in the medical field always try to do, from someone who's dying of a disease to a child who scrapes his knee on the ground. It helps to have someone who says I am able to get you to the right person, and I have enough confidence and experience that I can make you better.

[Danielle Tolman, DPT] I'm going through the audience Q&A, and we have a lot of great questions. One leads into medications. Is meclizine something that you see patients on frequently? Can it affect results if someone is taking Meclizine regularly for their symptoms?

[Ali Shabahang Saber Tehrani, MD] Yeah. I do not like Meclizine. To some extent it can affect test results. The side effects are important.

It can make people more loopy, while to some extent it helps with dizziness, but over the long term it loses that effect. So the side effects are a real issue. Many times I have patients we're the only cause of the cognitive decline is that they were on different medications that were not doing anything, whereas after the first week it loses its effect. And you are just dealing with the side effect. I think part of it is the culture of expectation when you go to a physician you expect a treatment that will help you feel better, but when you are on the Fifth Doctor in, dealing with five or six medications, these add up.

When you're on them all day every day, you're dealing with a lot of side effects. That's something that our primary care physicians can help to alleviate or rather remove some of these medications.

[Timothy E Hullar, MD] I was trained that Meclizine was counterproductive. Individuals with difficulties might not be able to adapt because they are on the Meclizine. I'm not sure that that's such a hard and fast rule. It's kind of the opiate of people with Dizziness. A lot of people take it because it treats the symptoms, but it doesn't get you to a more long-lasting diagnosis.

At the same time, if people are miserable they are miserable. And you know, I don't mind if someone's having a severe neuritis. And so they take some Meclizine. It's rarely the best medicine, but it's over the counter and I don't judge people for it, but I often try to get them off of it especially if there's a better medicine for it. If they're taking Meclizine five times a day during

Menieres attack and they are hypertensive, that's a shame, right? Now, at this point is, especially clonazepam seems to be a very good one for, for me, and some of my patients, or for my patients, I should say, and some of my patients just have a little stash. And maybe that's not the right best word, but they have a little bit of it in their pocket or something they carry around just in case. And I think sometimes it's just a it's a little bit of a psychologic crutch, but I'm glad they have it.

[Ali Shabahang Saber Tehrani, MD] Absolutely, totally agree that benzos are usually a better, better choice. I guess the question is also, you know, the underlying cause of dizziness and how we can address that, for example, if someone has misalignment of the eyes, and that is causing the dizziness and discomfort and they're on meclizine. Sometimes you can, if you fix that it is alignment, that's the right thing to do instead of another medication. When you're dealing with a dizziness issue where the underlying causes in your ear, benzos might be the best way to calm the body down while healing is happen. If there's a stroke, you want the brain to get adjusted to the new situation. You don't want to give them a crutch. You want the brain to practice daily, readjust itself, and you don't want anything to numb the situation.

[Abbie Ross, PT, DPT, NCS] And with that being said, I can't tell you how many people will come into physical therapy and say that they've taken meclizine that day. I have a couple of questions I'm going to combine from the audience. Can you tell us a little more about Vestibular migraine and what diagnostic criteria you are looking for to make that decision, and then also, I thought this was an interesting question, how do you use a provider recognize when a patient's Vestibular migraine is well managed? at what point are you thinking OK, this is the program for you?

[Ali Shabahang Saber Tehrani, MD] I think Dr. Hullar is seeing much more patients with Vestibular migraines and I am.

I don't do outpatient settings that much, but there is established migraine criteria -- presence of aura, presence of headache, and I think I'll let Dr. Hullar take this one because He is the true expert in this field.

[Timothy E Hullar, MD] Which is funny because if I get a difficult vestibular migraine patient, I say you have to see a neurologist because they're better at migraines. I'm a simple and very not-smart person. And I forget what the precise criteria are for Vestibular migraines, but history is the only thing that I turned to. I think if there is an element that sounds like Meniere's disease I might go down that route a little bit, But in general, it's just by history, you know, did people have kind of conventional migraine, classic migraines in the past? And what are their symptoms? Now? Do they get dizziness? Do they get any kind of typical migraine symptoms? Still? How long does it last for the last more than several hours? The concern for me is the overlap and diagnosis with that and Menieres disease. And we should probably come back to that maybe in a separate question. But how do I know when somebody's well managed? I, I really listened to them. And I think that some well managed for some people is shorter episodes, some people is fewer episodes, some people is maybe once a week, or once a month, I have patients who come in who get one episode of is what's definitely a vestibular migraine every year and I say you should probably deal with this. You are pretty well treated.

So I'd say it's patient desperation. We all know dizziness can become a big problem, and our job as clinicians is to untangle that. Along those lines, one of the things about VM is that you need to be on the medications for three months before giving up. And if I were in their shoes, I'd be so frustrated. But I say you know, you're gonna be on a migraine diet for three months, and then come back and see me and I know that Charlie Donaldson dean at Hopkins, has said the same thing that if they want to come back in less than three months, he's really pretty reluctant to see them because they haven't been doing their side of the of the work. And it is a trial and error thing. And especially if there's some overlap with Menieres disease, and as a clinician, you're really I mean, I don't want to underestimate the our abilities. But I find a lot of times I'm kind of guessing and listening to the patient, what a side effects are they willing to tolerate? If they say wow, I just can't stand my finger getting some temporary tingling in my fingers? Well, they're not going to try Acetazolamide, at least for at first. [Danielle Tolman, DPT] Very broad spectrum type of disorder, and everybody is different when it comes to the approach of treatment and triggers and what effect people. I will throw an easier question towards you guys, this is actually combining two of them.

[Danielle Tolman, DPT] The patient, their migraine is tough. It's a very broad spectrum type of a disorder. And everybody is different when it comes to the approach of treatment and triggers. And you know what effect each of those approaches that treatment has on them. This is actually combining two of them from our q&a. But what percentage of patients having Vestibular dysfunction have noticeable hearing loss, and is hearing loss testing also relevant for central vestibular issues in comparison to peripheral issues or is it just peripheral that we notice?

