

Life Rebalanced Live 2024

HOW VESTIBULAR DISORDERS ARE DIAGNOSED

CYNTHIA RYAN: Hello, and welcome to the third day of the Vestibular Disorder Association's Fourth Annual Life for Balance Live Virtual Conference. I'm Cynthia Ryan, Executive Director of VeDA. Yesterday, we had a great discussion about tinnitus, that constant ringing, or buzzing, or whatever noise that you may hear that many vestibular patients experience. And a big thanks to Dr. Rob Allen with topple diagnostics for sharing his expertise with us.

We learned what causes tinnitus, how it's diagnosed, and what you can do to treat it. Although there isn't a cure for tinnitus, it was super helpful and hopeful to hear from tinnitus patients like Glenn Schweitzer and Steve Schwier about what they do to manage their tinnitus successfully. Don't forget to check out Glenn's Whova booth called Rewiring Tinnitus.

I'd like to, again, thank our sponsors who've made this event possible, the James D. And Linda B. Hainlen Discovery Fund and the University of Minnesota's Department of Otolaryngology have generously supported LRL since its inception in 2020. A special shout out to Jim Hainlen who is also a vestibular patient. He inspired this event by holding his own vestibular conference in 2018 and 2019. Jim cares so deeply about supporting people on their vestibular journey and it was important to him to have not only education for people about vestibular disorders, but a platform where people could connect with others who are suffering like they are with vestibular illness.

A big thanks to Dr. Abbie Ross and Dr. Danielle Tolman from Balancing Act Rehabilitation who are also generously sponsoring this year's event. Many of you know Abbie and Danielle as the hosts of this conference, and some of you may know them as the hosts of the Talk Dizzy to Me podcast.

But you may not know that Abbie and Danielle also serve on VeDA's board of directors and have volunteered countless hours to advance vestibular advocacy. It's dedicated volunteers like Abbie and Danielle that have made VeDA what the organization it is today. I've been honored to work with them and glad to call them my friends. Abbie and Danielle, thank you so much for everything you do for VeDA and the entire vestibular community.

Thanks also to the Academy of Doctors of Audiology for sponsoring this year's event, and a personal thank you to Pamela Duncan who attended last year's event and was inspired to make a donation to support this year's event as well. So without further ado, I'd like to pass you off to our hosts, doctors Abbie Ross and Danielle Tolman.

DANIELLE TOLMAN: Thank you so much for the wonderful introduction, Cynthia. It is still hard to believe that this is our fourth annual Life Rebalance Live. We are so excited to continue bringing you an all-star lineup of health care providers to discuss various topics pertaining to the management of vestibular dysfunction, as well as the inspirational patients who will be sharing their vestibular journeys. We also want to say thank you to so many other people who have contributed to this conference in some way including VeDA's donors, staff, and volunteers.

ABBIE ROSS: And with their contributions, we're able to put the live version of the conference on at no cost to our attendees. If you do wish to gain lifetime access to the presentations following our live event, we will have them available for purchase for just \$55. And thank you to all who have supported the conference thus far. Your financial support helps VeDA's continued mission to spread vestibular awareness.

Our topic for today, day three, Wednesday, is, How are vestibular disorders diagnosed? We'll be discussing what the start of a vestibular journey may look like, what diagnostic tests patients may undergo, and what may be the next step when the testing comes back unremarkable, or quote unquote, normal.

DANIELLE TOLMAN: So without further ado, we like to introduce you to today's speaker, Dr. Jeff Sharon. Dr. Sharon is an Associate Professor of Otolaryngology, Neuro-otology and Skull Base Surgery at UCSF. He is also the director of the Balance and Fall Center. He is originally from New Jersey and completed a residency in otolaryngology at Washington University in Saint Louis, and a fellowship in skull base surgery at Johns Hopkins.

Clinically, he is active in treating patients with hearing loss, vestibular disorders, and skull-based tumors like vestibular schwannomas. His research interests focus on the vestibular system and trying to find out more effective treatments for dizzy patients. Dr. Sharon, thank you so much for being here with us today. We're so excited to dig into this talk. I have no doubt you are going to be phenomenal in giving us some great information.

JEFFREY D. SHARON: Thank you so much. It's a pleasure to be with you all today.

ABBIE ROSS: Dr. Sharon, thank you again for joining us. We're going to jump right into it. Let's start from the beginning of a patient's journey. Many people who've experienced vertigo for the first time end up in the emergency room. What might that look like and how can they help their provider discern what is causing their symptoms?

JEFFREY D. SHARON: So with the emergency room, I feel like it's important to keep a couple of things in mind. The first is the emergency room is great at doing some things, and it's not set up to do other things. So it is a great

place for delivering emergency care and diagnosing life-threatening or serious diseases.

In the setting of dizziness that a lot of times means stroke-- although sometimes it can mean heart attacks and other serious things as well. So when you go to the emergency room, sometimes there's a fundamental disconnect where you are trying to figure out what is the cause for my vertigo? And the emergency room doctor is trying to figure out whether or not you're having a stroke. And sometimes that disconnect can cause some frustration where you don't get exactly what you want out of the visit. But that is essentially how it's set up.

And so if you are worried about something serious going on like having a stroke, you have a first episode of vertigo, it's very severe, it's never happened before, the emergency room is definitely the right place to go to ensure safety. If you are having a recurrent episode of vertigo that has been going on for years, and years, and years and hasn't changed and you really need the care of a specialist, you might not get the answers you want out of going to the emergency room because that is not part of their training.

DANIELLE TOLMAN: They're making sure that you are not emergently going to have something happen to you when you walk in those doors and that you're going to be stable enough and OK. They're checking all the boxes of all the serious things. For somebody that goes in the emergency room, What kind of tests will they run just to rule all those things out? What can somebody expect in that battery of tests?

JEFFREY D. SHARON: So when going to the emergency room, they like to start broad and they like to start with basics. So first, they want to make sure that your vital signs are OK. That means your heart rate, your blood pressure, et cetera, because they don't want anything serious happening to you and want to make sure that you're not having an episode with really low

blood pressure or a heart attack or something like that. So they rely a bit on the vital signs to do that.

Almost every ER visit you get a basic battery of labs also-- meaning electrolytes and blood counts. And that's important when it comes to dizziness because sometimes people are dizzy because their sodium is really low, their blood pressure is too low, they have anemia, some non-vestibular cause for dizziness so it's important to be broad.

And that's why it's also important for everyone with a vestibular disorder to have a primary care doctor who's checking them and making sure that it's not their heart, their blood pressure, their electrolytes, an endocrine problem, a metabolism problem, some other issue that can masquerade as causing dizziness as opposed to dizziness coming from the inner ear or the brain, what we call the vestibular system.

Once they're done with that, depending on the severity and what's going on, you'll get a physical exam. I'm personally a huge believer in the ability of the physical exam to help differentiate different causes of vertigo. But it is something that takes a lot of practice and training to get comfortable with. And then depending on their suspicion, you might end up with head imaging. And head imaging can take the form of a CT scan, which is the quick one or an MRI which is the longer loud noisy one that doesn't work great for people with claustrophobia like myself.

ABBIE ROSS: Now, for someone who truly has vestibular dysfunction, meaning their symptoms are not associated with something more sinister like a stroke that needs emergent care, What would you say-- How often would you say that they get the answer they're looking for in the ED? Because what we hear as physical therapists is often, I went to the emergency room and they told me I have vertigo. But we know that vertigo is a symptom not necessarily a cause or a diagnosis.

JEFFREY D. SHARON: This is a really important point. And it speaks to a larger issue with the current care that we have for vestibular patients and the care models that we have. And unfortunately, it's my view that the current medical care system doesn't serve vestibular patients particularly well.

And a lot of times they seem to fall into the cracks, into the cracks sometimes between specialties like the crack between otolaryngology or ENT and neurology, or the crack that exists between a kind of specialty care and general care. So the vertigo is a symptom, it's not a diagnosis. If you go to the ER and say, I feel like I'm spinning around and they say you have vertigo, that is similar to them just translating what you have into a medical term but they didn't really provide any clarity in terms of what the cause of that was.

There is an exception. Sometimes people do use vertigo as a synonym for a particular type of vertigo called BPPV or Benign Paroxysmal Positional Vertigo. That probably shouldn't be done, meaning it's just too vague of a term and it leads to some confusions when that's the case. And BPPV is just one cause of many causes of vertigo. That's the one where you have loose crystals in your ear and you get dizzy with rolling over in bed for 20 seconds or so.

So I would say most of the time, you're not going to get a specific diagnosis from an ER doctor. That's a generalization but that's been my experience. Meaning if you think about the most common causes of vertigo like BPPV, like Meniere's disease, like vestibular migraine, like vestibular neuritis, most of the time the ER doctor is not going to want to make that diagnosis. They are going to make a diagnosis of stroke if that's applicable.

So if you have-- and this is important. If you have a sudden onset of severe vertigo, you're having trouble walking, you're nauseated, you might be vomiting, maybe there's other problems as well like double vision, you can't

see, your face is drooping, your face is numb, trouble moving one side of the body, anything like that, absolutely go to the ER immediately and then the ER doctors have some physical exam. Things they could do to help differentiate the two main problems that they're considering which is vestibular neuritis and a stroke, and they also should be using imaging as well.

ABBIE ROSS: I think this is a good place to also educate our audience on what are the signs of stroke that they could be looking at at home as well. If they have an episode of vertigo, What are some other signs of stroke that they may assess for to realize I need to get to the ED right now?

JEFFREY D. SHARON: So several things. The first is this-- you have to consider, Is this a new thing that's happened in someone who's never had a history of vertigo episodes before? Or is this something that happens very frequently all the time? Most of the time if you have something going on for 5 or 10 years and the episodes are fundamentally similar over that time period, it's not something like a stroke because you already have a serious problem if that's what the cause was years and years ago.

On the other hand, a new severe episode out of the blue, you do need to worry about that. When we think about strokes, we think about areas of the brain being damaged so it's looking for any signs of brain damage which usually manifests as nerve problems that the nerves aren't functioning the way they ought to.

One important thing with vertigo and stroke is to look at the eyes. A lot of times strokes that involve the vestibular system will cause the eyes to move, that jiggling of the eyes or rapid beating of the eyes is called nystagmus. So if you have a sudden onset of persistent nystagmus it's not your job to figure out what the pattern is. You just got to go to the ER and have them sort it out. There's certain patterns that are more likely to be caused from a vestibular neuritis which is a viral inflammation that is not a stroke or certain patterns that are more likely to be caused by a stroke.

