

Life Rebalanced Live 2024

VESTIBULAR MIGRAINE, PPPD, AND CENTRAL VESTIBULAR DISORDERS

CYNTHIA: Good morning, afternoon, or evening, depending on where you're tuning in from. And welcome to the first day of the Vestibular Disorder Association's fourth annual Life Rebalanced Live virtual conference. I'm Cynthia Ryan, executive director of VeDA. And I'm excited to kick off this year's event.

I'd like to begin by thanking our sponsors who have 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, a fellow vestibular patient who 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 not only educate people about vestibular disorders but provide a platform where people can connect. And that's what we do here today. Also, a quick shout out to Jim for being cancer-free.

Another big Thanks to Dr. Abbie Ross and Dr. Danielle Tolman from Balancing Act Rehabilitation, who are also generously supporting this year's event. Many of you know Abbie and Danielle as the hosts of the 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 have served on VeDA's board of directors and have volunteered countless hours to advance

vestibular advocacy. Its dedicated volunteers, like Abbie and Danielle, that are the lifeblood of this organization. I've been honored to work with them and glad to call them my friends. Thank you, Abbie and Danielle, for everything you do for the 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. And now I'd like to pass it off to our hosts, Dr. Abbie Ross and Danielle Tolman.

DR. DANIELLE TOLMAN: Thank you for the wonderful introduction, Cynthia. It is so hard to believe that this is our fourth annual life rebalance live. We are so excited to bring you an all-star lineup of health care providers to discuss various topics pertaining to the management of this fibular dysfunction and inspirational patients who will be sharing their vestibular journeys. We also want to say thank you so much to all who have contributed to this conference in some way, including VeDA's vendors donors, staff, and volunteers.

DR. 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 the live event, we will have them available for purchase for just \$55. Your financial support helps VeDA-- VeDA's continued mission to spread vestibular awareness.

Our topic today, day 1 of Life Rebalanced Live, it's a good one, vestibular migraine, Persistent Postural Perceptual Dizziness, also known as PPPD, and central vestibular disorders. We'll be discussing what a central vestibular disorder is and how it compares to a peripheral vestibular disorder. We'll talk about central vestibular disorders and how they're diagnosed. And then we'll also touch on treatment approaches for various diagnoses.

DR. DANIELLE TOLMAN: So without further ado, we'd like to introduce you to our first speaker, Dr. Kristin Steenerson. Dr. Steenerson is a board certified neurologist with fellowship training in otoneurology. After graduating cum laude from Claremont McKenna College, where she was honored as an All-American in Lacrosse, she continued on to medical school at the University of Utah in Salt Lake City, Utah.

After four years of medical training and annual ski passes, she proceeded to the desert or to the Mayo Clinic in Arizona for a neurology residency. There, she discovered the beauty of the desert as well as an unmet need in treating balance disorders and vertigo, motivating her to pursue a fellowship in otoneurology at Barrow Neurological Institute.

She joined Stanford University in 2017, with positions in both otolaryngology, head and neck surgery, and neurology to jointly address the junction of the inner ear and brain disorders. Her specific interests include vestibular migraine, benign paroxysmal positional vertigo, persistent postural perceptual dizziness, Ménière's disease, and international neurology. Dr. Steenerson, thank you so much for joining us. We're so excited to have you here.

DR. KRISTEN STEENERSON: Thank you so much for having me.

DR. ABBIE ROSS: All right, everyone, let's get right into questions. Dr. Steenerson, thank you for joining us today. And thank you, all our attendees, for joining us.

Please remember, you have the chat in the app. If you have any questions as we continue, if anything comes to mind, pop them there, and we'll try to address as many as we can within our hour.

First, let's kick it off with what is a central vestibular disorder and how does it compare or contrast to a peripheral vestibular disorder such as BPPV or a hypofunction.

DR. KRISTEN STEENERSON: Yeah, this is such a great question because it's actually turning into a more and more challenging question to answer as we learn more about the vestibular system. But for the purpose of this conversation, we can divide up central and peripheral vestibular disorders based on anatomy. So for us to have a functioning vestibular system, we need inner ear components, which are our little tiny organs inside our ears that help to detect different types of motion, like gravity changes and rotation changes. And then we need our brain components, which are different areas within the brainstem, the cerebellum, and then all the way up to the outside parts of the brain, the cortex, that help to interpret that motion and put it in the context of our other balance inputs, like our vision and our joint position sense.

So when we're referring to central vestibular disorders, we're really thinking about the disorders that are mainly based on dysfunction of those brain components. So is there a problem in how the brain's processing information at the level of the brainstem, the level of the cerebellum, or some of those other really complicated interconnections throughout the different connections within our brain?

DR. DANIELLE TOLMAN: And I'd imagine that at different levels of where you might have those areas of dysfunction, we might have different types of presentations or symptoms, is that right?

DR. KRISTEN STEENERSON: Exactly. And that's one reason that this central peripheral distinction has become more and more gray, if you will, in terms of saying, Oh, you 100% have a central vestibular disorder or 100% have a peripheral vestibular disorder, because it is a system. So when there is a change that happens in the inner ear, that sets off a cascade of changes in the brain, trying to adapt and change to-- respond to this alteration in the inner ear component. And then vice versa, if there's a problem in the brain,

the inner ear might sometimes have to change to try and see if it can compensate for how the brain is interpreting that information.

So it can be really challenging to distinguish between the two, but we do have some general characteristics that we'll attribute to more central or brain problems with vestibular function versus the peripheral problems of vestibular dysfunction.

DR. ABBIE ROSS: And oh, by the way, some diagnoses that we typically classify as central can coexist with some diagnoses that we typically classify as peripheral. So if we get into a little bit more specifically now, one diagnosis that we tend to call central would be vestibular migraine. Can you talk to us about how that is diagnosed?

DR. KRISTEN STEENERSON: Yeah, great question. Vestibular migraine is a clinical diagnosis. So what that means is that we, as the physicians or the providers, are listening to your story, doing a physical examination to understand what your neurologic system and vestibular system looks like in terms of specific examination techniques, and then make the diagnosis based off of that information.

So there's no other auxiliary tests that can make that diagnosis for you. There's no blood tests. There's no vestibular function tests. There's no MRI scan that can say you have vestibular migraine.

We generally get those extra tests because, just like you said, there's so much overlap between vestibular migraine and so many other vestibular disorders and neurologic disorders that we really have to do our due diligence to make sure that we've looked into those other possibilities as well. But other than that, there is no other test that tells you you have a severe migraine, except that conversation and examination with your diagnosing provider.

DR. DANIELLE TOLMAN: So that almost like a diagnosis by exclusion, we're ruling everything else out, which, I think, can sometimes be a point of contention for patients going through that vestibular journey because they want something to come back, telling them what's going on. And when everything keeps coming back, quote unquote, "normal, normal, normal," it gets very frustrating for them as they explore that possibility with their physician.

DR. KRISTEN STEENERSON: Definitely. And I think that there is a little bit of a communication difference when it comes to the clinician's perspective versus the patient's perspective because we as neurologists in particular, we're trained to trust our neurologic exam more than an MRI, more than many of the vestibular function tests. That examination is incredibly valuable. It tells us so much information about the integrity of your nervous system in general. And then specific techniques for targeting the vestibular system also can give us so much information about how well it's working, how safe you are. Is there anything worrisome on your exam that makes me think, oh, no, there might be something dangerous going on?