[Ali Shabahang Saber Tehrani, MD] Yes, it's very important. Sometimes it can -- what helps with us diagnosing is ruling out peripheral cause, so it helps a lot. But I see how Dr. Hullar likes audiology testing, And I wholeheartedly agree.

[Timothy E Hullar, MD] Some of my best friends were audiologists, but that's not why I like audiogram. I'm more convinced by their utility than I used to be. So I used to say, Well, if you have a normal audiogram, that is probably a central problem. But now I am growing increasingly, increasingly recognize that sometimes an abnormal audiogram actually can be seen in central problems. And vestibular migraine is one case where we're realizing more and more that something that fits the criteria of vestibular migraine actually sometimes does have hearing loss, it's probably attributable both to the migraine itself, maybe there's a vascular change in the inner ear, that can be that the migraine can cause and, you know, sometimes migraines are associated with benign positional vertigo. And that kind of, if they're affecting the utricle and saccule. That way, then they very well may be affecting the nerves and the hair cells in the inner ear as well.

So, in general, I think our diagrams are useful to help distinguish central from peripheral, but they're not really perfect at it. In terms of the percentage of people who have abnormal hearing, who have distributed problems, I guess the first thing I would ask the person who asked the question is do they mean hearing problems that are related directly to the vestibular problem, which probably is what they mean or just to Dizzy people tend to have a lot of hearing loss. And I would first say like, as people get older, they tend to get both. So it is sometimes hard to disambiguate people with kind of standard hearing loss as they get older versus hearing loss that is actually due to a vestibular problem. And a classic example of that is people have hearing loss and you say, Should I get an MRI scan, thinking that you might have a vestibular schwannoma. And that's also a source of a lot of clinical disagreement. One more thing about audiograms is we are understanding that hearing loss are treatable hearing loss. If you treat someone's hearing loss, sometimes their balance couldn't seems to improve. And so and the other thing is just we know so much about hearing loss, and how how much it affects people in terms of their cognition in terms of their mood in terms of basically everything and so for sometimes they say to people, I understand you're here because you're dizzy, but let's talk about your hearing. And that's like, let's choose the low hanging fruit isn't as complicated. Let's fix one thing at a time. This is the most obvious thing, come back in three months after your hearing is fixed.

[Danielle Tolman, DPT] Make a great point talking about the relationship between hearing and balance. I want to go back to what you spoke about a little bit earlier about vestibular migraine and coexisting Vestibular diagnosis, perhaps migraine and BPPV for example. I think the question it relates to is, how do I know that I have been diagnosed correctly and have gotten the best advice from my situation? So how do I know that that it is just migraine or just Meniere's? Talking about multiple diagnosis coexisting? How about these tough ones?

[Ali Shabahang Saber Tehrani, MD] I usually will trust in my clinician. I will listen to them. There are findings that can help point us in one direction or another, but diagnostic errors are a thing as well. Sometimes it's easy to know how the diagnosis was correct. For example, with BPPV repositioning maneuver is completed and then the dizziness goes away.

You know, that isn't that a diagnosis and treatment was correct. Or vestibular migraine that is super well controlled. But I'm not sure if you're always this fortunate and so many times, businesses complex. How are we going to know you're 100% diagnosed correctly? I'm not sure if we ever can in my own practice. I always am happy to refer my patients for a second opinion. If they feel that you know there is more that can be done. I don't feel offended I think would love it, it's if there are the more smart people the tried to think about a patient, the better for me as a as one of the clinicians. So I invite that. So that's, that's perhaps another thing to consider it perhaps a second opinion is, as a physician, I don't feel offended at all. But how do we know you're 100% of time diagnosed correctly? I'm not sure if we have a gold standard for that.

[Timothy E Hullar, MD] I think that's one thing where technology is going to improve things. Ali is at argulably the -- arguably the best vestibular Center in the world. It’s hard to know where to send someone from there. I mean, there's a few other centers, I say to people, there's somebody in Seattle, and there's someone in San Francisco. And other than that, why don't you go to off the west coast, you know, and that's not quite fair to my colleagues and other places. There just aren't that many folks who I feel that patients with complicated problems can go to. The other

The other thing I would say is be aware that sometimes your doctor doesn't want to figure you out. And this is horrible to say, but I think especially on the surgical side. Surgery, I mean, I'm I'm salaried, right. But surgeons make money by doing surgeries. And a patient who comes in who's got the nine Positional Vertigo is not that patient that that doctor wants to see. And again, it's, it's tragic. And I feel like I'm betraying very hardworking, conscientious people. But a lot of times, especially, I think surgeons just want to say, you know, here's a pat on the shoulder, and you don't have any ears and good luck. And in that case, I think that you just simply need to move on to a different doctor, but be aware that what you're sensing from that doctor, or that provider is not made up that a lot of people are not invested in fixing you. And I hope I'm not creating a riot out there among, among your people.

[Danielle Tolman, DPT] I think that I think that a lot of people are here watching this conference today, because they have learned to become their own advocates and find information themselves. I will say that vestibular patients in general, I think have become wonderful warriors for themselves. And they know when something maybe isn't responding correctly, or something's not right, and maybe that it's time for a second opinion. And unfortunately, a lot of times, we have to have our vestibular patients or people in the vestibular community bring information to their providers, because maybe they're in some sort of a medical desert where they don't have a specialist near them. And they have to do the research to then present it to the provider and say, Can we try this? Or what about this person? So I applaud all of you today, watching and informing yourself and educating yourselves about what is going on? Because the best thing you can do for yourselves is arm yourself with information about your condition, what's going on, who to find, to help kind of guide treatment and get you on the right track. I have I have one more question, which I'm actually kind of curious about. Somebody was asking about any advances in testing for superior canal dehiscence? Do you guys know? How would you normally test for superior canal dehiscence? And is there anything on the forefront that could be helpful in diagnosing?