With a stroke, you want to look for the typical stroke things. Is the face drooping? Is the vision blurred? Is there double vision? Is there trouble speaking? Is there trouble swallowing? Is there numbness in part of the body? Trouble moving part of the body? Is there confusion? Is there tiredness? Is there weakness? So you're looking for basically neurological deficits.

If there's any doubt, the consequences of not diagnosing a stroke are severe. And keep in mind strokes are time-sensitive. So you really don't even want to waste any time. So if there's any doubt, obviously you have to just get to the ER as quick as possible. But if you have something that seems to be pretty clearly benign and not a stroke, like let's say you for the last 20 years every time you roll over in bed to the left you get 20 seconds of vertigo and that just keeps happening, I don't think that the ER is going to be the best use of your time and money to get the care you need. You're probably going to want to see a vestibular physical therapist in that instance or a vestibular specialist.

DANIELLE TOLMAN: That kind of leads us nicely into transitioning out of the ER. Things are all checked off box wise, we're not having anything emergent, now we want to get to the next person that is going to figure out what's going on. So what might be some initial tests that patients undergo for seeing what's the cause of their vertigo and their symptoms?

JEFFREY D. SHARON: So the landscape of providers who take care of severe patients is confusing. So let me take a second to just review some of the words that we use to describe ourselves and who does what and what it all means. And part of the issue is you have neurologists who are fundamentally brain and nerve doctors, and then you have ear, nose, and throat doctors who specialize sometimes in the ears.

And because of that and because vestibular problems can arise from the brain, the ears-- and by that we mean the inner ears or both-- we have this

overlap. And we have also a little bit of a gap that patients can unfortunately fall into. So we need to be familiar with the different types of doctors who treat vestibular problems.

The first thing is it's always important to have a primary care doctor. And if you're having a vestibular problem, go see him or her and make sure that it's not something not related to vestibular system. Like a heart problem, like a blood pressure problem, like an electrolyte problem, endocrine problem, et cetera because a lot of times those can cause dizziness although they typically cause as much vertigo.

The second thing to be aware of is there's a lot of confusing terms out there for vestibular specialists. So I'm a ENT doctor which is ear, nose, and throat, which is also called otolaryngology, that's the same thing, who then did a fellowship in ear disorders. So I call myself a neuro-otologist. It sounds a lot like neurologist, but I'm not a neurologist. I'm an ear, nose, and throat doctor who deals with hearing and balance disorders, we call that a neuro-otologist.

Now, neurologists also see vestibular patients. And then there's a small of the very critical and important specialty within neurology where a neurologist will do extra training in vestibular disorders. And we usually call that autoneurology. So now we're talking about there's neurologists, there's neuro-otologist like myself, and then there's autoneurologist like many colleagues who are neurologists who then did additional training in vestibular disorders.

It's important to know about all this so that you can navigate the system because yeah, sometimes you meet with your primary care doctor or you go see a neurologist and an ENT doctor, they figure out the problem, and they fix you. A lot of times, unfortunately, the journey is longer and you end up needing a subspecialist.

Meaning you need someone who just does vestibular disorders because you might have a tough to diagnose problem, or tough to treat problem, and you might need continued care for months or years from someone who has expertise in vestibular disorders. And that's why it's important to know about neuro-otologist and autoneurologist and be able to find them.

ABBIE ROSS: I always tell my patients every medical provider these days is now some sort of specialized something or they have a mass amount of people that they refer to based on what you present with. So to expect every ENT to know about vestibular dysfunction and all the different diagnoses associated with it it's just not fair, not going to happen. So great point in figuring out which ones are the better ones to see based on the names that follow their bios.

With that being said, there's a great question in the chat that I think leads us into one of our planned questions which is, and I have to laugh at this because I can see how it would feel this way, Is diagnosing a vestibular disorder just trial and error? And with that question, let's talk about what type of vestibular testing is ordered and what we're gleaning from those tests.

JEFFREY D. SHARON: So yeah, that's an important point. So let's run through different tests. I will say there's no substitute for a properly done history and physical exam. And you really gained so much information from that and that often clarifies things. We do use a number of vestibular tests to help aid with certain diagnoses.

And I want to talk about them because there's a lot of confusion out there about the different tests and what they're capable of doing and what they're not capable of doing. Hopefully, it's not trial and error with diagnosis. That's not ideal. It shouldn't be that way. I will say sometimes treatment is trial and error, and we have to accept that because if we're going to be successful with treatment-- and oftentimes treatment is successful for vestibular

disorders, most of the time it is, but it can require having a good relationship with a care provider that you trust and then chipping away at a problem. So it's not always the case that the first treatment is the last treatment.

So there's a whole variety of different tests that are used. Probably the most common ancillary tests that's used, especially by ENT doctors is actually hearing tests. Which is a little counterintuitive because someone comes in for a vestibular disorder and then we get a hearing test. We have to keep in mind that due to evolutionary reasons related to the hair cells that enable us to sense hearing but also movements, the inner ear houses both hearing and vestibular organs. So they're located together and because of that, a lot of diseases affect both of them.

So the classic one that affects both is Meniere's disease. So a lot of times we're getting a hearing test to look for sensorineural hearing loss, meaning a type of hearing loss that affects either the inner ear or the nerve that would give us a clue that someone may have Meniere's disease. And there are certain patterns of hearing loss like low frequency hearing loss that are more commonly associated with Meniere's disease.

Superior semicircular canal dehiscence which in my experience is a very rare cause of dizziness, but it is one, and it causes a bevy of other symptoms like hearing your eyeballs move or hearing your heartbeat, and your ears also can have telltale findings on a hearing test. In addition, certain brain tumors that can cause dizziness such as a vestibular schwannoma typically cause a hearing loss, a sensory or hearing loss in one ear.

So because of that, it ends up being a fairly useful test to get a hearing test. I do want to step back for a second because I realize I wanted to say this at the outset. There is no single test that diagnoses all causes of vestibular disorders. It doesn't exist, I wish it did, but it just doesn't. So it's a combination of going through the history, physical, and getting ancillary testing as needed.

The next level of testing is brain imaging. And then there's also vestibular testing. So if it's OK, let me talk for a bit about each of those. So imaging roughly falls into two categories. There CT imaging and MRI imaging. And like I said before, CT imaging is nice and quick. You do get a little jolt of radiation with it but it's usually fairly low. That one's great for seeing the bone structures and especially the bone structures around the inner ear. So it's a pretty reasonable test for looking for problems of dizziness caused by anatomical issues especially bone anatomical issues.

That's not the most common cause of dizziness out there. It does allow you to see superior canal dehiscences most of the time, especially if the CT is done with good quality. And sometimes there are some ear problems that can cause dizziness, like a skin cyst that grows in the ear called a cholesteatoma. It can erode into the balance canals causing dizziness or other sort of issues that cause a loss of integrity of the inner ear. And you can see those.

I'd say most of the time you expect a CT scan to be normal when it comes to diagnosing dizziness. The second test that gets frequently done is an MRI. An MRI is a different way of looking at imaging. It doesn't see bone that well, but it sees brain and soft tissue really, really well.

It also sees the fluid in the inner ear pretty well. So because of that, it should be thought of as a complementary test to CT scanning not as an alternative test. MRIs are the best for two things, seeing strokes and seeing brain tumors. So it's very reassuring when an MRI is normal because it doesn't mean you don't have a stroke, that means you don't have a brain tumor.

Oftentimes, other neurological diseases like normal pressure hydrocephalus or multiple sclerosis or others will cause a pattern of findings on an MRI that can be telltale cerebellar degenerative conditions which can cause problems with walking. And vestibular loss can also show up on MRI. So MRI can be a really nice test, and it's very reassuring when it's normal. If you count up--

DANIELLE TOLMAN: I want to jump--

JEFFREY D. SHARON: Oh, sorry.

DANIELLE TOLMAN: --in really quick because I do have a question in regard to MRI. So I figured this would be a great place.

JEFFREY D. SHARON: All right.

DANIELLE TOLMAN: Two, does it matter to have contrast or without contrast? And are there different types of MRIs that look at different potential diagnoses?

JEFFREY D. SHARON: Yes, great question. So let me jump into that. So contrast matters a little bit. It depends what you're looking for. But there are some things that are easier to see with contrast. At this point in time, if you get high resolution sequences, you could actually see most vestibular schwannomas without contrast.

But little tiny ones 1 or 2 millimeter ones you see better with contrast. For strokes, it can depend. There are some sequences that are really good for stroke especially starting 48 hours after the initial event called diffusion weighted images that don't require contrast that see strokes really well. But if you're trying to look at the blood vessels, sometimes that's done with contrast, sometimes that's done without contrast.

So it's really up to the person ordering the test if they want to do it. We are also now in an era where we have specific inner ear MRIs. For the most part, they should probably be considered research level MRIs. But these are the ones that can see hydrops which is an inner ear swelling characteristic of Meniere's disease.

So there are some centers that have been doing this for a long time, for instance, UCLA. There are some other centers that have started doing this more recently in the US. There's a big center in Japan and Germany that

does this type of test. It's not yet mainstream, but it may come out in the future that we do more imaging for Meniere's.

The other thing I'll say is there is a difference between a brain MRI, and sometimes we call it an internal auditory canal or a temporal bone or an inner ear MRI because you do get better images of the inner ear if you get the inner ear level MRI. So there are some differences there. It is important to know that if you look at a list of all the different causes of vertigo and you get a bunch of MRIs, most of the time the MRI is not going to tell you the cause of vertigo.

So it's important to know that when you're getting this test, because inevitably when you get a medical test, there's a lot of anxiety associated with it. And it's important to have an expectation of what it can show, what it's capable of showing, and what it's not capable of showing. Most of the time when someone gets a test they want to know what's the cause of my symptoms. And the truth is they don't even care about that. They just want to know, How do I make my symptoms go away?

And an MRI isn't always the best test for answering that. A lot of times it's the best test for answering, Is the cause of this person's vertigo a brain tumor or is the cause for this person's vertigo a neurological condition or something like that? So there can be a disconnect there that can lead to some frustrations.

ABBIE ROSS: Let's continue on now to more vestibular specific testing.

JEFFREY D. SHARON: Yes. Let's get into vestibular-specific testing which is a confusing landscape because there's a lot of different tests. Sometimes I like to use the analogy of the hearing test because people are familiar with that. So when you have a hearing test done, you have someone testing your hearing at low frequencies, at middle frequencies, and at super high frequencies, and that all gets combined into one test.

In the vestibular system, we actually separate those-- and it's probably because instead of just using a tone or something like that and changing the pitch of it, you actually need different tests to test different frequencies of vestibular function. And what I mean by that is we move our head at different speeds, and therefore the vestibular system operates at different speeds.