All of that, we can glean just from a simple office examination. And that helps us, as providers, feel really confident, I'm not missing anything scary. I'm making a diagnosis that makes sense based on your story and your examination. That's incredibly valuable.

But for people who haven't had that medical training, it might feel like a somewhat arbitrary set of examination techniques that you're going through. And you just waved your hands. And I'm not sure that that really was very meaningful because I don't know what you're doing. And then you tell me that there's nothing else going on. Everything looks normal. So it can really feel like a disconnect that you're not getting a full workup, where from a neurology perspective, we're so pleased and happy to see that that neurologic examination is normal.

DR. ABBIE ROSS: Right. And when we talk about the patient's story being so important in diagnosing various vestibular dysfunction, what do we hear in the patient's story when we suspect vestibular migraine?

DR. KRISTEN STEENERSON: Yeah. So vestibular migraine, one of the reasons I'm just so enthralled by it is that the vestibular migraine symptoms can take on any symptom that the vestibular system can produce. So it really is the chameleon of vestibular disorders because it is so good at affecting every single point of function within that vestibular system, ranging from the inner ear throughout all those different connections that we touched on before in the brainstem cerebellum and cortex.

So those symptoms can have a wide range. The classic ones that most people think of are vertigo, which, as you and I know, means a hallucination of movement, but some people think that vertigo only means a spinning sensation. So you can have a classic spinning that comes and goes, but you can have any type of motion, so rocking, tilting, swaying, floating, any motion that shouldn't be there.

You can also have exquisite motion sensitivity. So that motion sensitivity could be what most people think of as motion sickness, like not being able to read a book in the back seat of the car, but it can also be motion sickness from things like just moving your head a little bit, just moving your eyes a little bit, breathing, just being in a complex environment that has a lot of motion or a lot of visual circumstance. So that exquisite motion sensitivity can also be a sign of vestibular migraine.

So I'm really looking for any type of motion dysfunction. Do you have a problem putting yourself in motion? Do you have a problem being exposed to motion? Do you have a problem interpreting motion? All of those are signs of the vestibular system is not working at its best and also a sign of some hypersensitivity to motion, which is a classic feature of vestibular migraine is hypersensitivity to your environment.

DR. DANIELLE TOLMAN: Now we have a very specific question in the chat. And I know we're going to touch on the end, but this is a perfect time to put this in here. But do patients with vestibular migraine also experience more physical symptoms, such as ear pressure or fullness with migraine?

DR. KRISTEN STEENERSON: Yes. So that's one of the challenges with vestibular migraine is that in the medical literature, we've made this dichotomous decision that central vestibular disorders are one thing, peripheral vestibular disorders are another thing. And so if it's something that's affecting you peripherally, you really have to think about a peripheral problem of the ear that might be causing this.

And of course, that's true. You need to do your homework, get your hearing test, have an ear examination, make sure everything's normal. But generally speaking, those are normal. And what we think is happening is that vestibular migraine affects all of the nerve endings that can give us our normal sense of sensation and orientation in our head and neck structures.

So what we'll see is that some of the nerves that help us to have normal sensation to our ear in particular can become irritated, can become hypersensitive. And so many people notice recurrent episodes of feeling fullness in the ear, having ear pain, having problems with extra sensitivity to noises. And depending on what clinician you're talking to, they might call that hyperacusis, meaning that you're super sensitive to sound, or phonophobia, meaning that you have a fear of sound because it's really frustrating to you or annoying to you or sensitizing to you.

So ear symptoms are so common, which is, I think, a wonderful example of how that central peripheral dichotomy can be so confusing and maybe not relevant when it comes to vestibular migraine because you have so much overlap between the two systems for good reason.

DR. ABBIE ROSS: Now we talked about how vast symptoms can present or across the spectrum, you can have anything when you have vestibular migraine. And therefore, we also recognize that the treatment approach is going to be specifically tailored to each person because there can be such differences. Can you speak generally about what a treatment approach would look like for someone with vestibular migraine?

DR. KRISTEN STEENERSON: Yeah. So first, education is key. So helping someone really have a good understanding of what vestibular migraine is, that it's not dangerous but it's very functionally debilitating, that it's probably a genetic disorder. So this isn't something that you cause. They're really trying to de-emphasize the blame game.

It's important, of course, to evaluate your lifestyle and make sure that we have your lifestyle daily habits and good care. But I always want to de-emphasize blame because I hear a lot of patients coming in and saying, I was told that this is something that I ate or this is something that I did or something like that. And I think there's a lot of guilt that goes along with that. And any stress that you have is a much bigger trigger, much more reliable trigger to vestibular migraine than some of these other environmental triggers that people may or may not read about.

So first, education, talking about how this is something that is probably just inherent to your body, might have been aggravated by different life events. So we see it so often happen at estrogen fluctuation changes in our life cycle. So lucky us women, around menopause, perimenopause, that seems to be a big trigger. But we know stress is a huge trigger too. So is there a big life event or you're just really stressed life situation right now? Bu 50% of the time or more, we don't know why this started. So trying to de-emphasize that blame.

Then we do really dive into lifestyle. So how is your sleep? Sleep is critical for your brain to recover and clean up after a long day of working really hard.

So you have to have really high quality sleep and making sure that you're getting enough sleep.

How's your eating habits? Eating and diet is somewhat of a controversial topic within migraine. I have a really common sense approach. We call the standard American diet, the SAD diet, S-A-D, for a reason because we don't have the most nutritious high nutrient diet in the world. So diving into maybe some more Mediterranean style diet changes, making sure you're eating whole foods, and making sure you're eating enough and frequently enough and have enough protein and those good fiber. High density nutrition is really helpful.

Then we'll talk about exercise. So are you getting both cardiovascular and strength training? We know both of those have evidence that show they can reduce the migraine burden as well as the number of migraine days that you have per month.

And then what does your exercise entail? So most people who have vestibular migraine will notice some form of motion sensitivity. And as a result, they might tailor their daily routine to avoid motion as much as possible, so that could be head motion, eye motion, body motion, visual motion.

And we really need to do the opposite, which is this desensitization protocol of incorporating motion. It can be tiny amounts at first. We don't want to overwhelm you and create this kind of negative feedback loop where every time you move, you say, this makes me feel terrible. I don't want to do this anymore. So you can have this very exposure therapy graduated protocol, but really need to incorporate motion into your exercise in addition to the classic benefits from cardiovascular and strength training.

We'll also talk about hydration or drinking enough water. Are you maybe dehydrating yourself accidentally with things like overuse of caffeine and

alcohol, which we both know are irritating to the brain anyway? So it might be helpful to reduce those.

And then finally, stress management, like we talked about before. Really diving into, what are your stress management toolbox? Are there ways that you can change that? Or can we get some extra help to change how your brain responds to stress? As well as maybe dive into your introspection about your vestibular symptoms because most people, when they first have vestibular symptoms, have a lot of catastrophic thinking. This is a really scary event. It must mean something really dangerous and potentially, harmful is happening inside my brain or my body.

And then when we get information to say, Oh, no, actually, that's just a really awful, annoying symptom, but it's not damaging, technically, a lot of people can help teach the brain, OK, just reduce that catastrophic thinking. Of course, give yourself some compassion. This is a horrible thing to go through, but you don't have to worry that you're in danger.

But some of us aren't able to train the brain as easily like that. And so we'll have that catastrophic doom feeling every single time you have a symptom. Or just thinking about it can cause that thinking to start again. So really diving into, what's going on with you, when you think about your vestibular symptoms. And are we inadvertently actually making them worse because that thought process is still really active and taking hold every time I have vestibular symptoms or even if I think about having them?