[Ali Shabahang Saber Tehrani MD] I feel it was the ENT side at Hopkins who did it? There are multiple tests. Dr. Hullar, I'm happy if you want to, if it's on the ENT side, I think I'm happy for you to take it and you mentioned the CT scan and, you know, VEMP etc to consider it.

[Timothy E Hullar, MD] yeah, I was fortunate enough to actually be in Dr. Minors lab when when Lloyd honestly discovered it together with other folks like Dave z at Hopkins. Again, I'm kind of a minimalist to me, it's a good history for it and a CT scan showing it or indicating it and a an audiogram demonstrating it is is really enough. Now I think that the criteria include also some vestibular testing and obviously vamps are useful I think, in many cases I think you you look at a CT scan you say I'm 99% certain they have superior canal dehiscence based on the CT scan, it certainly sounds like it are you willing to deal with your symptoms or would you like to have surgery where we will move your brain around and will make your dizziness different but we're not going to get rid of it because we're going to disable one of your semicircular canals and so many people are just so relieved to recognize that they're not crazy, but they also don't want to have surgery. So what people run into Uh, so I think for me, again, a kind of a minimal minimalist approach, you don't want to keep throwing tests at someone until something turns up positive. And if they don't start to sound like superior canal dehiscence pretty early on, then they probably don't have it. And this is a condition that's, at this point vastly over diagnosed, partly by surgeons because they can make an immense amount of money by operating on these people. And I've seen surgeons, unfortunately, again, throwing my colleagues under the bus who take a very liberal view of what constitutes a dehiscence when they will get a CT scan. And that's very unfortunate. So this is one. Yeah. So I guess that's an initial start to answering your question. But be be really cautious when you think you have severe canal dehiscence. So many patients come to me saying they have it, and they really don't. And then we need to untangle it again. So help us out and keep an open mind.

[Abbie Ross, PT, DPT, NCS] Dr. Hullar, Dr. Tehrani, We threw some tough questions at you guys today. But I do think that we can extrapolate that to vestibular care in general, it's challenging, it's complex. Sometimes it takes time and processing to get the answers that we're looking for. So you did a great job. Thank you so much for joining us today. We're going to pass the baton.

[Timothy E Hullar, MD] I have one question. I'm sorry. I don't mean to interrupt you. I have one question I would love if your listeners could think about, When should we suggest that people don't drive? And I would love it's not gonna be part of this session. I understand. But I don't know, sometimes. And patients say, Is it safe for me to drive? And I say, I'm not certain. So I would love for people to think about that.

[Danielle Tolman, DPT] Believe it or not, we actually we touched on that yesterday, too, because we are our audience was asking the same thing. And I, I think our general take on it was that it's difficult, and especially kind of again, on that case by case individual basis, you know, I think doctor Rizk said if your job is to drive a school bus full of children, and you're questioning whether or not you're safe, we should probably sit that one out and not be driving. So going from one extreme to the other. It is it's easy, but it's that gray area in between and starts to kind of bring in that patient competence, I think as to whether or not they should drive if you're ever questioning it, you know, maybe taking a backseat until until you feel a bit more confident, I think was our general rule of thumb. But that is a very excellent question that we should continue to pose to our listeners.

[Abbie Ross, PT, DPT, NCS] Maybe the patient panel coming up next can tell us how they feel about that. So well, we'll go ahead and pass the baton to the brilliant Laura Cala. She has patients ready to talk on this subject. And thank you again to Dr. Hullar. And Dr. Tehrani, for joining us today.

[Laura Cala] Just love it. So we're talking about I think following that. So now I'm very excited to welcome on our two next guests.

Hi, everyone. Thank you for joining us for day two, what an incredible session. For those that don't know me, my name is Laura. I am based over in Australia. I have vestibular migraine, my condition onset in 2016. In 2020, I was officially diagnosed and is sure has been a wild ride. But that is enough about me. I'm going to switch over across to our two guests today. I'm going to get them to tell you a little bit about themselves. And then we will kick off into their diagnosis. So Sarah, I'll kick off to you to tell us a little bit about yourself. And then I'll move across to you, Yannis.

[Sarah Kirwan] Hi, thank you so much, Laura. And I just want to thank everyone for having me today and everyone who's joining as an attendee today. I think this is a fantastic conference, and one that I really wasn't aware of. I was diagnosed with multiple sclerosis in 2011, January 2011. I also was diagnosed with semi or was superior semicircular canal dehiscence, or I think the doctor previously referred to it as superior canal dehiscence. So I don't know which was being used more appropriately. And that was in 2019. But I went undiagnosed and misdiagnosed for almost 10 years. So I'm really excited to share my story here today in the hopes that it will help people to advocate for themselves and to be able to talk about what they're experiencing with their providers. So thank you for having me.

[Laura Cala] Absolutely. We look forward to hearing more Yannis Can you tell us a little bit about yourself?

[Yannis Benaniba] Hi, everybody. Thank you for having me. As you can probably hear from my accent. I'm from France. So yeah, we're sorry, started back in 2019 after a flight to Japan. And yeah, till then I have this strange symptoms. And yeah, not yet diagnosed with MdDS, but I'm diagnosed pppd right now, because like, I think MdDS is not that famous over here, even though the name is French. And yeah, that's all I like to share my story, even though mine is pretty insane see young compared to some other people. But well, yeah,

[Laura Cala] that's fantastic. And it's, it's I guess that's the best thing about this conference and sort of Sarah touched on earlier, everyone has got different journeys. But there are a lot of similarities along the way. And that's why sharing your experiences is something that is so incredibly valuable. And I know so many people are gonna get so much from it today. So let's kick off. When your symptoms first started, who did you go to? I know, for me, I went through a rigmarole of so many doctors and specialists. And it took years before I found the right one. So Sarah, can you tell us about who you went to go see first? And those initial experiences? What were they like?