So a slow head movement, and keep in mind one of the primary functions of the vestibular system is to keep our eyes and our body stable during movement. And it does that by sensing head movement, so sensing every time you turn your head or bob your head or move your body. So it can sense really low frequency, meaning low speed movements. Middle frequency or high speed movement, so high speed movement would be like you're running on a trail and your head's bouncing up and down really quickly. Whereas a low frequency movement might be just turning in a chair very slowly.

Now, it's interesting. At the high frequencies, only the vestibular system can sense those movements. But at the lower frequencies, there are other body systems and other eye control systems that help stabilize the eyes, meaning your gaze, keep your gaze in focus, and also body movements.

So that is a long way of saying I think about the VNG, videonystagmography, rotary chair testing, and Video Head Impulse Testing what's been called VHIT as different ways of testing the vestibular system at different frequencies. And in that rubric, VNG is a low frequency test, a rotary chair test is a middle frequency test, and a video head impulse test is a high frequency test.

Let's talk a little bit more about what's involved with each of them. So the VNG test typically has a few parts. You're generally wearing infrared goggles. And that is important because if you can't see and when you wear infrared goggles, you can't see anything because you're in the dark but the

examiner can see and track your eyes really well. It gives you a more accurate picture of what the eyes are doing.

We use eyes as a window into vestibular function because the eyes and the vestibular system are yoked together through the vestibulo-ocular reflex which is a cardinal reflex of the vestibular system. So with vestibular problems, we typically can measure them indirectly through the eye movements because of this reflex. So it's a roundabout way of figuring out how the vestibular system is working.

Now, to test the vestibular system, you generally have to stimulate it and see how it responds just like any other test that you do. With a VNG, you stimulate it by putting hot or cold water or air in the ears which moves fluid in the inner ear. And this was figured out by Barany, and he won a Nobel Prize for it in 1915. And you can measure the eye movement. So it's a artificial way of stimulating the inner ear and measuring responses. But that's the way all tests work, stimulate and then measure the response.

Rotary chair test, we just spin someone around in a chair. So if I had infrared goggles on and a mechanical chair that would spin me, during a rotary chair test I'd be spinning around just like I am right now. And you can spin back and forth, which is called sinusoidal, or you can just spin in one direction continuously, which is usually called trapezoid or step velocity testing.

With the video head impulse test, it's even faster than the previous two so that is you wearing a tight fitting pair of goggles that has an accelerometer in it to measure movement. And has a high speed camera in it to track your eyes, and then your head is suddenly jerked side to side. It's a small movement so it's not as bad as it sounds. A lot of times when we do the clinical version of it my patients think I'm going to twist their head off or something like that.

And of course, if it were a movie their head would come right off. But in real life, thankfully, their head stays on and it's not that uncomfortable of a test. So quick head movement, that's the video head impulse test but it's the same thing. You're moving the head, the vestibular system should direct an eye movement through the vestibulo-ocular reflex that can be measured, that's a compensatory eye movement. Rotary chair testing, we're moving a whole body and head together. And then calorics, we're using an artificial stimulus to stimulate the vestibular system. So they are--

DANIELLE TOLMAN: Yeah, a lot of these tests--

JEFFREY D. SHARON: --similar.

DANIELLE TOLMAN: --with the goggles. Those are very high tech goggles that will quantify the amount of eye movement so that we can put a number to that type of nystagmus correct versus what patients might see when they go see their physical therapist who also have goggles. They're not necessarily the same thing measuring anything in particular in the physical therapy setting. But when you're doing these vestibular tests, you've got computers that are reading that eye movement, quantifying it, and giving us a readout and a report to indicate to us what's going on, is that right?

JEFFREY D. SHARON: Yes, entirely correct. So a lot of physical therapists, sometimes ENTs and neurologists will use infrared goggles as an extension of the physical exam to be able to see eye movements both at rest in different positions with different provocative maneuvers you can do in clinic which can give you clues as to what's going on. In a vestibular testing lab, you generally using a computer. You're tracking someone's pupil and you're using that to measure eye speeds in response to these different stimulations.

ABBIE ROSS: Now, a question from the audience that fits in nicely here. We are stimulating the vestibular system with our vestibular testing. So can a patient expect to be symptomatic? And if so, for how long?

JEFFREY D. SHARON: This is an important point. So the answer is yes. And I want to discuss this issue. So I'm happy this person brought up this question. The tests are-- I think of them as better designed to determine if the vestibular system is functional or not. So simplistically speaking, you're stimulating the system and you're trying to see, Do I get a normal response? Or do I get no response indicating that one or both ears doesn't have a vestibular system functioning?

And when we do caloric testing, we don't talk about this a lot. But it's really a test of one part of the inner ear. So we have to go into a little bit of anatomy here. There's three semicircular canals that measure head movements in the three different planes of movement that you can move your head.

And then there's two other organs that sense linear movements. That means like side to side, and also tilts like tilting your head, and also gravity. When we do a caloric test, we're really measuring the horizontal canal. So just one of the semicircular canals. When we do a rotary chair test, we're measuring that same one, the horizontal canal.

With video head impulse, you mostly measure the horizontal canal, but you can-- oh, and I see that's a great model that Dr. Tolman is showing there of the blown up inner ear. So you can see the three semicircular canals. She's pointing to the horizontal canal which is the one that most of these tests measure. With the video head impulse test, you can measure the vertical canals although it's a bit more tricky to get accurate info out of them. But you can do that.

There are other tests, which we might talk about a bit more in a bit that measure these other two parts of the inner ear, the utricle and saccule, and

those are called the vent tests. These tests are great for determining if there's function or not. Unfortunately, a lot of people with vestibular disorders don't have loss of function, they have hypersensitivity.

And the two most common causes of that are vestibular migraine and what we call PPPD or Persistent Postural Perceptual Dizziness. Vestibular migraine, keep in mind, so when you have a migraine and it differs from person to person, but part of the migraine disease is sensory hypersensitivity. What that means is lights that don't bother everyone else bother you. Sounds that don't bother everyone else bother you. Smells that don't bother everyone else bother you.

And that also means that levels of motion that don't bother everyone else like quickly turning your head might bother you. When you have someone with a hypersensitivity disorder and then you give them a strong stimulus, that doesn't work that well. So most of the time people with vestibular migraine hate testing.

In fact, a lot of physicians think the level of complaint that they get about how painful the testing is a good indicator of whether or not someone had a vestibular migraine. Because of this issue, I personally prefer to use vestibular testing judiciously especially if vestibular migraine is suspected because it may not provide necessary information and it may cause someone to feel pretty sick and out of it.

It's very hard to put a specific time frame on that because people are individuals. And it's not totally clear, but I would say that if you are worried about that, suspect you might have vestibular migraine, know that you're sensitive to these sorts of things, get carsick easily, stuff like that, et cetera, definitely don't drive yourself to vestibular testing. Have someone else take you. Check with your doctor and make sure that it is actually necessary that you have the testing, and that there will be useful information that's actionable based on the testing that will improve your care.

And you might want to set up some medications. Not for before because generally speaking, most vestibular testing centers won't let you take medications ahead of time because they don't want to alter the test. But for afterwards like nausea medicines, or vestibular suppressant medicines so that you could at least zonk yourself out and start feeling better. I've had patients tell me that a few days that knocks them out for a few days. Unfortunately, it can be longer. So in those situations best to use vestibular testing judiciously.

Now, there are some other parts of the testing. So I would say in terms of feeling bad, probably caloric so is going to be the worst. Rotary chairs probably in the middle. And actually after the video head impulse even though it sounds bad because it's such a quick sudden jerk, it's a pretty quick test, so most people don't feel that bad after it. And VEMP testing unless you're very sound-sensitive, you don't feel terrible afterwards. But if you are very sound-sensitive, you can feel bad afterwards because that test does involve loud sounds.

DANIELLE TOLMAN: Going back to something you said earlier in lines of there's not one specific test that kind of rules all, it's very rare that one test gives us the one answer. So going back to your statement about being judicious with testing is that we can bolster up all different types of tests to get a better idea of what's going on while trying to stay away from the things that make you feel terrible like the VNG or the rotary chair testing. So even if somebody's super sensitive, if you're working with your physician, it sounds like you can work together to order some other things to get background information before having to go into these more provoking tests if you need further answers.

JEFFREY D. SHARON: Yeah, I would agree with that. There are some things that you think, oh, this probably doesn't need testing. For me, the classic one is BPPV, the loose crystals in the inner ear. There's a physical exam

maneuver called the dix-hallpike where he puts someone into a certain position. And there's very, very telltale and characteristic eye twitching which we call nystagmus that happens in that position.

And that test even though it seems so simple, it's just you looking at someone's eyes, it's better than an MRI, it's better than an audiogram, it's better than anything else in the world, and it's specific for this one disease if you see the crystals. So that's the most accurate test for that. And therefore those patients don't really need any other testing.

On the other hand, if someone comes in, the hearing test shows a big asymmetry in their hearing loss. They do need an MRI to look at these things. So there's a lot of different pathways, but I believe that it's better to think about what could be going on at the different stages, rule out things that can be ruled out based on physical exam, and then sometimes if a severe migraine is the most likely thing based on the history and physical, try treating it first.

And use vestibular testing in certain situations. There's definitely things that are better diagnosed based on vestibular testing. So one of them, a classic one is superior canal dehiscence testing. For a bunch of complex reasons, the vent tests are actually really good tests for that one condition. So that's a really good one.

If you suspect unilateral or bilateral vestibular loss, vestibular testing can be really good to confirm that. If you're thinking about doing something destructive to someone's ears, like let's say-- and this is less and less common these days, but let's say someone has terrible Meniere's disease, nothing is working and you're thinking, I may chemically destroy that inner ear with a gentamycin injection, or I might do a labyrinthectomy even in a surgically destroy that ear.

Generally speaking, you want to make sure the other ear is working well. So that's a great time to do vestibular testing to ensure that you're not going to cause a bilateral vestibular loss because you took out the only ear that works. So that's a good time to use testing also. But most of the time, testing doesn't give you a specific diagnosis so it should be used thoughtfully.

ABBIE ROSS: And I want to touch a little bit more on the impressions that patients read at the bottom of their reports. Can you tell us a little bit about what that might read? Like let's say I get a VNG, What might my impression say if I have a hypofunction?

JEFFREY D. SHARON: Yeah. And this is a good point because sometimes the impressions will mention minor abnormalities that are not clinically relevant. And the reason for that is when you put on infrared goggles, you are going into the vestibular closet and finding a whole bunch of stuff that may or may not be relevant and may or may not have come out without infrared goggles. So sometimes you see a little bit of spontaneous nystagmus with the infrared goggles if you lay someone in a certain position.