DR. DANIELLE TOLMAN: What I love about everything that you just covered was that these are all things that everybody watching today can start diving into resources and making changes with at home. That's a lot of-- it sounds like a lot of the foundation of where treatment for vestibular migraine starts. And if it has to go further, you're going to have your team in place to work with you in approaching medication approaches or other medical management or complementary and alternative options as well.

But everything you just covered is stuff that everybody can look into and start with today. So we're only like what? 20 minutes into our conference, and everybody watching can walk away with a huge chunk of knowledge already of how to already start feeling better. And I really love that approach. I think it's really wonderful how you stress the importance to give yourself grace to help ease that burden and placing that guilt or that blame elsewhere. I think that's really important for everyone to take away from this talk, at least up to this point.

Now talking-- shifting gears a little bit and looking into a couple other diagnoses that might be considered or are considered part of central dysfunction, one that very closely either overlaps or coincides with vestibular migraine would be persistent postural perceptual dizziness. Could you maybe introduce us to that diagnosis and how we might come to that diagnosis with a patient?

DR. KRISTEN STEENERSON: Yes. So persistent postural perceptual dizziness is describing what it is. So first, I'd like to break down the words. So persistent means it's there most of the time. Postural means it's there when you're standing up or upright. Perceptual means it's changing your perception or sensitivity of your perception. And the dizziness is a catch all term for any type of disorientation or motion challenge that you're experiencing.

So what PPPD or Persistent Postural Perceptual Dizziness is referring to is usually a change in how the brain perceives your sense of balance and motion experience. And what's interesting, at least the most classic form of PPPD that was recognized, is this can be a really sudden change. So what most people come in and tell me is, this thing happened to me. And they can tell you the exact date. And ever since that thing, I've had this persistent or this continuous sense of rocking or floating or just feeling disconnected. And it's been there for as long as that event occurred ago.

By definition, it should be at least three months of symptoms that are there the majority of the time. So it doesn't necessarily have to be there 100% of the time, but usually, over 50% of the time. And it's there exacerbated when you're standing up or moving around, worse when you're in complex visual environments, like grocery stores or watching lots of movement on a screen. And it really should occur in response to a balanced challenging event.

So a balanced challenging event could be a classic vestibular disorder, like BPPV, rolling over in bed, having a horrible spinning attack. But the spinning goes away, and you're left with this persistent rocking sensation that will go on for months and months and months.

But it can also be a non vestibular disorder. So having a panic attack, having a really stressful event, having an unexpected change that comes out of the blue, the more unexpected, the more shocking it is, the higher likelihood of potentially triggering something like PPPD.

DR. ABBIE ROSS: And a lot--

DR. KRISTEN STEENERSON: If that answers your question question. OK.

DR. ABBIE ROSS: A lot of the lifestyle approaches that we talked about when we talked about VM also translate to PPPD. But is there anything else in addition from a treatment perspective that you recommend for patients with PPPD.

DR. KRISTEN STEENERSON: Yes. And sorry, going back to the overlap between vestibular migraine and PPPD, which is, I think, a really big challenge for most people. The challenge is that we know vestibular migraine can trigger PPPD. We also know that vestibular migraine and PPPD share a lot of the same symptoms, and it's because those similar areas of the brain, that central vestibular area, can be irritated in both of them. So that's why we can see so much overlap, but also, they like to trigger each other, which can be a big challenge.

There's even a really nice paper from Jeff Staab at the Mayo Clinic in Rochester, who showed that 25% of patients who have vestibular disorders will go on to develop PPPD. And we think it's because vestibular disorders, especially vestibular migraine, will have recurrent episodes of dizziness that can come on, sometimes expectedly, like BPPV, rollover. Oh, yeah, I know it's my right side, that's going to be a problem. But vestibular migraine, by definition, comes on spontaneously.

So the more you have these unexpected attacks, the more likely that's going to prime your brain, your central nervous system to be on the ready, to be as cautious as possible. This could strike at any moment so I need to be on guard. And as a result, those on guard centers of the brain might overactivate and might get stuck to be in the activated state, which is what we think PPPD is, is that it's causing you to stay on guard in response to a potential vestibular threat. And as a result, vestibular migraine and PPPD love to play off of each other, because then, the PPPD being activated is a super stressor. So now your stress level is much higher, that means your threshold for having migraine is much higher, making the two like to interact really, really frequently.

So in terms of--

DR. DANIELLE TOLMAN: Did you have a-- oh, I'm so sorry. Keep going. I don't mean to cut you off.

DR. KRISTEN STEENERSON: Oh, I'm so sorry too. I'm all over the place. But-- so going back to the question on treatment options, I actually approach them very similarly for vestibular migraine and PPPD. I first think about lifestyle. Then we think about physical therapy and your physical activity.

So is that engaging with a formal vestibular therapist so that they can help figure out, what are your challenges functionally? Is this mostly a visual motion problem? Is this mostly a standing balance problem, walking balance

problem? Is it a motion sensitivity problem? Is that all of the above?

Vestibular therapy is so critical for helping us to map out those nuances and then create a plan to help strengthen those and desensitize those, as well as incorporating great cardiovascular and strength training for your overall health and brain health.

Then we'll use a lot of psychotherapy, depending on how open someone is to this. This isn't a psychiatric disorder. Jeff Staab is a psychiatrist, but he also has a neurology background too. And he stresses so much, this is not a psychiatric problem. If we send you to a psychiatrist, they're going to send you back and say, what are you talking about? This is a vestibular problem. I can't help you.

But we know that because of that interconnectedness between the vestibular networks of the brain and that stress response system, our fight or flight system, a lot of times, using psychotherapy techniques, like cognitive behavioral practices, acceptance commitment practices, that can help teach that threat response system when it is appropriate to have that significant stress response and when it's not appropriate to have that significant stress response, as well as just help with the coping. This is a horrible invisible illness that came out of nowhere that is changing your entire life. That's an awful thing for anyone to go through. So having different coping techniques to also support you with this big change can be really valuable.

And then the final thing that we'll talk about is medications or more classic prescription therapeutics. So in that case, we'll talk about migraine medications, but we'll actually use a lot of medications that work on serotonin pathways like antidepressants, not because I'm treating depression or anxiety, I'm a neurologist, I'm here to treat neurologic disorders, but those serotonin effects of antidepressants seem to be really critical for both migraine pathways and PPPD pathways. So we can get a lot

of help if those other interventions aren't working as well or if you just need a synergistic effect from a few different modalities working together.

DR. DANIELLE TOLMAN: You're hitting on so many amazing things that I have on my checklist that I want to keep making sure we hit on, but you're just knocking right down. You perfectly answered a question from the chat that I was going to bring up. Somebody had asked about, how do you tell the difference between vestibular migraine symptoms and PPPD? They have both disorders but they overlap so much, it's hard to tell them apart.

And from what you just said, it sounds like starting at the foundation and treating them both very similarly, you might find reduction in those symptoms not having to discern between vestibular migraine and PPPD because it's likely they are driving or overlapping. So as long as you have those tools and those foundational means for trying to address your symptoms functionally, you might have a good time or an easier time addressing that and calming that down.

But I don't think that is the same for, say, overlap between the singular migraine and BPPV. That might take a little bit more work to try to discern the difference between them. And the treatment for both of them are not the same. So in those cases, do you have any words of advice for patients in how they can help discern that and help their treatment a little bit better?