[Sarah Kirwan] Yeah, so because I had already been diagnosed with multiple sclerosis, I think that there was kind of a different path for me as well. I feel like once the MS diagnosis was there, and all the focus for the providers went on to MS and the reasons for certain symptoms were blamed on Ms. And so originally my original symptom just like neon as was a full year on the left side. It claimed in Los Angeles after a flight from Chicago, and I just couldn't hear out of my left ear, all of a sudden it didn't unpop I guess for lack of better terms. And I spent seven days in bed following that with severe migraine, migraines with aura, and dizziness, vertigo, just very sick. And they thought originally, that I had a vestibular schwannoma because I also started having what's called acquired nystagmus where your eyes jerk back and forth uncontrollably. So I had these the symptoms, I also have learnmate symptom, which is from MS, where you look down and you get a shooting sensation down your spinal cord, and a multitude of other symptoms. And so like I said, January 2011, once that MS diagnosis came, it was really difficult. I, I kept going to my neurologist that I was seeing for my multiple sclerosis. And a lot of it was blamed on the MS. I was also told as the years went on, because this went on for nine years before I did have surgery, but I was told that I was schizophrenic, potentially bipolar, that I had adjustment disorder that I hadn't adjusted to my diagnosis of Multiple Sclerosis and that I hadn't adjusted to this new structure of my life. So it was very much like I felt like I literally couldn't share anything because I felt like there's something mentally mental health wise, wrong with me, right? And then I started to realize now this is not me, this is you. And that's when it changed for me. But originally it was it first, it was my neurologist.

[Laura Cala] That is so interesting. And to sort of hear you explain there was that moment where you're like, well hang on a minute. No, there is so much more to this. And we sort of touched on it yesterday as well in the patient panel, is it's that moment where you've got to start advocating for yourself, isn't it as you know, you know in yourself what is happening. And while there might be mental health issues that they're sort of in addition to. And that's how I always explained it. And I think with your story, it is that notion of you almost give up trying to explain yourself to the same person over and over because they're going to tell you the same thing. Yannis What is your experience has been like, especially in those those early days where you're trying to explain your symptoms to medical professional.

[Yannis Benaniba] Yeah, to be honest, my early early days, were probably the best, as I recall, compared to the rescue as I was traveling. So to be honest, I didn't pay too much attention about the symptoms themselves. Because, I mean, at first I thought it was the jetlag to be honest for maybe One week. Then I took another flight to get to Taiwan. And then I, yeah, I got the idea that something was wrong with me. But still, I had like an entire month's a bit more than a month traveling plan with my brother. So I didn't pay too much attention until I get back to friends. And then I went to first ENT, which was my mothers ENT. . It was a good doctor and so we did a few tests at 1st and we tried and medication for one month and after one month I end up explaining to him that I -- and he was just telling me this is not proven yet or this is like not existing in the books let's say. He told me I looked pretty anxious and I was looking like and acting strange so he sent me to Psychologist but yeah I complained to the Psychologist she sent me back to the ENT here that is the point.

I think the 1st, to me the worst thing I really didn't like was this information when you don't have any clue and you're just cruising around seeing doctor to doctor and just asking them, just explaining yourself trying to explain the same thing and trying not to be too anxious or not looking too anxious to them even though it's pretty complicated here you have hoped that maybe this person will know and maybe she or he has the magic pill you never know. When you're not prepared you didn't have any condition or health issue before that you'll never be ready for that.

For me I don't know. I had surgery in my life, I broke my nose, I broke things. I don't know. You can fix more or less everything in your life but then you end up with something you can’t. That's the worst part. New information and things you cannot do anything about.

[Laura Cala] That's exactly right here it was even yesterday we were talking on the patient panel and someone had asked the question and I was like I don't think I've experienced that but it's being clear on what your symptoms are and in those early days you just know there's something wrong and I remember going in and saying I just feel really dizzy like I remember waking up one morning and I couldn't feel what was around me. Doctors looked at me like I was crazy person but now I know that the way to describe that symptom is this equilibrium.

Let's talk about your symptoms from then to now here we briefly touched on them before but when you talk to your medical provider or you go to the practice for something else, how has that description of your symptoms changed to get someone to understand what it's like to go through what you're going through? Sarah can I pass that to you?

[Sarah Kirwan] That's a really good question you get to a point where you're in survival mode.

Just trying to get someone to hear you and see you and to listen to what you're trying to explain as the expert of what you experience in your life. So for me, one of my worst symptoms was when I would look peripherally I would hear my eyeballs, like the muscle, grinding around my eyeball and it would make me so nauseous and it was really interesting. I never noticed the body's pretty amazing. My body worked around that basically I will close my eyes turn my head and reopen them. Your body just kind of does these work arounds and so I would explain that.

I could really hear my heartbeat in my left ear so -- and I'm excitable person so before, the more passionate and excited I would get the worse this heartbeat would get in my ear, to a point where after years of having this I was so isolated from people because the noises of my body were so much louder internally than the world was. And I tried to explain that to my provider as well and that was difficult. And I have to say I started keeping a journal and one thing I think is really great and I don't know if Yannis or Laura have done this but I kept a journal of what my symptoms were and then I was able to identify different symptoms like what was the one symptom that could not be attributed to multiple sclerosis and that was the hearing of my own internal organs.

That is called autophony. I had no idea how to explain it and finally literally this started June of 2010, fast forward to October 2018 , I have left my job, I left LA, I moved to Colorado and slept on couches. I was checked out I had a lot of suicidal ideologies at the time and I'm still working through now as I look back on that I would continue to share all of this with my provider and then I finally, I don't know what I searched one day because I identified that this is the different variable, the hearing of my organs and I identified that and I don't know why it popped up on Google that day specifically but it did and I could give it a name.