I'm of the belief that if you can't see that with your own naked eyes and you only see it with infrared goggles, I just haven't found that correlates with anything. So sometimes that gets reported as an abnormality where I think it's just our eyes are designed to stay still in light because that's what makes sense, that's our evolutionary function. They're not designed to stay perfectly still in the dark in a whole variety of system of positions.

Now, with caloric testing or VNG-- and part of that is caloric testing-- the most common abnormalities you'll see are going to be either unilateral or bilateral vestibular dysfunction. Now, this is important to know is that for unilateral dysfunction, we're basically deciding if one ear is significantly weaker than the other ear. And that means we're stimulating both ears typically with two conditions, hot air and cold air, or hot water and cold air.

We're measuring the eye speed, how fast the eyes are twitching, and then we're comparing the speeds between both sides. Now, normal eye speeds can differ a lot with stimulation between both sides. So because of that, most labs use a cut off of around 25% or so as abnormal. What that means is if your right ear total eye speeds 35 degrees per second and your left ear total eye speed is 30 degrees per second, it's a little off from each other. But that's not going to be considered abnormal. You really want to see big differences to consider something abnormal.

There's another important thing to know about caloric testing which is it relies on the assumption that you have a normal ear canal free of wax, and that the person doing the testing did it correctly meaning they put the hot air and cold air against your eardrum. I will see patients sometimes who are told they have a bilateral loss but really they have bad earwax.

The hot air/cold air never got to their eardrum, never stimulated the inner ear so their eyes didn't twitch, and then the test just measures that their eyes didn't twitch. So it really is a test that you have to check the ear canals, the eardrums, and make sure it's all good and it's a test that has to be done by someone who is familiar with this type of testing and knows what they are doing.

DANIELLE TOLMAN: That leads into a question, just kind of piggybacking off of the earwax impaction issue, But are there any things or contraindications that would keep somebody from being a candidate for vestibular testing? Is there anything like a heart condition, or seizure disorders, or anything, central findings, other comorbidities that might prevent somebody from being able to tolerate or undergo vestibular testing?

JEFFREY D. SHARON: Yeah, that's a good question. There are a few things I think about. First of all, I do think about things from the ear perspective. So for VNG testing, you need to have a normal ear canal. So that means if you've had ear surgery, you've had a canal wall down mastoidectomy, you

have a lot of earwax, something like that, someone's removed your ear canal because of a tumor or something, caloric testing just won't work. You need normal ear canals for that test to work and never have had ear surgery or even ear tubes will throw off the test a little bit.

For video head impulse testing, it's a quick movement of your neck. So you basically have to have the ability to do that. Now, a lot of people have had cervical spine surgery. And most of the time you're fine doing the video head impulse test on them. But if someone has an unstable spine fracture, that's a contraindication to doing the testing.

I always like to do the testing in slow motion first, explain it, and say we're going to go from here to here, is that painful? Is that OK? And then with that, the patient can tell you, no, that does cause pain in which case we won't do the testing. Or they say, no, that's fine, I think we'll be OK. So the vast majority of the time you can do that test.

There are some things that probably aren't good for testing. People with uncontrolled seizure disorders you really can cause a seizure or cause issues with testing. People who are medically unstable aren't good for testing. Generally, you want to be an outpatient and your body needs to be fit enough to undergo a pretty strong stimulus for testing to occur.

So if you are, I don't know, this has come up before where we have someone who's in a nursing home, bed-bound, very unhealthy, feels dizzy all the time, I don't think vestibular testing is going to help you in that patient. I think the doctor should be going to the bedside doing their best to help figure out things based on their physical exam, but that's not someone who's a great candidate for testing.

ABBIE ROSS: Now, I have a two-part question that comes from the chat that. I'm adding on a little bit more. One is, let's say you undergo vestibular testing. It helps determine what's going on, Is there any indication for repeat

vestibular testing down the road? And then on the flip side, What if you're testing comes back unremarkable? Is there a reason to retest down the road in that situation? You're still symptomatic.

JEFFREY D. SHARON: Oh, I like these questions. I'm happy you brought them up. Generally speaking, you should not be doing that much repeat vestibular testing unless you suspect that the original testing was inaccurate or you're adding in other tests that weren't done. For instance, not every center does video head impulse testing or VEMP testing.

So you might want to add that in if there's something you're thinking about. I don't know, every now and then I have someone who has it looks like they just loss function in their superior canal or posterior canal. You won't pick that up on a rotary chair but you can pick that up on a video head impulse test. So that's very reasonable to do.

Repeat testing there are some things that can be informed by it. And by that I mean if you lose function sometimes it's a partial loss of function, and sometimes you can track recovery with testing. So one example of that is when you do a video head impulse test, I have someone stare at a target, and then I quickly move their head their head moves, their eyes are supposed to move opposite and stay on the target.

Now, if I lose vestibular function, their eyes won't do that. The eyes will move with the head. And then once they realize they're not staring where they're supposed to, their brain will say let's have the eyes go back to the target. And that compensatory resetting eye movement's called a saccade.

And there's a timing to that. So if I go in and cut someone's vestibular nerve, the next day their saccades are going to be super late, 400 milliseconds after I turn their head. And as the brain compensates-- and as especially as you do physical therapy, the saccades get earlier and earlier and earlier. So

they'll go 300 milliseconds, 200 milliseconds, down to 100 milliseconds, and that's a sign that normal compensation is occurring.

So if you have someone who had, let's say, a vestibular neuritis where they loss function and you're trying to figure out, Are they compensating appropriately? You can use repeat testing to try to get at that. And there are some features on rotary chair testing that are similar that can be used to track recovery.

With that said, sometimes I see-- I don't know, recommendations that someone gets twice a year vestibular testing for life after some vestibular problem. And I have to be honest, I don't understand the rationale behind that level of testing. Testing is uncomfortable, it's time, it's expensive, I was taught in medical school that you should order a test if it's going to provide useful information that will impact a management decision. And not out of curiosity, or wanting to make money because you run a vestibular testing center, and you can bill for it or whatever else is going on. So I believe that each test should be thought out and you should order a test if it's going to help you take care of your patient.

ABBIE ROSS: I really like this question from the chat to help clarify this. Can you have recurrent neuritis? Or is it just decompensation that's happening if you get recurrent symptoms?

JEFFREY D. SHARON: Oh, yeah. I think both can happen. I like that question as well. I was taught that vestibular neuritis is generally a one time event. But one of my mentors would say that you can have aftershocks which were generally lighter in intensity but could happen months or a year later. And then they generally would fade over time.

I will say that from a knowledge standpoint when something is happening for the first time, you don't know if it's the only time or the beginning of some other recurrent thing happening. So sometimes you think someone has

neuritis and then they have repeated episodes, and you should reevaluate them because maybe it's turning into a recurrent condition like Meniere's disease, or maybe they need brain imaging, or something else is going on.

Decompensation definitely can happen as well, and is usually best treated with another course of physical therapy. So sometimes people think that physical therapy is a one time thing and you do it and it's done. And that's not always the case. Sometimes it is and that's great, but sometimes people do need repeat courses of physical therapy. So generally speaking, if someone does have a recurrence, the best thing to do is to do the physical therapy again, but also see the doctor again and see if any other workup is needed.

DANIELLE TOLMAN: How do you counsel patients where all of their testing comes back within a normal range and they're frustrated because they're symptomatic? What do you tell those patients when they're asking, How is this possible that everything's normal? I feel terrible.

JEFFREY D. SHARON: This is really important because I think we have an innate tendency when we are suffering. And vestibular patients suffer so much to want to point to something on the MRI and say that's the problem because it provides validation that we're not going nuts, what's going on is real. And that it's something that the doctors can see and find.

And this is an issue not with our patients, but actually with our tests-- that a lot of times, the tests are just not designed and not able to see the problem. So I'll just say the issues and the problems and the symptoms that people are feeling are all real. But a lot of times, the tests don't show that. So we need to understand that because we can't get frustrated when the tests don't show the cause.

There are some disabling causes of dizziness. I see my research interest is in vestibular migraine. I see patients with chronic vestibular migraine who are

disabled from their condition. And not one lab test or vestibular test or hearing test is abnormal. And that doesn't mean that they don't have a serious problem, it's the opposite.

This migraine is the most common cause of disability for everyone in their working years in their entire world. So this is an issue where we just don't have good migraine tests and we rely on criteria generally from The Barany's Society to diagnose a whole variety of vestibular conditions. So it's important to understand that because we don't want anyone to feel that they're not going through something real or that their symptoms aren't going to get the validation that they deserve.

ABBIE ROSS: And this circles back to what you led with and that your patient report is so important in guiding treatment. So even if testing is all quote unquote, normal, there is still ways to help you manage your symptoms and live life without those tests done, without those tests showing anything, I should say. I want to dive-- in our last 60 seconds, I want to dive a little bit more into VEMP testing. We didn't exactly describe what that looks like. So can you tell patients what they could expect if they have that test done?

JEFFREY D. SHARON: Yeah. There's two flavors, there's the ocular VEMP or eye VEMP and the cervical VEMP or neck VEMP. It's a lot of electrodes going on your face or your neck. And then hearing a loud sound and then we're measuring muscle responses from those electrodes that are attached to your eyes or neck.

So the main thing to know about it is that it's a loud sound test. So if you're sensitive to the sounds, you may not like the test. But unlike the other tests, it doesn't involve movement to stimulate the inner ears. It is a test of the two other parts of the inner ear, the utricle and saccule that sense gravity and linear movements like going up and down in an elevator or accelerating in a car. Those organs are actually sound-sensitive at really loud sound levels.

And it's been shown that the responses these muscle responses that are measurable actually run through these organs, the saccule and utricle.

So it's kind of an odd test if you think about it. We're using sound to stimulate the vestibular system and measuring it through muscle responses but you really can do that. Now, due to the changes that one specific condition superior canal dehiscence causes in the inner ear, you get very elevated responses on this VEMP test.

So because of that, it's a really good test to screen for that condition. But also-- and this is something that is probably longer than a 60 second discussion. I think we need to, as a field, learn more about when someone just has saccular disease or just has utricular disease, and what that looks like and how we should be treating that. I don't think we have all the answers there at this point in time.

DANIELLE TOLMAN: That's a good explanation to show how interconnected everything is. There's more than one issue that can affect the vestibular system. And our field is still growing, the research is still piling up, and we're still trying to figure out ways to test that tiny little small organ in its system to help patients start to feel better.