DR. KRISTEN STEENERSON: Absolutely. And I agree with everything you just said because central vestibular disorders, because of this direct connection with our fight or flight response system, the more introspection, we give them, the more we focus on them, trying to tease apart the little nuances, we actually will aggravate them more or we can intensify the symptoms. So I'm not telling anyone to ignore their symptoms. They're real. They're impactful. We have to have tools to deal with them. But when we're trying to dissect away each little bit that might be coming from a slightly different etiology, that actually amplifies the symptoms.

So I completely agree with what you said there, it's important to recognize, these are together and interconnected, but what can I do that is helpful? When we have a combination with peripheral vestibular disorders and vestibular migraine, which is so common, you are two to three times more likely to have BPPV if you have vestibular migraine, you're two to three times more likely to have vestibular migraine if you have BPPV. So it's another version of one irritating the other and causing a lot of overlap and symptoms that can be really challenging to distinguish.

With BPPV, though, we have a totally different treatment that we have to think about. So as you know and as probably a lot of people listening know, BPPV is a change in the inner ear that when we have little crystals that fall out of place, they can get trapped or fall into one of three little tunnels that we have. And in order to stop the vertigo that happens when you move your head a little bit, you have to go through physical therapy or through some targeted head motion or head position changes like the Epley maneuver to move those crystals back into place.

Well, no migraine medication I'm going to give you, no sleep technique that I'm going to give you is ever going to move those crystals back into place. So we have to have some physical maneuvers that we can use as needed if you also have BPPV on top of vestibular migraine.

What's tricky is vestibular migraine can also cause positional symptoms, meaning that you can have symptoms that might sound a little bit like BPPV. And definitely, to a non-vestibular clinician, that's the first thing they're going to say, Oh, it must be BPPV because you're telling me, when I move my head in this way, I get dizzy, so I'm going to give you a bunch of exercises to do or send you to PT.

But there are some important differences between the two. We know that vestibular migraine will cause positional symptoms that will last as long as you're in that head position. So some people will say, Oh, I can't really tell a

side necessarily, but I just know that every time I lay down, I feel really sick, I feel really dizzy, and it will go on as long as I'm in that position. That, to me, is a sign, this is really unlikely to be BPPV. There's a tiny caveat there with cupulolithiasis, which is where the crystals get stuck. That is really rare. So for the purpose of this conversation, we'll say, that's probably not it. What's much more common is positional symptoms from vestibular migraine.

So instead, I like to teach patients to look for the classic BPPV characteristics, which are being able to tell which side it is. So a lot of times people say, Oh, I have to sleep on my other side because every time I sleep on my right side, I know I'm going to get spins.

Also, it should be short and brief, so their paroxysms. That's where the name comes from. So when you lay on that side, you should get this crescendo, decrescendo, vertigo that lasts just seconds. So you can feel it build, Oh, my gosh, it's going, it's going, it's going. And then it should calm down over the next 5 to 10 seconds. Some people are unlucky, you can have it up to a minute, but really, that's the spectrum that we're talking about, seconds to minutes maximum. Nothing longer than that. And really have this up down crescendo, decrescendo pattern to it.

So if you've got violent vertigo and really vertigo spinning that's lasting just seconds and you can tell which side it is, I'm much more suspicious that this is a mechanical BPPV problem than a vestibular migraine positional sensitivity. And so we have to have a different tool for you to help improve that BPPV symptom that you're dealing with.

DR. ABBIE ROSS: And also, if you're in that boat where you're having symptoms with physicians, always go seek the medical advice of a professional because something else that we use in the clinic, aside from just your story, is something called nystagmus. So by looking at what's happening with your eyes in those positions, we can help discern, is this likely more VM or is this likely more BPPV?

And with that, we're already halfway through our talk-- more than halfway through our talk. I can't even believe it. But there's another diagnosis that we want to touch on today, and it's MdDS, Mal de Débarquement Syndrome. Can we shift gears a little bit and talk about what that is, what a storyline might present as for a patient that you're diagnosing with MdDS?

DR. KRISTEN STEENERSON: Yes. And just one quick comment on what you just said. Completely agree. Please go see your vestibular professional. Ideally, if they have some goggles, that also makes it easier because the goggles help to amplify the eye movements. And we can also see what your eyes are doing in the dark much more easily. So if you can find someone with goggles, they can really help you distinguish between those two.

DR. DANIELLE TOLMAN: Which the goggles are very important for central findings too because central--

DR. KRISTEN STEENERSON: Exactly.

DR. DANIELLE TOLMAN: --is the brain. It does a really good job of suppressing nystagmus. So clinicians with goggles can put you in complete darkness. And they can tease out some little signs that there's something going on more centrally to clue you into the rest of your evaluation. So we highly recommend those goggles.

DR. KRISTEN STEENERSON: And I think it's a little bit of a good litmus test too. If someone has goggles, they're probably working with vestibular enough that you're going to have a more helpful experience.

All right. MdDS, Mal de Débarquement Syndrome, this is a really interesting symptom, it's a-- syndrome, horrible for patients to go through, but the onset is just so classic in terms of the classic form of MdDS. So the story that we'll hear is someone says, I was in motion for an extended period of time, so the classic story of being on a cruise. Went on a cruise. And when I got off the cruise, I did not readjust to land. So it felt like I was still on the

boat, this rocking sensation. Interestingly, usually, the exact frequency of what the boat was. And it didn't go away.

And to meet those criteria, it really has to be present for greater than a month or three months, depending on which diagnostic criteria you're looking at. And patients will say, I have this persistent sensation. It's there all the time. But interestingly, it gets better when I'm back in motion. So these are motion seekers, unlike PPPD, who are the motion avoiders, they want to stay away from motion. MdDS, you're looking for motion because that helps to cancel out that rocking sensation so that you can feel steady again. You're back at sea. You feel back to your normal self.

But it's also a central vestibular disorder, so we'll see a lot of similarity with PPPD in terms of the other cascade symptoms that people get, where you'll notice that you might be much more anxious, you might be a lot more sensitive to your environment, you might have more headaches and more migraines now, you might have problems with cognitive function because your brain is so distracted by dealing with the vestibular symptoms that you're not able to focus as much or your short term memory feels low or you can't get the words out, word finding difficulty, a lot of neck pain, neck problems because you're tense all the time, trying to keep yourself still and stable. So there's a lot of overlap between those as well, but the classic story is this persistent rocking following a motion exposure that just hasn't gone away.

DR. DANIELLE TOLMAN: And what does treatment approach look like for MdDS? It sounds like it might be potentially a little bit different than what we would do for others.

DR. KRISTEN STEENERSON: Yeah. So this is definitely an evolving science. And so it's a little bit unclear what the exact treatment protocol should be. There's clearly physical therapy techniques that are helpful. So there's more general vestibular therapy practice. I'm sure you guys could say way more

detail about than I can to try and help with adjusting to the symptoms and becoming more functional. But there might be some more targeted physical therapy practices, like optokinetic retraining, that might be helpful in retraining the brain, teaching the brain to cancel out that motion.

So one idea behind this is that the exposure to the passive motion actually changed how the brain interprets normal motion now to think that this rocking sensation is the new normal. So if we can present to you a passive motion exposure that can cancel that out, so much like getting back in motion makes you feel better, sometimes, that can reduce symptoms. That's really hard to find, practically speaking, so a lot of physical therapists don't feel comfortable with it. And there just isn't great guidelines or any type of protocols that are published, so a lot of it is a little bit trial and error. There are some academic centers that might offer it, but it's really inconsistent. And so it's really challenging to make that recommendation for patients because the access is just a big problem.