I then had a follow up appointment with the same Neurologist and this is now 8 years later since my first symptom. I went into my Neurologist and I said I have it I pointed it out I know this is what it is and they were very defensive. It was very much I'm the doctor I told you that we think your schizophrenic we thank you have bipolar more onset of bipolar I'd like for you to get some other help. I said all I need you to do is a CT scan of my temporal lobe and you will know they will see it.

She said no you will see an MRI. In this country I am most well positioned to get the cure that I need. So what really angers me is the fact that I have a bachelor's, a masters, I worked at a hospital I worked in healthcare administration, insurance. I have all of these years of experience in health care and yet I can't get a provider to listen to me and that has really that a fire under me to amplify voices of women and men and children from other communities that aren't heard or seen at all. She shot me down she said nope not going to do the CT scan for temporal lobe you see in the MRI I was begging her please my insurance will pay for it, I'm trying.

I'm about done with at this point she says no I go back in six months I was like where does it show on my MRI because it's not there. There was probably three or four months where I just isolated and I was really depressed and I was just really struggling then one day I was like you know what she's not going to get the better of me at this and so I found Neurologist and neurosurgeon that specialized in Superior Semicircular valve Dehiscence I said tell me where to go. I don't want to throw anybody under the bus but I think this is really important for patients and everyone to understand that the two departments I was going to, neurology and neurosurgery, we're part of the same healthcare systems .

Same doctors under the same neurology department so I had to go around my Neurologist to the neurosurgery department begged them to get me in, finally got in the woman the office manager said get her in next week so it was five days I got in they diagnosed me on site on no tests, no nothing. After that they did have me go down and do an audiometry test because I've been telling people for years, they're like you have perfect hearing I said I can't hear out of that ear hear I'm telling you I can't hear and finally they were able to really go over that.

This is the thing that I think we all wait for as patients and this was the moment where, I've never been more seen or heard in my life this young woman put her hand on my leg at the neurosurgeon's office and she said we believe you and we're going to help you. I don't want to get teared up but I just felt like for the first time I could relax for the first time in nine years I could just breathe. I hope that was not too long.

[Laura Cala] I think that is important for you to share.

People are right there with you on the chat as they are commenting away. There's that thing as you mentioned before what about the people that are just taking what their doctors have said as gospel? And I went through so many doctors and I remember having some breakdown at one of my specialists there is something wrong. I know it's not an anxiety issue. You've got to do something about this and he goes there's the therapist and that I know that specializes in dizzy and he me off just the and his name in west Australia is Alexander ring.

He was the first person that sat with me and said I know what this is. It's that real moment of it's all been worth it, the first time in years that you can just relax because you think we've got a solution now. It's that real defining moment where you know there's that diagnosis but we'll go on post diagnosis in a short moment. And do you want to tell us about your experiences and how over the years explaining those symptoms have changed and any frustrations you've had around that?

[Yannis Benaniba] First I remember, I have something to explain to you explaining this in French is kind of complicated.

We do use the word which is vertige -- so for Dizziness you can have a lot of even to describe like rocking, bobbing and this kind of other stuff so your language is pretty precise compared to ours we just use this word vertige. And you have to explain I have from side to side and that kind of stuff so it was kind of complicated to be honest here between the two entities I've seen maybe a Neurologist and then I saw any anti and change you about -- she told me she cannot do anything about it for me hearing it was no relief at all because to me as I read on the information website it's like and neurology disorder with no known cure.

I remember after that maybe one year resulting -- and then I tried to my whole life just trying to make it disappear so I ended up destroying myself up here I went pretty down, I mean I just tried to do everything that I can I was asking any help from a doctor or medical care just trying to find out -- I just wanted even though today it's is complicated for me.

[Laura Cala] You get tired of having to explain yourself over and over and you almost, there are moments where I look back now here I know Cynthia is posting different links on the chat as well which are really useful around that mental well being Eric it's hard not to think at times is this in my head, let's just take a step back.

As you said, it's hard and there are days now that are still hard with our diagnosis. For me it's not really knowing that there is that diagnosis and there are things that we can do to move forward. We are going to go to the positive I promise. Tell us about the most frustrating thing about your diagnosis. Now that I have that medical validation it is sometimes explaining it to people. There are people that have come and gone in life that have not been on the journey with me. I still have issues with people that ask me you've still got that I did not realize you were sick I almost make you feel guilty about it but it's that notion of having to explain yourself.

For me that's probably the most frustrating thing about my diagnosis. What about you Sarah?

[Sarah Kirwan] I want to piggyback on what you said because I think it's interesting to share it with people and that you have a different reaction everybody has a different reaction and some people do feel aren't you over that yet you didn't get healed from that or whatever it is. I just had something I really wanted to say but it's just frustrating when you try to explain it to people and you try to explain that it's not something that just goes away.

Although yes I did have surgery I did have it bilaterally. I'm starting to hear my heartbeat in my right ear now those symptoms are coming back on this side. Even after being diagnosed in 2011 with MS I still struggle with the structure of it. I get really irritated when people say you're such an inspiration. I'm just trying to help myself and I will help other people help themselves because we all deserve to get the care we need. I do get irritated when people say you know you motivate me you don't have a choice.

The other thing would just be the disability of microaggressions of you look so good I would have no idea. I think it's just hard to understand it also people like to get really sad when you share diagnosis. For me I feel like it should be just part of a typical conversation where I can see I have SSCD, blah blah blah and move on but there's a pause in conversations where people don't know how to react or how to give space for your thoughts and feelings or think about their own thoughts and feelings around it and need with more empathy and grace a little bit.

[Laura Cala] Have you tried this, have you drink more water? do you think if I could drink all the water in the world to make this better I would. Do you think I've not explored that? I know for me that's a big one.