Dr. Sharon, thank you so much for joining us today. I can concur with somebody who wrote in the chat asking if you could stick around for another hour and talk some more because we could listen to you talk all day long. But we really enjoyed having you here. I think you've provided us with so much great information and knowledge, and we really truly appreciate your time and expertise in this subject.

JEFFREY D. SHARON: It's my pleasure. Thanks so much for having me.

ABBIE ROSS: Thank you so much, Dr. Sharon. And now we're going to switch gears. We're going to our patient panel led by Heather Davies and Patrick Parkinson. And I think a great question to ask the two of you to kick off our

patient panel is, Can you tell us a little bit about the start of your vestibular journey? Did you have vestibular testing done? Who did you see? What was helpful?

HEATHER DAVIES: Yes. Actually-- hi, guys-- I did have vestibular testing done. And the interesting thing is that I found with Dr. Sharon is each clinic I went to they did their own testing. So that was very frustrating and trying time. But I did do the testing. And I wanted to mention something. I did go to the emergency room the first stop and they did find a meningioma, but it was not the cause so it kind of delayed the process of being diagnosed. So and it has nothing to do with any of my symptoms, and it's still sitting there today not causing any problems. So I just want to say if you do get diagnosed with a brain tumor, don't freak out because it may not be anything causing issues.

ABBIE ROSS: Wow, wow. I didn't know that about you. I just learned something. And what about you, Patrick?

PATRICK PARKINSON: Yeah, yeah. So I was diagnosed with Meniere's when I was 15. And the main test that they used for that up front was just monitoring the hearing. I had failed a school administered hearing test like a couple years prior, so we were monitoring it and then I had the vertigo attack. And that's when they labeled it Meniere's. And like I said, the hearing test was really the only physical test that they used to make that diagnosis. And then later on in life they did some caloric testing to measure the amount of vestibular dysfunction. But that was the extent of my testing.

ABBIE ROSS: Thank you, guys, both for sharing that. We'll pass it off to you and thank you all for joining us on day three. Dani and I will see you tomorrow.

HEATHER DAVIES: Thank you.

PATRICK PARKINSON: Thanks so much.

HEATHER DAVIES: Hi, Patrick.

PATRICK PARKINSON: Yeah, good to see you. It's so great--

HEATHER DAVIES: Hello, everyone.

PATRICK PARKINSON: --to see you every day in one week.

[LAUGHTER]

HEATHER DAVIES: I know, I know it. Hello, everyone. And for those of you that don't know me, I am Heather Davies of the Meniere's Muse podcast where vestibular warriors regardless of their diagnosis share their journeys. I was diagnosed with Meniere's and vestibular migraine in 2016 and 2017, and I am super excited to be here with you, Patrick.

PATRICK PARKINSON: Thanks, Heather. Yeah, and I am Patrick Parkinson, and I've lived with Meniere's disease for just under 20 years now. I'm a VeDA ambassador and I'm also the owner of My Meniere's Coach which provides resources and support to those living with Meniere's disease and other vestibular conditions. And you're all welcome to learn more or reach me directly at my website at mymenierescoach.com. And I will be doing my best here as always to keep track of questions and relay them on to the panelists. So looking forward to get started.

HEATHER DAVIES: Yes. Well, let me share a little bit about one of our panelists, Mary Ziegler. Before Mary's vestibular disorder, she taught pre-school, high school, edited magazines, and served as a speech language pathologist. Then in 1999, Mary learned that she had Meniere's disease and vestibular migraine.

Eventually, her vestibular symptoms forced her into retirement. She has adjusted to being a different version of the active grandmother and young retired senior that she had planned to be. During the last years conference,

Mary met other young retirees and together they formed-- excuse me, a support group for medically retired vestes.

PATRICK PARKINSON: Great. Thanks. And have the honor of introducing Pat Filipek. And Pat's vestibular journey started in 2021 with a severe vertigo attack and migraine without any aura or warning. The diagnosis for the dizziness was BPPV, which was an easy fix at first and then diagnosis for migraine was more difficult because all her tests showed that her brain was healthy.

Her only symptoms were dizziness and 24/7 head pain. Pat is still on her vestibular journey and she says that participating in an invisible illness support group has helped her a lot. Pat is a VeDA ambassador and hopes to raise awareness by sharing her story and paying it forward for all the support and kindness that she has found from the community.

HEATHER DAVIES: Yes. Hello.

PAT FILIPEK: Oh, hello.

HEATHER DAVIES: Mary, I think you are muted.

MARY ZIEGLER: Everyone's used to my muting myself and forgetting about it.

[LAUGHTER]

HEATHER DAVIES: That's all right. Well, we're so excited to get started. Let's just jump right in. I want to pass this first on to you, Pat. Really briefly, can you tell us about your vestibular journey and how long did it take for you to get a conclusive diagnosis on how-- and how many physicians did you see?

PAT FILIPEK: Well, it took about three months to get diagnosed with the BPPV. The first neurologist I went to did a temporal biopsy and everything was fine with that. And then he didn't know what to do after that. So I ended

up going to my ENT and he referred me to another neurologist. And I saw him for about a year and a half and he said he doesn't know what to do next.

HEATHER DAVIES: I know that's tough.

PAT FILIPEK: So--

HEATHER DAVIES: Yeah.

PAT FILIPEK: --I ended up going to Diamond Headache Clinic and tried more medication. That hasn't worked so I put that on hold and now I'm doing a functional medicine. I don't know what you call it.

[LAUGHTER]

But it's a six month program. And they told me that they can get to the root cause of the headache. So I'm waiting to see. It's been interesting. So just wait and see what the final outcome is.

HEATHER DAVIES: Well, Pat, we follow your journey, a few of us, and we hope for you to have some relief really soon.

PAT FILIPEK: Thank you.

HEATHER DAVIES: Mary, how about you. What was your journey like and how long before you were finally diagnosed?

MARY ZIEGLER: Well, it was three years, I'm sorry, at least from my first symptoms to my diagnostics. But I also just didn't recognize my first symptoms. So there's a lot of symptoms you can see on lookback. I was afraid to go to my basement and I couldn't figure that out. I'm not afraid of the basement, generally. And I kept smashing into the garage wall. So I read a good book eventually by PJ Haybach which explained to me that depth perception was an issue for people with balance disorders.

So the first thing that happened that got my attention was the room spinning. I woke up and the room was spinning it 5,000 miles an hour and that happened for six hours. And I was throwing up. My husband called the doctor who over the phone he could rule out heart attack and stroke. So I just had kind of six scary hours. Previously, my primary care doc I had said I think I'm having fluctuating hearing loss and he had prescribed Claritin which seemed to work.

And the reason is Meniere's disease symptoms fluctuate. So he could have said have three Jack Daniel's every night and that would work too. But it wouldn't have been such a good idea. So anyway, I went to-- I found an ENT here in Chicago where there's five major medical centers, so I'm lucky.

And he was very highly regarded and I went through all the testing that Dr. Sharon described. But what they ended up telling me was I had Meniere's disease which I was quite sure I didn't have even though I had lots of graduate education in audiology. Shows the power of denial. But they also said, well, we think of something more central. But then they didn't refer me to anybody. So that was kind of challenging because they wouldn't say what they thought-- what did they mean by more central?

So then I got an MRI and I saw a neurologist who told me my MRI is normal but the neurologist told me I was not interesting to him. Then I saw a neuro-ophthalmologist who said, I think you have Meniere's disease. And I think finally through VeDA after seeing about nine people I got to Dr. Hain here in Chicago who's pretty well known in the community.

And I was very happy to get to him. I'm old enough and I've had this long enough that I found Dr. Hain through my VAX computer connection which most people probably haven't heard of and used an educational web search to find him. So anyway, he's I think that I'd like to tell people that are on their journey that once getting diagnosed is the absolute hardest part of your journey, I think. And once you find a doctor who understands you and

doesn't think you're crazy, you feel 1,000% better. So just that empathy is a big placebo. I think that's about it. And then eventually I got diagnosed with vestibular migraine too.

PATRICK PARKINSON: Absolutely.

HEATHER DAVIES: Yeah. Go ahead, Pat.

PATRICK PARKINSON: No, I just wanted to call out between both of your stories and thinking about what Dr. Sharon said. I mean, it's been a journey for both of you to actually get that diagnosis and get that validation that you're talking about, Mary, which is so, so important and helpful to have someone say like, hey, this is the reason why you feel the way you do, it's invaluable.

But I found it refreshing Dr. Sharon calling out that there are gaps in care right now and in the process. And anyone who feels like it's a challenge is absolutely not alone in that which I don't think a lot of physicians will willingly present. But I found that to be very, very refreshing. And I'm curious, Mary, one question I was thinking about with your experience in audiology, Is that something-- How did that help during the process?

MARY ZIEGLER: Well, it helps a lot. I'm a speech language pathologist, so I'm not an audiologist. But I had had experience with audiologists and I knew the anatomy and the structures of the inner ear. And I know the language. So I think for me that was-- I guess I'd say two things about that.

Number one, I had a-- I was getting a master's when I developed this. I had it when I got diagnosed. And I had all this background knowledge. I took Latin in high school and college. And so if I can't get a diagnosis, all the people who are struggling out there trying to get a diagnosis, it just shows how challenging it is. I also live with so many good docs. Now, of course, I have forgotten the second thing I was going to say. You were-- what did you ask me, Patrick, Do you remember?

PATRICK PARKINSON: No, I think you were answering it. It was just more about, How did your professional training--

MARY ZIEGLER: Oh, sorry.

PATRICK PARKINSON: --impact your journey now?

MARY ZIEGLER: So what it really helped me was just knowing all the terminology. I understood what an inner ear was because most people think it's your middle ear.

PATRICK PARKINSON: Yeah, yeah, absolutely.

MARY ZIEGLER: So-

PATRICK PARKINSON: And I'll say--

MARY ZIEGLER: --brain fog for everyone here.

[LAUGHTER]

PATRICK PARKINSON: Well--

HEATHER DAVIES: You're in good company.

PATRICK PARKINSON: --I have been involved with this for like 20 years now. And listening to the clinician speak there's so much good valuable insight in there. But yeah, a lot of it it's really hard to keep track of all this terminology. And so that is a very real part of the process.

MARY ZIEGLER: Yeah.

HEATHER DAVIES: Absolutely.

MARY ZIEGLER: And another thing about diagnostics and then I'd like to give Pat a turn, but for those of us who are long haulers, remember it's ongoing and you do change over time different medications work and then they don't. Your symptoms may change a little and keep reporting that and report

it to your whole team. So it's important for your whole team to know that your vestibular disorder is the thing that most affects your life. And that might give them different insights into ways they can help you. And also keep all your doctors in the loop all the time.