And then we'll also think about migraine treatments, actually. So look into lifestyle. But interestingly, a lot of [INAUDIBLE] department patients can respond to migraine treatments, not perfection, we're not talking a cure, but can see a reduction in their symptoms, usually in the 50% range if we try some different migraine medications or again, the antidepressant medications because of that overlap with the different neurotransmitters that are used in vestibular function.

DR. DANIELLE TOLMAN: Is there any evidence out there that suggests that patients who are prone to migraine are more susceptible to developing MdDS?

DR. KRISTEN STEENERSON: Yes. So we-- I like to think of migraine, in general, as a hypersensitivity disorder. So motion sensitivity is definitely included in that hypersensitivity spectrum. So one of the theories is that because migraine hypersensitizes your brain, you are especially susceptible

to developing MdDS, especially when in motion for an extended period of time.

DR. ABBIE ROSS: Now with all of these diagnoses that we've discussed today, we've talked about vestibular therapists, we've talked about neurologists. Is there anyone else that might make up the health care team for someone with these types of symptoms?

DR. KRISTEN STEENERSON: Definitely. So health psychologists can be really helpful. Again, there can be some stigma associated with psychology and psychotherapy in general, but health psychologists can really give great tools for retraining that stress response system, as well as helping you to become more functional. So because introspection can actually be a risk factor for intensifying vestibular symptoms, sometimes, it's really helpful to find other modalities besides introspection to help deal with the stress response. So finding a great health psychologist in addition to an excellent vestibular therapist and clinician can be a really powerful team.

DR. ABBIE ROSS: Go ahead, Dani.

DR. DANIELLE TOLMAN: I'm scrolling through the chat here. And there-- I keep seeing a buzz word that I think would be great to hit on because I think this is very common with vestibular dysfunction in general but a lot more with central findings, but brain fog. Can you talk a little bit about why patients may experience brain fog? And what exactly is going on?

DR. KRISTEN STEENERSON: Great question. So I hear brain fog from almost every single one of my patients. There's definitely a spectrum in terms of how severe their brain fog is, but almost every single person will experience some brain fog with their vestibular disorder.

And I think one simple way to think about it is that our balance system is critical for us to be safe and functional. So our brain really highly emphasizes those balance inputs and those balance inputs being correct. What's strange

for us, though, is that we have been able to rely on our balance system without thinking about it for our entire lives. So when we suddenly have a change in our balance system, where we have to almost micromanage the individual components to make sure that we're safe when we're standing up and walking around, that requires a large amount of attention, a large amount of cognitive function in order for you to feel safe standing up and walking around.

Well, you've never needed that much of attention prior to your vestibular disorder. So the brain only has so much bandwidth. If you're having to force so much activity towards what was supposed to be automatic into now this manual micromanaged sense, that takes away bandwidth, that takes away a lot of ability from your other cognitive functions.

So those cognitive functions that are easiest to sacrifice, if you will, they're not critical for survival, are the ones that we see impacted first. So that's usually things like short term memory, processing speed, and word finding difficulty. All of these cognitive processes that require the most quick response time, those are going to be impacted first because they're not critical for your survival.

And so I tell patients is this isn't a permanent change. There isn't an increased risk of dementia. This isn't some sign that there is a serious neurologic problem. It is simply a bandwidth issue where you're having to pay so much more attention to your balance system.

Once your balance system feels more steady and stable and routine, mundane to you, then that attention can shift back to those cognitive processes. And they will come back. So there isn't any type of permanent deficit that's happening and said, you just don't have enough attention to spare at this moment.

DR. ABBIE ROSS: That's one of the best explanations I've heard of that. So thank you. Question, I'm actually going to combine two questions here from our audience. One wants a little bit more guidance on what to do if weather affects their symptoms. And another question pertains to whether or not elevation can impact symptoms.

DR. KRISTEN STEENERSON: Yeah. So migraine literature has shown connections to changes in our environment as "migraine triggers," quote unquote, for decades. So we know that that exists in literature already for more migraine headaches. But it's very clear that vestibular migraine will follow most of the same triggers that migraine headaches will have too. So many patients will notice that altitude changes. Many will notice that barometric pressure system changes, especially low pressure, high pressure shifts. High pressure to low pressure will be more triggering for them.

So there are a few different techniques you can think about. First, what is your overall prevention plan? So prevention plan is referring to the lifestyle, the physical therapy, the medication regimen that you've found may or may not be helpful for you.

My-- because I think about your overall sensitivity to elevation changes, to altitude, to other environmental factors as a sign of what your threshold activity is. So threshold, what I'm referring to is, every single person is capable of having a migraine. It's just some of us are born with thresholds way up here, and some of us are born with thresholds a little bit farther down, or some of us go through an event that causes our threshold to become really low. And so now simple changes like having a bad night of sleep or not being able to exercise very much or having something stressful will trigger a migraine much more easily compared to before, where that thing would happen and we never passed our threshold.

So to me, when I hear someone's having consistent issues with altitude or barometric pressure or certain trigger, that, to me, means maybe their

threshold is still a little bit too low to be functionally effective for them. So we need to do something to help bump up that threshold so that you're not as susceptible. First thing is prevention plan. So is there a lifestyle change that we can make? Is there a medication change that we can make? Is there a physical therapy change that we can make to try and help better equip your brain tolerance for those environmental factors that are, for the most part, out of your control? There might be some control things you can do about altitude, but barometric pressure is definitely not.

Then there might be a role for targeted rescue medications. So using rescue medications as a mini prevention plan. So if you found a rescue medication that's helpful for you, that could be as simple as ibuprofen or naproxen. It could be a prescription medication like meclizine or a triptan.

Whatever your combination is that's been helpful for you, if you are going to be in a circumstance that you know you can't avoid, then it can be really helpful to take that medication combination an hour or so before you know that's going to happen, or if you know the weather system is coming in, just go ahead and take it, because that could help transiently bump your threshold up so that you're less likely to get impacted or impacted as severely when those environmental changes occur.

It's not perfect, but having that education about what's going on isn't harmful. And then having some tools and techniques to reduce the overall burden can be really helpful to get through it.

DR. DANIELLE TOLMAN: That's where I think the success comes from a lot of that emphasis on the foundational work of education, understanding your triggers, knowing your body. Starting in that foundational area there is going to set you up for success.

So knowing that you counsel all your patients on these aspects, how do you advise them on their expected prognosis for central vestibular dysfunction? What do you tell them the journey ahead looks like?

DR. KRISTEN STEENERSON: So I first like to start with saying that generally speaking-- and usually, by the time they see me, they already know this, but generally speaking, vestibular migraine is a chronic medical condition. So this is something that you were probably born with. And this is something that will probably be present throughout your life, it just depends on the severity and the extent to which it's present. So I like to bring up things like blood pressure control or diabetes control. Those are also chronic medical conditions that we find a regimen to help keep them in check so that it's not changing our life function as much. It might be an annoyance, but it's something that is likely going to be around for a while.

So first, trying to frame it as this is a chronic medical condition but it's manageable. And also helping to understand that there isn't a cure for vestibular migraine. This is a genetic disorder. So I don't want anyone to feel completely distraught or depressed that this is a chronic medical condition, instead, that's to empower you to understand, nothing I do is going to take this away entirely, but everything I can do can help to manage this over time. So to try and reframe that because I think a lot of people want to get rid of this entirely. And that's going to be an exercise in futility. And that's actually going to have increase your symptoms over time. It's going to make you feel much worse, lose a lot of functionality. So first, we have to reframe that this is a chronic medical condition.