[Sarah Kirwan] Magazine articles, everything. I believe these are loved ones trying to help us probably and care about us but it's not really that helpful. It really needs to be as the person who's experiencing this, we get to take the lead there's no one in our spirit that gets to take that lead away from us.

[Laura Cala] Yannis what have your experiences been?

[Yannis Benaniba] Yeah, to me, to be honest, right now I'm not talking too much of it anymore. If you don't explain about it they cannot see it because it's something pretty invisible when they look at you and so I don't know right now a part of me is oaky with this idea of people not finding out. And then there’s family and relatives. I'm just fine with them just asking the time to time but don't want to speak too much about it. There is a good for me and there is also a bad. It can turn you a bit lonely sometimes.

At some points, I just feel like it does not really matter anymore if I'm telling other people how I feel because I'm feeling more or less the same sense for years now in the years after years after years and nothing really changed. I've tried many things and yet people give me advice because I'm speaking about it but now I'm not speaking that much about it and yeah. People can just try to -- you can be happy and it's a bit strange to explain but it is what it is.

[Laura Cala] I think you raised so many things here.

Beautiful support we get from VeDA and our community that's why it's so important. I remember when I got given my Vestibular diagnosis and I spoke about it yesterday, I go on and I went and walked and I found David the ambassador who has this amazing group, I found other people just like me and I can still relate to you Yannis because you just stop telling people and when you do and you are having that bad day and someone says to you, you don't look right, I know Kevin talked about it yesterday you've just got to say I'm actually not.

They look at you like, well I don't know what to say to you. They don't let you have that space they think that you're asking for a solution but you're not. Because I know many are saying in the chat it's that knowing. We do it because we have to survive and it's that notion of we talk about it and it's so important to talk about it as many people have logged on to the conference today because if I don't talk to other Vestibular patients I would have no idea that there were people out there just like me I remember that first night searching David's Facebook and I was like crying my eyes out because I'm not a crazy person this is exactly what I've been going through.

One thing that people are talking about, I know we've sort of touched on it, the experience around an emergency room. Just like you Sarah you'd mentioned before I'm quite an excitable person and it goes the opposite way so when I'm feeling not right everything heightened. Back then my anxiety would heighten and I would want that solution straight away and explaining that to an emergency room doctor wasn't Iran impossible I remember going to the emergency room a handful of times and them saying I had anxiety issues or a virus and the virus would go away in a week and things like that so tell us about any emergency room experiences.

I know there are so many people just to have that validation and I remember looking at that myself and thinking how did I not know and now even when I go to a doctor, emergency what's going on and I go to my doctor and I tell him what I would like to do. Tell us about your experiences in that manner.

[Sarah Kirwan] I've never gone to the emergency room for this and I think that was purposefully done. I was in the emergency room often with relapses of MS but it could have been both because they put me on ivy steroids but I would never share about my eyeballs moving or anything like that.

I would stick to the multiple sclerosis pieces because they could understand that better, something doctors were talking about more, you would have better access to a specialist that would know something about it because I never wanted to be denied to care that I needed because if I brought forward something else, if I said OK I get a solid medrol drip I get it for five days, maybe 7 for my MS, I can move on here if I say I get that and by the way I hear my eyeballs moving in my head and my heart beats really loud in my left ear I just knew there was no way I would be able to explain that away or get the care I needed so I stuck with the story that worked for me to get what I needed.

I know that -- I don't know dual diagnosis which I think would be interesting to find out. That has my experience.

[Laura Cala] That's incredibly helpful. Yannis have you had any experiences with the emergency department

[Yannis Benaniba] To be honest never went to emergencies in the hospital . Even though to be honest I've never even taken a day off my job about that. It just happened to me once how to be honest I explained to you I was willing to try everything. I ended up to having prescription for a doctor. I spoke to people and they explained to me this doctor gave me some medicine and so I ended up continuing medicines you better not doing that for one week I was just stuck because I cannot even move. But yeah, this is only experience.

[Laura Cala] That's fantastic to hear.

[Yannis Benaniba] But that's really true. I mean, when you're desperate and you don't find relief and you were just wanting to disappear and one for you being sick or being weak is not an option you just end up doing whatever you can. I did that. Just want to try -- It's best for you going to the emergencies or a health care provider speak with people who are more experienced in their journey than yours then trying everything on your own even though right now I cannot say I'm happy that I did -- I feel like I'm fine with the idea. People watching this can probably understand when you are on your own with this kind of problem and this kind of trouble and there is no answer, when you're stuck at some point you go and you face it your way, good moves or bad moves, sometimes you will end up doing things making you worse but yeah this can happen. Also I'd like to share that I tried to be more positive after all. Like people I have met and they changed my life people from VeDA and a researcher in France helped me a lot. So yeah, I can speak about it.

[Laura Cala] We appreciate you sharing that. But you've also raised and a lot of people have talked about it in the chat as well. Yeah we talked about explaining our diagnosis to friends and family come on what about our workplaces? I remember back -- I have back to working full time now back in 2016 this started to happen and long story short I had to resign from that position because they just did not let it I was calling in sick every other day, I had requested for a four day week they did not understand it because in their eyes I looked fine and it ended up after a good year or so it ended up being we don't have a position for you here with the current situation.

A master slap in the face because at that stage I was not diagnosed and I almost had felt like I had failed and like you, Sarah, I went to my second masters degree very highly qualified, I've always been a go getter and someone that has always put 110% in so almost being told you aren't good enough anymore and we can't accommodate this is something that will never come something that took me a good while to sort of be able to emotionally and mentally get over that. Have your -- how have your experiences, how did you deal with explaining it and how have you managed it as the years have gone on since diagnosis?