HEATHER DAVIES: That's great. Great advice. Pat, I'm curious, I know that the functional medicine is new to you. But when you were seeing the doctors before, was it difficult for you to understand what the doctors were telling you? And did you look at different resources like VeDA or anything like that to understand exactly what was going on?

PAT FILIPEK: Yes. It was really hard to understand that my brain was perfectly healthy but I'm in pain. So I tried different places to go. VeDA was actually very helpful with the support groups. Just learning how to cope was a big thing.

Not getting discouraged that has been probably the biggest help. And I spent about a year at home just doing nothing, just thinking about the pain. And so after I joined VeDA and stuff, you just got to move on and don't let it stop you. And the support groups are wonderful.

HEATHER DAVIES: They are. They're a godsend. I know I met you in a support group.

PAT FILIPEK: Yes, yes.

HEATHER DAVIES: And you've been a wonderful support. And list of those support groups is on the VeDA website. So you guys be sure to check that out, they have online and in person. So make sure you check that out. I have a question for you guys. I know at the beginning of my journey I really didn't know what was going on.

And the most difficult thing for me to talk to my doctors was I didn't-- when I didn't understand what was going on, expressing my dizziness and things

like that and what was actually happening in my body so I started journaling. Did you guys do anything like that? Mary, did you do any kind of symptom journaling or anything that tracker to talk to your doctors?

MARY ZIEGLER: I did. And I would say first I tried because I'm an overachiever and type-A personality. First, I tried to journal everything. So like what I ate, and what time it was, and when I was dizzy, and I don't know, if the moon was full or whatever. And I found out that I was driving myself crazy with over-journaling.

HEATHER DAVIES: OK. Sure.

MARY ZIEGLER: So what I did, I did all the elimination diets all that kind of stuff. But what I did do was try and maybe track maybe two things at once. So dizziness and food, and then dizziness and weather, or how long and maybe how long big vertigo attacks I always would note. But often they seem to-- they usually seem to come out of nowhere is what the honest answer is. So it's good to journal, I think, but don't be like me and get so caught up in journaling you're making yourself nervous journaling.

[LAUGHTER]

I don't know if Pat journaled, did you, Pat?

PAT FILIPEK: I did. And it was for the neurologist. And so and I didn't actually ask him exactly what he wanted. So I was doing what I thought he wanted, and then towards the end he said, I just need the level of pain. He didn't need all the other symptoms and stuff. So I did that.

Didn't seem to help because then I started focusing on just the pain. I never thought in my head as just my head, it was a number. So I stopped that and I feel better. I'm doing some mindfulness now which helps. I'm finding it difficult, though, but I'm working on it.

HEATHER DAVIES: Takes practice for sure.

MARY ZIEGLER: Yeah, mindfulness--

PAT FILIPEK: Yeah, for sure.

MARY ZIEGLER: --is good and I always think that a good way to start out is I breathe in, I breathe out. Because if that's all you're saying to yourself, it's relaxing and you don't concentrate on how you're so terrible at mindfulness. So I've done that too in yoga and gratitude practice has helped me a lot.

HEATHER DAVIES: That's awesome.

PATRICK PARKINSON: Yeah.

HEATHER DAVIES: Patrick, I'm curious about you and your journey. Did you do any journaling? I know you do mindful practice. I'm familiar with that with you.

PATRICK PARKINSON: Yeah, definitely. Mindfulness is big for me. Journaling, yeah, I know in the context of your question, Heather, I think you're originally asking about journaling for the intent of capturing information for your physician.

HEATHER DAVIES: Right.

PATRICK PARKINSON: I didn't do as much of that. I did as many people do use journaling to or some kind of symptom tracker to try to find triggers. And I ran into a very similar experience than what you all talked about which was very useful--

HEATHER DAVIES: Over the top.

PATRICK PARKINSON: --for me to do that. And all the while, there was one important variable, I wasn't really solving for which was that stress piece. So I was chasing my tail a little bit there. But I've used journaling for other things. I don't want to get too off topic, but helping with the emotional side of things.

And the more I've learned about how our emotions actually impact the sensitivity of our system too and if we're keeping some of these the challenging emotions and discomfort from living with these conditions, if we keep all that bottled up it can keep our system at a higher level. So using journaling to just get things out I found very, very helpful.

MARY ZIEGLER: I really liked the first days doctor who's name I might mispronounce. But she was talking about that activation. It's kind of like allergy. The more you react the more you react. And I thought her description was really helpful. Whereas if somebody says, oh, you need not to be so stressed out, that's not helpful.

[LAUGHTER]

HEATHER DAVIES: No.

MARY ZIEGLER: Our support group is full of people who literally were wheeled out of their-- I'm not kidding, their workplaces by coworkers because they just really wanted to keep working and they weren't listening to their body. Everyone recovered somewhat, not completely but with rest. So I agree with you, Patrick.

PATRICK PARKINSON: Yeah. Yeah, definitely.

HEATHER DAVIES: Back to the health care professionals that you both have seen, Is there any one in particular that you wish you could go back and say something to prior to diagnosis? So I know we all have those horror stories that you want particular health care professional to know when dealing with vestibular migraine or vestibular diagnosis. Pat, sorry.

PAT FILIPEK: Well, with the first neurologist, I would like to tell him to at least pretend to care. After it wasn't this horrible disease that he was testing for, he asked me if my neck hurt. And I said no, he said, oh, well, that's too bad. What?

[LAUGHTER]

And then he said that again after he ask me some other questions. So I figured he really wasn't interested. He didn't have this horrible disease he could work on. So I went other places. I've been to behavioral vision doctor, I'm trying to look at all avenues to get some help. [LAUGHS]

HEATHER DAVIES: I hear you. Like what you have to-- and I feel when I was listening to you talk about your doctor. If they're not on board and they're not giving you what you need and you don't feel heard, move on. This is your body. This is-- you're trying to figure things out. Of course, sometimes doctors tell you things that you really don't want to hear but you know you need to take that in.

But you know in your gut you just have to move on. I've had to fire, I say loosely, a couple doctors. And it was hard because that's not the way that we're raised. We're raised to trust the white coat, put them on a pedestal, and things like that. And how about you, Mary, is there anything that you've discovered in your past?

MARY ZIEGLER: Well, yes. Sorry, Heather, the first--

HEATHER DAVIES: Yeah.

MARY ZIEGLER: --ENT I saw was I know he was a really good ENT, I researched him. And I really wished he would have referred me to a neuro-otologist. So why he didn't do that he could have saved me three years of kind of panicking and searching and also thinking there was a cure which for some of us, there really isn't. There's treatment but there's not a cure. The second person, though, is I know I feel like one of us should say some of my best friends are neurologists.

[LAUGHTER]

[INAUDIBLE] neurologist. But the neurologist who told me that I was not interesting to him I too, Pat, I described these horrible symptoms one after another that were making me miserable. And I have four kids at home, I'm working full time, and he would say, that is not interesting to me. And he was really lucky he was in a modern building where the windows didn't open because I'm basically pacifist, but I would have pushed him out the window. I was so upset.

So I did tell my primary care doc never refer anyone to him again. But I would like-- I was too angry to talk to him even about. And I don't think it would have done much good. But just what I've noticed is when I first looked for a chronic illness psychologist, I couldn't find one. When I first looked for vestibular therapists, they were like two of them, and they were too far for me to get to. And now, we longhaulers know there's way more vestibular therapists. There's people that can see you online in your state, and there's more psychologists. So just keep looking, as you said. Don't stick with a doctor who isn't helpful and keep looking for another person.

PATRICK PARKINSON: Yeah, absolutely. And Mary, on that note, there was a question here about experiences using telehealth to both get a diagnosis and manage your condition. Do either of you have experience with that using telehealth?

PAT FILIPEK: No.

MARY ZIEGLER: I really-- I have just a little during COVID. I saw my doctors online. And it to me like regular office visits with the neurologists are valuable. I think, again, just to be sitting in a room with somebody who gets it. So I wasn't crazy about it then, but I just started vestibular therapy online with Dana Tress, who also has connections to VeDA and it's fabulous. So I think that that's the ticket for-- if you can't get to a big major medical center, it's certainly the ticket to step one.

PATRICK PARKINSON: Absolutely, absolutely.

HEATHER DAVIES: Yeah, I have seen a lot more on social media about physical therapists doing online consultations. And I think that's fabulous especially at the beginning of our journeys we're not able to get out like we used to. And having that available is just an invaluable resource. I didn't know that Dana did that. That's great.

MARY ZIEGLER: Well, maybe I shouldn't have said it. But in Illinois--

HEATHER DAVIES: No, no, no, that's awesome.

[LAUGHTER]

MARY ZIEGLER: I live in Illinois and so does Dana. So I think most people are they're only licensed in their home state or maybe one or two states. But yeah, it's wonderful because she's too-- I can't drive anymore and she's too-- there's no way to get to her.

HEATHER DAVIES: Oh. I see that the VeDA's directory also includes people that do telehealth. That's interesting, I didn't know that. That's fantastic.

MARY ZIEGLER: No.

HEATHER DAVIES: What do you guys think was your biggest hurdle in getting an accurate diagnosis? Pat. I know you're still struggling with--

PAT FILIPEK: Getting doctors to believe you. When I first went to ER, it was kind of the ER doctor basically said, you're old and dizzy. It wasn't until the second time I was in ER this woman doctor was spot on. And she knew I had BPPV and she referred me to an ENT that she liked the one I had. So I already had an appointment with them, so that she told me to keep him, and then sent me to a neurologist. And then she did the MRI which they normally don't do in the ER setting.

MARY ZIEGLER: That's great.

PATRICK PARKINSON: Yeah.

PAT FILIPEK: Yeah. I just want--

MARY ZIEGLER: That's the only good thing about the ER is you can get tests done quickly. Sorry, Patrick.

HEATHER DAVIES: What were you saying, Pat?

PATRICK PARKINSON: No, no, no, you're OK. I was just going to call out Pat. I'm so sorry that you received a message like that, and I've had similar instances and I don't think that the people delivering those types of messages realize how damaging they can be for a patient. It's kind of like I received a similar message which was I was seeing the ENT I've been seeing and I kept saying like, stress is such a big trigger for it.

And like even just a couple negative thoughts turn on my symptoms. In my head I'm wondering, like what is going on with that? And my doctor just kept keep coming back to the treatments that he had at hand which was he wanted to do steroid injections, more invasive procedures, and I'm thinking, hey, if this is about stress, that doesn't feel like the right approach.