That being said, we have great success rate with vestibular migraine in terms of managing symptoms. So the vast majority of patients will be able to find a regimen that decreases their overall severity and frequency of attacks by at least 50%. So I first start there. Our goal, you and I, is to get a 50% reduction in our overall symptoms, but I have a lot of confidence that we

might be able to do even more than that. So consider this a period that we're trying to figure out what your regimen is. And so work with me for three to six months while we figure out what your regimen is. And then that should help to get things under much better control so that you are independent and can function and do everything you need to do and want to do with these tools now in your tool belt.

DR. ABBIE ROSS: I like that. Another symptom that is often associated with vestibular dysfunction, and it reminds me of the conversation you spoke about with bandwidth and brain fog, how does fatigue play a role?

DR. KRISTEN STEENERSON: Yup. Very similar conversation as to the cognitive dysfunction and brain fog. So we know that fatigue, this is a high energy requirement activity for your brain to go through. So many people will feel fatigue before their vestibular migraine attack because we have a prodrome period where our brain is starting to go through the dysfunction of migraine. So it figures out, uh-oh, you need to reduce your activity because you've got a big thing you're about to go through. But then we'll also get a postdrome, so the after effects of going through migraine, where you did go through this huge metabolic requirement of an event, and now your brain has to recover.

Well, depending on how frequently you're having vestibular migraine attacks or how long they are, that's going to cause a significant energy deficit overall because it just requires a lot of energy. But there's also a psychological fatigue that happens too. Some people feel helplessness. They'll feel like their life is unpredictable. How can I plan anything because these attacks come on unexpectedly? And so that will create a psychological fatigue that can feel exactly like a physical fatigue because you've lost control of your environment, you've lost control of your life.

So we'll see a combination of those two working together. And then common sense thing that happens, if there's a lot of motion sensitivity, people aren't

moving as much. If we don't move as much, we get deconditioned. So we lose a lot of our cardiovascular, but also other types of physical endurance that can contribute to fatigue.

So we'll see fatigue from several different directions that will all combine to have a significant impact on levels of fatigue. So we really have to focus on your prevention plan to do everything we can to reduce your overall fatigue burden.

DR. DANIELLE TOLMAN: I'm seeing some of these questions sprinkled throughout the chat on different types of complementary or alternative approaches to medication. So could you maybe speak to some of the approaches that patients might benefit from, whether it's neuromodulation, or supplements, or Botox, what exists in the field out there that helps address central symptoms?

DR. KRISTEN STEENERSON: So in terms of specific vestibular migraine research, it's still quite small that is available. So we've extrapolated a lot of migraine headache research into vestibular migraine treatment plans. So along those lines, we will use nutraceuticals or supplements that have been used in migraine headaches really often. There is finally a paper published just last year that showed that over 50% of people with vestibular migraine, when put on a migraine headache vitamin regimen, had a reduction in their symptoms. So it does seem like the extrapolation is reasonable because we have at least one study showing that very similar results in vestibular migraine.

So along the nutraceutical lines, we usually recommend things like magnesium, B2, coenzyme Q10 for reasons that one, they're well tolerated, and two, they seem safe. There's a lot of caveats, though, when it comes to supplements. We have no FDA regulation or no oversight when it comes to supplements, so buyer, beware. There's a really interesting article out of The New York Times that showed some supplements might just be carrot dust,

or they might be sawdust, or they might be something totally different, because as long as they're not technically dangerous, they can give you any type of food supplement.

So we have to be a little bit careful and cautious and hopefully, look for what's known as a third party certifier, a separate company that evaluates the vitamin to confirm it is what they say it is. That being said, many people just feel more comfortable taking vitamins. So I have to warn them, make sure you're doing your due diligence. But unfortunately, there's no greater regulatory body that can confirm this, unlike prescription medications, where we have a really intense regulatory body that helps to make sure everything you take is safe. That is not applied to vitamins and supplements. But there probably is a role for them. They can be helpful, as long as, hopefully, you're getting a good source of the vitamins.

There are a few safety concerns with vitamins. So coenzyme Q10 may interact with blood thinners. So you want to be really careful if you're on blood thinner medications. And then any vitamin might have B vitamins. B vitamins are really cheap, so they'll add them in, sometimes, especially, B2, if you're taking a B complex. And some B vitamins like B6 can actually cause toxicity, if you get too much of it. And that can cause peripheral neuropathy. It can cause cognitive symptoms. It can cause pain. So we want to be really judicious with supplement use and make sure that if you are taking supplements, there is a reason, and hopefully, a trusted company behind every single one that you take.

There might be a role for acupuncture and acupressure. That also is evolving. We have headache research that indicates it's probably helpful in targeting the cervical spinal muscle groups and the upper shoulder back muscle groups. But there might be some specific acupressure points for vestibular areas in particular, still need research there, but that's something

that's generally very safe. So many patients might consider trying that out as well.

DR. ABBIE ROSS: And now I'm going to go to my medicine cabinet and check all my supplements. [LAUGHS] There's two questions I have. We've talked about how stressful events can trigger vestibular dysfunction or these types of diagnoses. What about COVID and also pregnancy? Can you touch on both of those?

DR. KRISTEN STEENERSON: Absolutely. COVID has been a really big challenge for everyone. But in particular, we know that COVID is a really challenging medical diagnosis to have for so many reasons. It's just a really high stressor to your body, physically speaking. There also might be a harder response or recovery time for some people after the fact. But I try and generalize it more that for vestibular migraine, any stressor that you go through, that is a potential threshold lower. So that's an opportunity for the brain to get distracted because it has to heal, it has to recover from something else, that means that you're going to be a little bit more vulnerable.

So we've had a lot of occurrence of people noticing that either they get first vestibular migraine after the fact or their vestibular migraine, which is previously well-controlled, is now much more severe. The good news is for those exacerbations, they're usually transient, meaning, they usually last for a few weeks to a few months, and then will calm down. And that, I think, is just the natural recovery of that threshold over time so that you can get back to your normal baseline.

Pregnancy and estrogen, in general, is super interesting in migraine. And that could be a whole other hour. But just really briefly, there's a well-described pattern that as estrogen drops, our serotonin levels in the brain might be affected. And that's why we might see so many other nervous system

changes. So we might see mood disorders like anxiety and depression. We also see changes in migraine.

So there's this really important change that as we start menstruation as women, that painful migraine headaches are much more likely to start up. And then as we start to lose estrogen, then our painful migraine headaches might transition to vestibular migraines. And we think it's because of that change in serotonin presence in the central nervous system that you might now have more motion problems instead of pain problems.

Not everyone has that. Some people are unlucky and continue to have the headaches and get the motion problem, but there's clearly a connection for a lot of people with those estrogen withdrawals. And that might be a reason that we see changes around periods too that you might become more sensitive.

So for pregnancy, the most-- majority of people actually have improvement of their migraine symptoms. But majority, I mean, 2/3. So there's 1/3 of people that might have worsening of their migraine or just continuation of their migraine. And it's probably because not everyone has this estrogen sensitivity but those that do might notice actually an improvement in their pregnancy. But that means that the opposite is true too that postpartum, you might notice an exacerbation in those first two to three months can be really challenging.