[Sarah Kirwan] It's really hard topic for me. I'm like you very type a, high performing, fast-paced paced and I just at some point I guess I should say seven years because about six years into it I had to leave my job as a hospital administrator. It was because I was denied accommodations and that's really hard for me to understand as well why basically accommodations are just making it passable for us to be successful in that role by working in a different type of way. So I never really understood that that do want to say after that I did go work for another organization for about a year and that's when I really checked out.

Nobody is listening to me, nobody is helping me and I went to Colorado and slept on couches and in guest rooms. What I really struggled with and I want to identify is our feeling of being a valuable member of society and what we are valued for. I think a lot of times we place so much value on what our job is what our title is that's part of our identity, when all of that identity is stripped away, what are we? what are we at the truest core? And when you're going through something like this you have so much time to think about what am I and what's my value and it goes to very dark places because even if you think about it in the world when you meet somebody new what do you do?

I started telling people I work after MS people asked me what I did I just say I serve and I just leave it at that because it's so much like what is my identity and it took me a long time to figure out what that identity would be. I had a consulting business I started a consulting business because I couldn't do any other work after I left LA and I was so sick. I could not consult -- I had word of mouth clients, very easy for me to do at my leisure depending on how I felt when I was making no money and I think that that was difficult because you need money and you need medical care and when people don't want to give you a reasonable accommodations how are supposed to have money or healthcare? You can't.

All of this took me to a very dark place and it took me a very very long time and I had kind of been sharing my diagnosis for a while and in 2020 I was like I'm over it or maybe it was 2019. 2020 I launched my website. I could help support them and so that, that is kind of it.

[Laura Cala] I often say Vestibular is one of the best things for me because it grounded me out it taught me about what was important. I don't know how I would go, going through the whole thing all over again.

As you said it gave me a lot of thinking time and I did things like yoga so people ask me the same type of questions. I've had to change my routine I had a big reshuffle and a rechange and within that it was hang on a minute I'm so much more then this title and that to me and that is why I said my Vestibular is one of the best parts of me and I'm glad I'm now going through the journey and it's so hard if you are in the minute to feel that way. I guess from listening to Sarah as well it's that notion of you will get through it. You've just got to keep going.

[Sarah Kirwan] You brought up a really good point - when you go to these dark places there's a lot of self medicating that can go on and I tried to self medicate to get rid of some of my symptoms I just want to say that however, what you need to do for yourself, that is, no one can shame you for that or judge you for that you are in survival and you are getting through it the best way you know how and with regard to relationships I'm just going to say in my experience it's been a constant process. When people don't understand I can't have a relationship with them. And so I just wanted to say that there are some things that get smaller but like Laura said they are more quality I feel at this point.

[Laura Cala] Grieve with what the new normal is but also allowing space and working out what is best for you and putting yourself first because that's the most important. I love that. How about yourself?

[Yannis Benaniba] As I told you I never really had a day off from my job and working as a freelancer for cyber security consultants. Probably spoke with a few of my colleagues depending on the mission different colleagues I'm seeing people sometimes I'm not.

Probably spoke a few times with people I cannot really understand it. Usually men don't complain that much. You end up with you being sick. And the place I probably spent on with days of derealization and just me doing my job, going to meetings and stuff. Me just watching yeah -- the day I had the relief double when he was speaking about it and then because I never spoke to anyone about this and then I was OK. yeah now I've got the idea. Vestibular issues can bring you. There's another point, me just being crazy. To be honest here about working, for me the point is if I did stop or so for this it was me just giving up so until today I still did not stop.

I probably should I guess at some point. Trust me thinking about it, if I do stop it can be later in life. I'm not doing thing right now when I'm supposed to be fine just me pushing it. Yeah, doing it actually.

[Laura Cala] Back in 2020 when COVID first hit everything went remote so do you work from home or do you work out of an office how do you balance that

[Yannis Benaniba] It depends. During the war COVID phase, I was in the mission - we had no working from home. Now that COVID is done the job that I'm doing right now I'm supposed to get once or twice a week in the office and if I don't really want to I don't get there but to me it really depends. During the COVID that was strange we were probably the only French people doing working at the office.

[Laura Cala] I think that's a valid point for everyone as well.

I have had one request for you, Sarah, to share your website so rather than perhaps saying it out loud you're welcome too but maybe if you answer the question on the Q&A when we jump off and you can respond to that question that would be fantastic.

Let's move across I know we've only got 10 minutes left by the quality of conversation I'm getting so much listening from the both of you. Interesting to speak to other people on a journey because things are so different but so similar let's talk about Vestibular testing.

I know there's some I know this is something that I initially never heard of. Really just confirming and I know Abbie touched on it in the previous session and there are the two around journaling. My therapist got me to write down what was going on I went on the migraine diet and that's where it started for me. Sarah have you gone through any of that testing with your MS or is that something you've managed to avoid.

[Sarah Kirwan] I have not avoided any of that but I did have to look up what types of Vestibular testing there was because I did not remember what I had done I had the electro video nystigmagraphy the rotation test the Vestibular myogenic potential I also had the auditory brainstem response task but that's used to diagnose MS as well.

They were probably looking for something different and then audiometry and MRI. I've had quite a few. The frustrating thing for me was it never ended with anything and it was just like these tests nothing came of it. So I don't even know what the results were of it. There had to be something there but again I did not have much luck but I did a lot of testing and it was uncomfortable.

[Laura Cala] Cynthia will pop it up on the chat she's popped her website up there as well so thank you Cynthia for doing that.

I remember the water with water being flushed across. I know, like you at the time, I don't remember taking what my actual results were but they're coming back in line with a Vestibular disorder. It's interesting when you go back and you listen to this mission before and they are talking about individual test something sort of sitting back and being able to understand what they are looking for is interesting. Yannis have you gone through any Vestibular testing or had you heard of it prior to today

[Yannis Benaniba] I've done all the ones Sarah has explained. All of them I've done them many times. They all end up with no results to be honest. That's why at some point they say to you it's all in your head. As it's neurologic disorder meaning your brain is sick and your brain is located in your head because those people are right it's all in your head it's all located in your brain right?