And there were some comments about you people with these vestibular conditions tend to be anxious, I don't know why. And I don't think that-- I think the doctors they're well intended and they are trying to get us better but sometimes when we don't fit in the box of what their diagnosis is and what the available treatments are. Sometimes those types of things can come up. And it ends up making us ultimately feel like we're an anomaly and that there's something wrong with us. And all of that directly impacts our symptoms.

As we know, when we feel like we're not in a place where we need to be that keeps us our system on high alert and impacts all of our symptoms. So getting that explanation that really matches what we're feeling is so

important. And I think it's the reason that some of these support groups are invaluable. And in the notes here I just wanted to call out in the exhibit section of Whova. There is a list of the VeDA support groups right now and other support groups that people want to check that out anyway. Sorry to blab on there a bit.

[LAUGHTER]

MARY ZIEGLER: No, it's good.

HEATHER DAVIES: Yeah. No, you're fine. Patrick, did you find at the beginning, did you have a problem accurately describing your symptoms?

PATRICK PARKINSON: Yeah. I don't think I had a problem just describing them. I mean, I would tell them how I would feel. But there was-- to go back to what I was saying, there was a little bit of like guilt or not wanting to really fully express the way you're feeling when you don't feel like it's going to be received as well on the other end. When you feel like it's going to be met with a comment of, hmm, that's kind of weird. There were times where I was like, I'm not even going to go there today with this particular person.

HEATHER DAVIES: You relate with that Mary?

MARY ZIEGLER: Well, I think at the beginning even I read a lot of-- I read everything I could get my hands on so I knew I had something real. But you still keep asking yourself, am I crazy? Maybe this is so goofy. Nobody else-- I look fine. And I remember even once I saw Dr. Hain and that was really my moment was getting to a neuro-otologist.

And I would say if lots of people that I've known have gotten the name of a neuro-otologist, but it's eight months before you can see them. Make that appointment anyway. And if you are magically cured before, then that's fine. But make the appointment anyway. And even if you have to travel, that neuro-otologist could help direct your care closer to home.

But even with Dr. Hain, who I really trusted, I had this weird experience where I have a friend whose voice is kind of loud but it's fine in person. But there was something about her cell phone message if I called her and I heard her answering machine. It gave me it was like an electric shock of vertigo that went from one ear to the other. And it's the only time I got that.

And I didn't mention it because it sounded so goofy. And about the third time I saw Dr. Hain, I mentioned that. And he said, oh, Tullio's effect. So there was even a name for something that I was experiencing. And I think it's a good reason to-- especially once you find someone you trust then you should tell them everything that you can think of because until you tell your other doctors as well because they may have suggestions for you.

HEATHER DAVIES: I know we do tend to minimize at times. And I'm not even sure why that is because we want to be OK and we want to push on and yeah, so I know I'm guilty. Guilty. Minimizing my symptoms.

PATRICK PARKINSON: Yeah, yeah. Well, the other piece is like self-compassion there. And we talk about seeing support groups to get the validation. Finding people who understand what we're going through. But at the end of the day, being able to apply that compassion to yourself because if you can think of someone that you care for and say imagine them going through what they'd be going through, you'd be willing to give that compassion to that person. But a lot of times we have troubles giving it to ourselves.

HEATHER DAVIES: Sure.

MARY ZIEGLER: My sister got diagnosed with a really terrible form of leukemia and only had about a 20% chance of living and she's fine now. But so when I first got the diagnosis, I didn't even talk about it because my life wasn't on the line. So she's mad because she's really well, she went back to work and she traveled the world, accomplished a lot, but then she got

Meniere's disease and she didn't think it was fair to have leukemia and Meniere's disease--

[LAUGHTER]

--even though her health is great.

PATRICK PARKINSON: Yeah. I've got another question that just came in here about whether either of you like to check in with your primary care provider about your ongoing vestibular symptoms. And if you find that you're ever in a position where you're having to educate your primary care physician on your condition. Mary, I don't know if you want to start with that.

MARY ZIEGLER: Yeah. I think that even-- I think that at least for me and for most people I've met with vestibular disorders we know more than every doctor with the exception of the specialists we're seeing. So I'm lucky I have really good doctors. And when I talk to them, they listen and then that might trigger ideas for them.

So I had a primary care doctor who put me on thyroid medicine and vitamin B12 just because those levels were kind of borderline. So keep everything even and my OB/GYN put me on something called Femring that-- it's used for contraception but also for HR, hormone replacement.

And again, it's very low dose, it's very safe, but it keeps all that stuff-- all your hormones in balance so you're not dealing with a million other things fluctuating. So I think you don't have to be a know it all, but you are in the position where you have to educate really everybody. I only check in with my regular doc about vertigo when I see her at a regular yearly checkup. I don't call her. I don't know about you, Pat.

PAT FILIPEK: Yeah, I have been educating my primary care. Because when I first saw her when I was first diagnosed, she didn't think I was eating right. And so I have been educating her and she's listening, so that's good.

PATRICK PARKINSON: Good, good, good.

MARY ZIEGLER: Back to what Heather said, if somebody's not listening, then find a different person. Yeah.

PATRICK PARKINSON: Yeah. What about you, Heather? Are you working directly with a primary care?

HEATHER DAVIES: I will tell you. Unfortunately, my primary care physician passed away. But I loved him for the simple fact when I was going through the height of all of this, he told me I have no idea what's happening with you but we're going to figure it out. So I love him for that for being completely honest and saying, I don't know, but let's dive in. And that's what the best thing for me at that time.

But I am more open about it with the doctors that I see. Sometimes I think I sound crazy telling them the symptoms that I'm experiencing. And that goes for friends and family too. But it's what it is. And we just do the best we can and we move forward. So yeah, What about you, Pat, Patrick?

PATRICK PARKINSON: No, you're OK. I don't have a primary care physician right now. And I may not be the perfect example of--

[LAUGHTER]

I actually recently bailed on my ENT doc. And-- [LAUGHS] but I had an ENT, I had a primary care physician that I was working with for a while but I didn't feel like I was getting too much added value. So right now I actually just work with an audiologist who manages my hearing and I kind of stay focused on lifestyle and stress management is kind of my first line of defense right now. And I still have an ENT within reach if I ever need it and he refills some prescriptions like meclizine and things for vertigo as needed.

MARY ZIEGLER: Yeah, I think having a good PC really helps you. And they should be your gateway into a whole system. I forget where you live, Patrick.

But for me then I can get to anybody at Rush Memorial. I go to Rush, and Northwestern, and University of Chicago for different things. But that's a huge and good medical care system. So you're young enough that you don't have too many allergies like the rest of us.

[LAUGHTER]

HEATHER DAVIES: Right. I will tell you also now that you were just speaking, Mary, I ended up going to a multidisciplinary clinic where they did a slew of tests and the doctors came back together and then discussed-- for those of you that don't know what that is, discuss what they thought was the problem.

And that's where I got my basis, my first diagnosis. And then we just went on from there. And that was I guess they're doing that more and more frequently. I mean, if you're not getting the answers, that's something I would suggest to seek out a multidisciplinary clinic. Just my two sense that helped me along the way.

MARY ZIEGLER: There's one of the people that came to our support group this week was new is from Calgary. And so in Canada-- well, I shouldn't say in Canada. In Calgary, anyway, they have a whole dizziness clinic where everybody you need is right there. And I agree with you that usually is especially back when I started there weren't even none of the hospitals here even had integrative medicine.

So the idea that you could try and get all your doctors at one table to agree on something even two different specialists, it was hard. That's probably another benefit of telehealth, though, that it's probably more possible to grab two doctors at the same time if you do it on telehealth. Because I did have an experience where actually three different doctors had three different ideas. And--

HEATHER DAVIES: Oh, goodness.

MARY ZIEGLER: And that's hard when you're the patient.

HEATHER DAVIES: Yeah, that does happen too, for sure.

PATRICK PARKINSON: Yeah, you feel like that ping pong ball, right? Going back and fourth.

MARY ZIEGLER: Well, and you end up deciding instead of the doctor, which it kind of goes. That's like, couldn't the doctor decide this? Do I really have to?

HEATHER DAVIES: Mary, I have a quick question. You mentioned that your doctor put you on hormones. Do you think that hormones play any relation into any of your vestibular symptoms? And what doctor prescribed those for you?

MARY ZIEGLER: My OB/GYN did, her name is Marybeth Lore at Northwestern in Chicago. And I think my honest answer because I've been on this so long is I don't know. So from watching other friends of mine go through-- well, I'll take that back. I don't know for me, but I know other people like they'll have an onset of symptoms with pregnancy, or their symptoms go away with pregnancy.

Other people, especially migraine, Pat, some people seem to experience new symptoms at times of hormonal change. So like in your early teens, after menopause, so I think there's a relationship between hormones and a lot of things. But I haven't ever seen documentation on it other than just talking to people. So we just all hope there's more neuro-otologists that do or more doctors that do more research. And thanks to VeDA for encouraging it.

HEATHER DAVIES: Absolutely. We love VeDA. And you've had-- have you had-- are you prescribe to any hormones that are related to prescribed because of your vestibular symptoms or anything like that?

PAT FILIPEK: Yeah, I was put on-- and this was through the functional medicine. And so it seems to have evened me out a bit.

HEATHER DAVIES: So you're feeling a difference?

PAT FILIPEK: Yeah.

HEATHER DAVIES: Awesome. How did you find your functional therapist or your functional practitioner?

PAT FILIPEK: Actually, Dana Truss--

MARY ZIEGLER: [LAUGHS]

PAT FILIPEK: --referred me. And it's something I had been thinking about for a while but I'm going, I don't know. But I'm glad I went. The first blood test was 43 vials of blood. So they checked--

HEATHER DAVIES: Oh my goodness.

PAT FILIPEK: --everything.

HEATHER DAVIES: Wow.

PAT FILIPEK: And so we're working on the worst thing first, and which is a leaky gut and that can cause a headache. So hopefully once I'm done with this part it'll start going away. Yeah.

PATRICK PARKINSON: Another thing you mentioned earlier, Pat, and this was a question that I didn't get around to addressing was the idea of how your symptoms change due to how you're interacting with them and focusing on them. Can you talk a little bit more about your experience with that and what advice you may offer around that?

PAT FILIPEK: When I quit focusing on the pain, because I mean luckily, at night it doesn't wake me up. I can maybe five times, this whole time it's woken me up. But if I keep myself occupied with something else, I'm not concentrating on just the pain and I'm able to function better like driving, I

can still drive because I have to focus so much on the road that it takes my mind off of the pain. It doesn't go away, it's in the background but it helps--

PATRICK PARKINSON: Sure.

PAT FILIPEK: --to focus on other things.