DR. DANIELLE TOLMAN: There has been so much covered in this last hour that I want this played on repeat for every single one of my patients and everyone who comes to see me in the future because you hit on, I think, everything that I was hoping we'd cover today and then some. We thank you so, so much for joining us today and for really kicking off this conference on a really high note. We feel extremely lucky. And we're so excited to have you here and share all of your knowledge.

So now we are going to switch gears and pass this over to our patient panel hosted by Heather Davies and Patrick Parkinson. Hey, Heather. Hey, Patrick.

HEATHER DAVIES: Hi.

DR. ABBIE ROSS: Well, what'd you think?

HEATHER DAVIES: Oh, my goodness. What a great start.

DR. ABBIE ROSS: No, it's so exciting. Day one, great topic. We're going to hand the baton off to you. I hope you guys have a great session.

HEATHER DAVIES: Thank you.

PATRICK PARKINSON: Sounds good.

HEATHER DAVIES: Awesome. Hey, Patrick. I guess we're bringing--

PATRICK PARKINSON: Hi, Heather. Good to see you.

HEATHER DAVIES: You too. I guess we're going to be bringing in the panelists in just a moment. For those of you that don't know me, I'm Heather Davies. I host the Meniere's Muse Podcast. And I was diagnosed with Meniere's disease and vestibular migraine in 2016 and 2017. And I am so excited to be here with Patrick, moderating this year's Life Rebalanced.

PATRICK PARKINSON: Yeah, definitely. Thank you, Heather. And I'll introduce myself real quick. My name is Patrick Parkinson. And I've lived with Meniere's disease for just under 20 years now. I'm also a VeDA ambassador and the owner of My Meniere's Coach, which helps people living with Meniere's and other vestibular conditions find and address hidden causes that may be contributing to their symptoms, and really helping people build a personal plan to address many of the lifestyle factors that Dr. Steenerson just mentioned herself so eloquently. So happy to be here.

HEATHER DAVIES: Yay. Awesome.

PATRICK PARKINSON: And yeah, throughout this, I'll be keeping track of questions here and relaying them on to the group. And I'll do my best to make sure that I hit on everything or hit on as many as I can.

HEATHER DAVIES: [LAUGHS] Awesome. Awesome. Awesome. So are we still waiting on Brian and Darilys? Oh, there's Brian. Hi, guys. Darilys, can you tell me, first off, before we start, how to say your name?

DARILYS: Darilys.

HEATHER DAVIES: Darilys. Beautiful. Beautiful. Well, I'll pass this on to you first, Brian. Can you tell us briefly about your vestibular journey? And how did you find out that you had a central vestibular problem?

BRIAN PLATZER: Yeah, sure thing. About eight, nine years ago now, I smoked pot with my wife. I'd never been a big drugs guy but I smoked once in a while in undergraduate. And then I was dizzy for that whole day and not really concerned yet. And then I kept on being dizzy for that week or so. And during that week, I made some appointments with various ENTs and vestibular testing places. The original dizziness subsided. But then when I had that caloric intake test where they put water in your ear, and that triggered it for another year or so.

So I-- the test set me off. I initially thought it might be Meniere's. That was ruled out. I was then diagnosed with vestibular migraine. We eventually got that under control with Klonopin and an SSRI, but I was having really bad nightmares. So the doctor, six months in, tried to start cutting me down on the amount of medication I was taking. I was on Topamax at that point. And we went down 50% and 75%. And then I tried getting off of it, at which point, the symptoms came back dramatically, that imbalance, and brain fog, and inability to function, to work, to be alone with my kids, et cetera.

And once I went off that Topamax, I couldn't get back on it. I tried going back on the Topamax. I tried the SSRI. I tried all the other medications. And it was a full year and a half where I was pretty much completely incapacitated.

During that year and a half, I wrote a couple articles for The New York Times about it and received a whole bunch of suggestions. And we can get on-- get into this later on, if you'd like. But I tried them all. It was a really, really hard year and a half or two years, where nothing was working until a doctor sent me to the Mayo Clinic, where I had a full workup in Minnesota, was re-diagnosed with PPPD, was put on a combination of verapamil, Zoloft, and Xanax. And since then, I've been able to have a good five, six hours of clarity per day, where I'm able to get up and get my kids to school and do a few hours of work. And then starting in the early afternoon, it begins to get increasingly difficult for me again until I rest up enough to be able to parent my kids to bed. And then I wake up. And I'd do it all again.

HEATHER DAVIES: Right. Well, I know it is tough. I know a lot of people can relate with that. So well, I can't wait to dive into more of your story. Darilys, would you mind telling us briefly about your vestibular journey and how you found out you had a central vestibular problem?

DARILYS: Well, I spent about two years and a half, undiagnosed, going through it. So I was one of those people that it took me a long time to get a diagnosis and jumping from PCP to oto specialist and a lot of doctors that did not know anything about vestibular disorders, and a lot of tests that came back normal, which is, again, what helps you get the diagnosis in the end.

But yeah, finally, after me asking for the test and the referrals, I got oto-neurologist. I got an oto-neurologist to diagnose me with vestibular and PPPD last April I think it was. Yeah, last April. But then he did not take me on as a patient.

HEATHER DAVIES: Interesting.

DARILYS: I know. Yeah. He had favorites. He preferred the structural kind of vestibular disorders to treat. Yes. So he just left me with a diagnosis and off you go. But that at least gave me an answer of where to look. And that led me to VeDA. And then VeDA opened up the doors for me to find, finally, a specialist who would treat me.

HEATHER DAVIES: No, that's great. Great. Great. Great. Brian, what types of health care specialists did you see along the way?

BRIAN PLATZER: I saw every type, I think. I began with my primary care physician who similarly said, it'll go away. Don't worry about it. And then from there, ENTs. And from there, psychologists and psychopharmacologists and all sorts of eye doctors and other doctors who took blood and prescribed diets because of it. But I really went through every possible both Western medicine and holistic option I could find. I did full diet changes where I eliminated pretty much everything other than white rice and baked chicken and salmon from my diet. I did acupuncture. I did chiropractics. I saw an herbalist, craniosacral massage. I took supplements. I did all of it. And none of it worked.

So I went back to Western medicine and finally, found the cocktail of medications that have been able to mitigate the symptoms to some degree. But yeah, it was a full two years of cycling through a lot of-- a lot of folks who saw me, who promised they'd be able to help, and then who weren't able to. And that's been a difficult and fascinating aspect of the experience, I think, so many people who have versions of what we have, where there's some promised enthusiasm and optimism which then gets eventually, disappointed or hopefully not.

HEATHER DAVIES: Yeah. It's so crazy how similar a lot of our symptoms are and then different treatments for different people. I love that you went to

craniosacral therapy. I know Patrick and I have talked about that. There's a lot of different therapies that work for one person and don't necessarily work for another. But you got to keep trying.

And what about you, Darilys, what treatment options did you try? And what worked for you and what didn't?

DARILYS: As for treatment options, I started vitamins and supplements first on my own, just because I started treating myself with the victory over migraine book, not just because I was recommended that before I was able to find a specialist and that was what I could get. Magnesium and the B2 vitamins, I noticed made a big difference for me. And just the intensity of the dizziness.

And then once I found a specialist, I am on Topamax. And that has-- it's really-- it's helped me to-- it got rid of a lot of the symptoms that I initially thought was like-- when it was at its worst, I thought it was one-- I called it one big monster. And once I got on that medication, I realized, it was just a lot of symptoms at the same time. It wasn't until I started taking that, I noticed when some of them started going down, that they were separate things. And some of them went away and others have stayed but at a lower intensity.