[Laura Cala] It's amazing isn't it? I've actually had a question come in and it sort of works really well -- before we finish Laurie has written - I've been dizzy for the past 22 months I've seen many doctors I've been diagnosed with Vestibular migraine yet I've had no headaches in the past 22 months.

I've been on many different medications nothing has helped. My Neurologist is not able to help. His experience in Vestibular too. Any suggestions I will pass over to Sarah to give her opinion first.

[Sarah Kirwan] I kind of have a follow up question was there a reason given by this individual how this provider could not help? That would be my first question my second question would be get a new provider. I think that one of the scariest things for me was to get a new provider. When you're in survival mode the last thing you want to do is to have to get a new provider that now needs to look through your medication list, look at this, do an overall and whatever it is with your body and you have to start over the thought of starting over is exhausting in and of itself but I also think that I would have loved for someone to be able to identify this for me, go to a different provider.

Is there a way that I can help you to access that other provider because you will continue to hit your head on a wall if that provider is not going to listen. If you don't need a recommendation to another provider I would not ask for one. And I would just go around that provider and do what you need to do for yourself.

[Laura Cala]. Absolutely. Yannis how about yourself?

[Yannis Benaniba] Never forget that things are evolving every time, so place is not a straight line. Life is like ups and downs. It does not mean if you're down today it does not mean that tomorrow you cannot be here you just have to remember that you are maybe down sometimes but like, it does not mean that , you are like this today it does not mean tomorrow or the day after tomorrow you have to find out tomorrow.

With him for the provider it's going to be really challenging for them because they don't know really about you to understand that these people are most of the time they are amazing. They had the best person to probably give you options and so but then when you try it and it does not fit your need you're going to try something else. Just be careful with medication and this kind of stuff. By now it doesn't really matter anymore I'm glad but I ended up with a bad story and I know now.

[Laura Cala] Doctor Habib made a good point yesterday you can't get the reasons we can't get the answers is because they need more education and I'm 100% with what you have said. It's our right to go to another provider I had someone from work , I don't actively talk about it as much anymore, the fact that I get to work from home, she had said she's on the other side of Australia and she had mentioned that her doctor had said this is the way your life is always going to be and my first reaction was what do you mean? I said you need to get another opinion because to me -- when I did find my Vestibular therapist and then my neurologist they were able to understand the input me on the right path. It's not going to happen overnight I'm not going to try to -- I know people are so frustrated and we will go over treatment in tomorrow's session. It would be great if we could say in a week time that you're going to be better in a month, year, to me it's a journey and it's a journey of learning and things change and they will get better but just know that it will never be as bad as I think what it has been previously so on that note before we close out what I'd love to do is go to Sarah and Yannis with your piece of advice to someone at the beginning of their journey my advice is to keep going and keep advocating for yourself and it will get better.

Sarah how about yourself?

[Sarah Kirwan] That would be mine as well. Keep advocating and if there's a portion of access to internet, computers – go to the library, get the education you need because even if a doctor isn't listening to you, you have this data. I'm a very data driven girl so I always it was data it's helpful for you to have that in your head and to be able to explain that from a data perspective. I would say keep advocating and find someone or a group of people, I know people don't necessarily like self help groups or support groups but there is so much information that you get and shared experiences that you get and this is where I feel like we continue to feel empowered because we hear other people's stories and we think.

I'm not alone I know that other people are experiencing this and I can talk to this group and see if there's anything that they can suggest for me. It's really an individual journey but like Laura mentioned we have shared experiences and we can lean on one another and provide that support and what I found is that through self help for myself myself it grounds me. I'm really able to, sometimes it's hard to go back to when it was really bad. When I was really in that space where driving around a corner I wanted to go off road and run into a sign.

That's bad and it changes from there but it's important to remember how that felt so we can help empower other people. I would say find someone who supports you. Let their relationships go that don't work and do what you need to do for you and prioritize yourself and I know we have families and things like that but there's still a way to prioritize yourself in this process because you deserve to have an answer and you deserve to have someone listen to you and complete you and work with you even if there's not something they can do a surgery this or that, how to restructure this new knife that we have, how do we restructure that?

I have these two walls and I stand between here with my diseases but how do I structure my life in between here so it's super meaningful for me and it's a high quality? And I work around my diseases and disabilities. And when you talk to other people you will start to find some of those ways you can put yourself first in those ways

[Laura Cala] I love that Yannis how about yourself?

[Yannis Benaniba] More or less the same as Sarah and the right information and to advocate, to share with people. If I have really two of the best advice I told you, one is things are evolving you're not stuck, your brain even though is just changing overtime can be better depending on what you do and also just be compassionate with yourself and trust yourself.

It does not mean that the doctor says no this is not you probably know best for yourself than any doctor. It makes sense because they are not in your body and they cannot really know about it they know it from the books. We are glad there is doctor helping us and there are people working on those fields which is helping people and this is great and we are, we can see thank you to many people -- medical people for sure but in your journey trust yourself

[Laura Cala] I know we could continue talking I hope everyone that's joined has gotten something from this.

A big thank you to VeDA and all the volunteers making this happen. To close out I just want to thank you again to the James D and Linda B. Hainlen Discovery Fund and the University of Minnesota Department of Otolaryngology for sponsoring this conference. As a reminder, you can purchase lifetime access to the recordings and transcripts of this entire conference at t vestibular.org/lrl-recordingsand you can help make us make sure the valuable information that is presented at this annual event remains free to everyone by making a donation at vestibular.org/LRL-Donate. Those links will be posted on the description box at the end and I know we posted it in the chat. Thank you Sarah and Yannis for sharing with us today. Your insights have been truly valuable and I hope we continue to follow your journey.

[Sarah Kirwan] Thank you.