PATRICK PARKINSON: Yeah, absolutely. Heather or Mary. What about you two? Any thoughts there?

HEATHER DAVIES: I'm sorry. The question was about the symptoms?

PATRICK PARKINSON: It was around kind of just how-- it was how relating to your symptoms kind of impacts your experience of them. And the specific question was around, does focusing or fixating on your symptoms--

HEATHER DAVIES: Honestly, I have had to change my relationship with my body and my symptoms. Before I was very reactive. And I think that is what stopped me from getting an accurate diagnosis for so long because I was so heightened. My anxiety was taking over everything. And so the clear picture of what was going on with my body was not evident because I was so anxious.

But once I was able to calm that down with meditation with a daily practice, even though my mind would wander too, it still does occasionally. Once I was able to calm and not be so reactive, I was able to try to-- sorry, the word distraction, sorry, I couldn't find it-- is used distraction whenever I have those symptoms and just not really put so much energy into them as far as how I'm feeling. And I know that's so easy for me to say because I am where I am, but it wasn't easy at the beginning to think of where I want to be instead of where I'm sitting, if that makes any sense.

MARY ZIEGLER: Right.

HEATHER DAVIES: Yeah. What about you, Mary?

MARY ZIEGLER: I think my first episode was so-- the first episode that got my attention was so dramatic. I was scared then because I wasn't really sure what was happening despite the-- I figured I had terrible vestibulitis just because I knew about vestibulitis but that was scary. I'm trying to remember it.

I think you do have to befriend your illness, which is not a very nice word. But if you can accept it and just-- well, you have to accept the fact that sometimes you're going to feel terrible, sometimes you're going to be on the floor, sometimes in our family missing a party is like it's a, immortal sin, and b, miss out on a lot of fun.

But you just have to come to terms with that and let go of that. I think the big things that help in terms of acceptance with me is it's not as much noticing symptoms or not noticing, but learning to ask for and accept help. And I was not good at that which many friends would point out.

[LAUGHTER]

So and even again, I learned to ask for it. But then I'd say, oh, never mind, I'll do it myself. So learning to ask for and accept help and trying to learn not to mourn for your former self. Those would be my first two things. And I might have gotten those from PJ Haybach, I'm not sure, something like that. But I think those are the things that help me just realize just it'll pass.

The worst of it'll pass and trying to-- I take diazepam which is generic for Valium on very low dose so instead of meclizine. I don't take the anxiety dose because I've really never had that panicky anxiety. But I take a low dose, and I'll take one of those and try and sleep. It's worse if you can't get to sleep, I think. You can't read, you can't watch TV, and you can't get to sleep, that's bad.

HEATHER DAVIES: Yeah, absolutely. Sorry, we're just-- there's questions popping up in the Q&A.

PATRICK PARKINSON: I'm trying. One thing about us is we overuse our peripheral vision. So I'm concentrating like Pat said. I'm concentrating really hard on you guys and ignoring the screen.

HEATHER DAVIES: Good. Good, I know.

PATRICK PARKINSON: This is kind of a follow up question for you, Mary, on what you were saying about asking for help. How were your families involved? Maybe friends and family will include both in helping you through the early days of your diagnosis of your journey and diagnostic process.

MARY ZIEGLER: My husband-- this is putting me on the spot because my family's probably all watching. My husband, wonderful, and almost perfect and he was always great. So I kept saying, but I'm really sick, and he's like I know you're really sick. I can see you being really sick. So I really have to-- he's the person that really has saved me in the most ways.

And I think friends and family because it affects you all the time. There's at least for a lot of us because you always have this. At first it's hard because if you do try and explain it people can feel like all you're doing in your relationships is over explaining your illness. If you don't try and explain it, you'll get depressed and lonely and have pity parties for yourself at the end of the day. And both of those are kind of unhealthy.

So I have a wonderful family. My own kids were really-- we have four kids and they were-- oh, boy, high school down to maybe fourth grade when I got sick. And they've always been a huge help and really kind. And the rest of my friends and family have too. At first I know it was hard. I'm thinking of a shower that my brother had and one of my-- we have a huge family. So one of my cousins was taking flash photos when I was early in my illness.

So every time a flash photo went off, I got a blue light. I don't know, Pat, Have you ever had these with your migraines? So there were blue. She kept taking them and there were blue lights all over the room and I couldn't leave.

And I didn't have a ride home and nobody really got how scary it was for me to ride home because everybody else saw you dizzy so take a cab. And I'm like, I don't want to take a cab. My brother drove me home. But I think it just takes time for people to get it. And in general, I think people only understand if they live with you.

PATRICK PARKINSON: Yeah, yeah. There's another question in here about who on your team either your health care team or friends and family is would you say is your champion? Pat, What are your thoughts on that? Who would you say has been kind of your champions on your team?

PAT FILIPEK: I have a really good friend that was in the beginning driving me to doctors. I could drive, I just couldn't walk from the car to the building. And she's been with me this whole time. And my son is also very helpful.

PATRICK PARKINSON: Absolutely.

MARY ZIEGLER: It's an embarrassing question I think to ask. So I mean, the biggest difference was finding my diagnosis and meeting Dr. Hain. And my biggest champions, my husband and our four kids. And then I really am grateful to all my friends who are first of all, understanding when I cancel things but who offered a help.

Everybody's learned to say, Mary, where do you need to sit? Mary, we could take your-- I have a walker because I also fell and wrecked my legs seven years ago. I have people that are willing to put this big honking walker in their cars. Even my high school friends that at a reunion. So I don't know if I can really name anybody but my husband and kids.

But I think that you do learn most people are happy to help you. And when you help somebody, it makes you feel good. It's an act of generosity to ask for help. My mom has-- my mom died last June at 93 or 94, I have to think, do the math. But I couldn't drive. When she was in hospice, I was already at a point where I couldn't drive or before. And I had friends who drove me out

there once a week for three or four years. I mean, that's pretty incredible. So I could name them but I'd forget somebody. So I feel like I'm giving an Oscar acceptance speech.

[LAUGHTER]

PATRICK PARKINSON: No, that's OK, that's OK.

HEATHER DAVIES: Yeah, that's awesome. That is awesome. Well, we are unfortunately winding down, ladies. And I'm curious on what you would say to someone who's just starting out in their journey towards diagnosis and recovery. Is there anything you'd like to say? Hope I'm-- sorry, I'm so sorry. Mary, Mary first.

MARY ZIEGLER: Boy. I guess the thing that I'd probably say, find a neuro-otologist, even if you have to travel. And after that, I'd say it really gets better. So you may not get better, but having this illness gets better. And you learn to appreciate new things in life. I think that I'm more humble. My husband's pointed out to me that now I make mistakes, which I absolutely never made a mistake before.

[LAUGHTER]

My younger siblings would probably be happy to hear me acknowledge I do make mistakes. And I'm certainly more empathetic, which I was like a nice person before but now if somebody says they have fibromyalgia, or back pain, or migraine, I'm a lot-- I understand it much better. So and I think that you can build your own network. I developed a gratefulness practice and that has helped me a whole lot. So I would tell people those things.

HEATHER DAVIES: Awesome. And what about you, Pat?

PAT FILIPEK: I would say don't lose hope. If the first doctor doesn't work out, move on to the next one. Don't wait a long time to do that. And just be

around people that are going to support you. And even if they don't understand, they're there for you.

MARY ZIEGLER: Yeah.

PAT FILIPEK: I think that's been an important thing for me.

HEATHER DAVIES: Absolutely. Those are great, great. I think something's coming through the Q&A real quick that they want us to ask.

PATRICK PARKINSON: Oh, no. I think-- Heather, do you want to chime in on this question?

HEATHER DAVIES: On this one.

MARY ZIEGLER: [INAUDIBLE]

PATRICK PARKINSON: Oh, just the final question. What would you say to someone. Yeah, yeah, I'd love to get your take.

HEATHER DAVIES: Who are starting their journey and looking for-- I just say just don't give up and just be sure to find your voice and make sure that you find a team. That was the biggest thing for me is finding someone who believed what I was saying because the symptoms can make you sound crazy. And just keep looking and until you feel that perfect fit and that you feel heard, that's all I can tell you.

PATRICK PARKINSON: Yeah, absolutely.

HEATHER DAVIES: [INAUDIBLE]

MARY ZIEGLER: I agree.

PATRICK PARKINSON: Yeah, I agree 100% with what's been said. And on the topic of diagnosis, it's like we can use our diagnoses for information but we can't let it dictate our stories. And if I would have listened to my first doc which I did for many years and I thought that I only had a handful of tools in

my toolbox, and if I believed that the whole time, I would be in a completely different position than I'm in right now and it wouldn't be a good one.

MARY ZIEGLER: That's a really good point because I think pretty sure there's robust research on it but negative thoughts kind of stick longer than positive thoughts, negative news and events. And so that's part of practice is don't dwell there. Put it to this-- put the negative thoughts like in a bag by the front door and dwell in positive. I don't mean be a goody two shoes, but dwell on positive things.

HEATHER DAVIES: I think that's a great way to end the session. Perfect. The practice of gratitude, for sure. Thank you guys so much for being here and sharing so much of your stories.

PATRICK PARKINSON: Agreed, thank you so much

MARY ZIEGLER: Thank you.

PAT FILIPEK: Well, thank you.

PATRICK PARKINSON: Good meeting you, Mary and Pat. Yeah.

MARY ZIEGLER: Yes.

PAT FILIPEK: Take care.

HEATHER DAVIES: Thank you. Wow, that was a lot. [LAUGHS]

PATRICK PARKINSON: No, it really was. It was. I know we could have kept talking forever, I think.

HEATHER DAVIES: I know. I know. Well, thank our panelists, Pat and Mary, for sharing so much of their stories. Cynthia, Kyler, Elizabeth, everyone behind the scenes. And as a reminder, you can purchase lifetime access to the recordings and transcripts of this entire conference at vestibular.org/lrl-recordings. And you can help make sure that valuable information that is

presented at this annual event remains free to everyone by making a donation at vestibular.org/lrl-donate. Those links are also listed in the description box below.

PATRICK PARKINSON: Yeah. And wanted to extend another thanks to the James D. And Linda B. Hainlen Discovery Fund and the University of Minnesota Department of Otolaryngology. Abbie and Danielle and their physical therapy practice, Balancing Act Rehabilitation, and the Academy of Doctors of Audiology for sponsoring this amazing conference.

HEATHER DAVIES: Yeah. Well, thanks so much, you guys, and we'll see you tomorrow.

PATRICK PARKINSON: Yeah, take care.

HEATHER DAVIES: Bye, Pat.

PATRICK PARKINSON: Yeah.