So right now, I'm only left with the PPPDs, like the ongoing vertigo, but mostly, I have my baseline. And it's triggered by-- everybody has their triggers. And everybody has other symptoms.

HEATHER DAVIES: Right. Well, before we go into the symptoms, Patrick, how's that Q&A? Anybody asking anything, want to know anything of Brian or Darilys?

PATRICK PARKINSON: No, I haven't seen any new questions specifically.

HEATHER DAVIES: OK. That's all right.

PATRICK PARKINSON: A lot of comments on-- I think-- I mean, both of you, what stands out to me is just, I mean, the amount of things that you've tried. And as it patient, it can be so overwhelming to say like, where do I even start with all of this? And you continue going down the checklist. Maybe some things provide a little bit of short term relief, but they don't really get you where you need to be or maybe they just don't work at all.

But what I'm hearing on both of your cases is that you continue pressing forward with that attitude that at some point, I'm going to find something that works for my unique situation. So just applaud you for both of that. And just calling out the level of challenge that clients are or that new patients are faced with.

DARILYS: Yeah, my last try has been, since last year, PRT. I don't know if you guys have heard about that one. That's been working pretty well for me. It's got me a lot more progress. And I'm continuing with that, along with the medications.

HEATHER DAVIES: And you've been doing that for about a year, you said, the PRT?

DARILYS: I started in last August. So not a year yet but maybe around, what, six months or so.

HEATHER DAVIES: That's great. That's great. Well, Brian, how about you? What are some of your symptom triggers?

BRIAN PLATZER: So I find that anything that disrupts my regular routine makes things more difficult. So lack of sleep definitely does. That'll be difficult the following day. I find lack of control over my environment. I-- definitely, my two largest triggers are my two-- my 8 and 10-year-old sons, who combine the combination of everything that is triggering. It's like, they're moving around physically, which is difficult for me to see. They're physically pulling on my body, which is disorienting.

It's also emotional instability, I find very difficult, whether it's anxiety or uncertainty that leads to more triggers. But also little things. I find reading out loud, for some reason, makes me real dizzy, longer conversations, talking on the phone. There's something about a-- when I'm projecting even in a conversation like this leads to triggers.

And then there's the typical walking through supermarkets or busy aisles or bright lights or uncontrolled sounds. But any of the-- anything that takes me out of my regular routine or what's to be expected, I find, leads to a severity of symptoms more quickly.

HEATHER DAVIES: And you as well, Darilys.

DARILYS: Yes, for triggers, similar to what Brian said, visual vertigo triggers that encompasses that visual stimuli of either fluorescent lights, just complex patterns that you find in supermarkets, for example.

Sounds, I have a lot of sound sensitivity. It tends to be more towards high pitches, I've noticed. And it's funny because when everything-- when I can't-- the catalyst for my vestibular migraine and PPPD was like construction work near work for like a week. And then that's when everything happen for me.

And yeah, stress and anxiety, definitely, are very big triggers for me or just I have a lot of emotional triggers. And that could be interesting just because it could be good or bad. I don't know. It could be super excited about something, and it's good, but my emotions are really high up or that I could feel like dizziness go up a bit.

And yeah, the-- I have set myself a sleep routine because that really, really helps me. And if I veer out of that for whatever reason or I have a bad night, I could definitely feel it. So sleep is very important in these kind of things.

HEATHER DAVIES: Yes. I love that you said that stress, the good and the bad, both affect you. I'm the same way. If I'm excited about something, I've got to keep it on the-- I keep it down a little bit or my symptoms do flare as well. And I'm sure a lot of people can relate with that.

So here, the questions are now coming in, Patrick. Do you have anything for us?

PATRICK PARKINSON: Questions are starting to come in, yes.

HEATHER DAVIES: Yey.

PATRICK PARKINSON: And yeah, on the topic of triggers, one that I saw coming up before-- a lot of questions I saw coming up before were around things like travel and driving. Is that something that you two could speak of a little bit and whether you struggle with travel during-- or when you have symptoms? And what you can do to help mitigate that?

HEATHER DAVIES: Brian, do you travel at all?

BRIAN PLATZER: Sure. Yeah. No, I dread travel, which is a shame because I love travel. So it's that the-- so many aspects of travel are triggering, from the trip to the airport, and then the fluorescent lights and the noise of the airport, and then the altitude within the plane and the tight quarters and the frenetic moving back and forth. But also any travel with-- to other time zones resets the medical clock in odd ways, where medicine-- the time gets truncated or expanded. And it ends up taking me a few days to get back to the standard feeling. So I find travel to be very difficult.

Driving a car, I can do, but it definitely is fatiguing neurologically and unsettling in terms of the imbalance. I find-- I live in New York. I find subways are the best way for me. But in terms of air travel, it's really frustrating because it's one of the-- one of the great pleasures adds an

element of anxiety and fear to it, just that I won't be able to be myself on a vacation or for work or for whatever it is for my family.

HEATHER DAVIES: Yeah, definitely challenging. It does have its challenges. And what about you, Darilys? Do you do any traveling?

DARILYS: Yes. Actually, I'm outside of my state right now. I had to travel for work. So this is-- I'm taking the conference-- I had to-- it's my first travel that was for work. So I was nervous about this one because it was a bit more out of my control. But before that, I had already traveled a few times for vacation, to visit just family. So I tried vacation to places that just brought me comfort.

And I just-- the first time was the only time that was harder because I didn't know what to expect. But I did prepare myself with-- I mean, VeDA gave a lot of-- a lot of articles and support groups, helped me out a lot with how to prepare myself. And I just went just extra prepared with my medication toolkit. I-- my routine is I have my earplugs in as soon as I get out of the car to get into the airport, before I go in. And I wear my-- the glasses that their specs that I use. But I use-- inside the airport, I use the outside ones for extra with all the lights. And I always use the wheelchair assistance, because if not, I won't make it to the gate.

So that gets me through-- because for me, all the triggers are there. It's basically the airport. I don't have an issue with the plane itself. So it's getting out of that crazy part of the airport. So I get the-- I get in the wheelchair. They get me quick wheel me out, past the security.

HEATHER DAVIES: It's nice. I've had to do that before. And I was nervous about it the first time. But we went right to the front of the line and right to the airplane.

DARILYS: Yeah. And then once you're-- once they-- at least, I-- they leave me at the gate . And over there, it's like, everybody's sitting down because

they're just waiting for the plane. It's less people. So it-- there's none of that crowd that everybody's walking around, running with their suitcases. So I don't get the visual vertigo triggers there and none of the sound triggers there because everybody's just relaxing and waiting.

And then for the airplane earbuds to just listen to something the whole way, and then again, the wheelchair out. And then I just plan just schedule myself some relaxing time for after-- to rest and recover from it, from that. And that usually helps.

And after that first time, and knowing what to expect, that takes away the anxiety stress factor. And that helps like other trips that I had.

HEATHER DAVIES: Great.

PATRICK PARKINSON: So--

HEATHER DAVIES: Patrick.

PATRICK PARKINSON: So Darilys, yeah, you mentioned, it sounds like you try to do a lot of preventative stuff up front to help deal with potential attacks that may come on later on. One of the questions that I'm getting a lot here is, what do you do when in the event that you do feel a symptom flare coming on? Is that something that you two could elaborate on? And Darilys, you can chime in first if you'd like.

DARILYS: Yeah. Well, it depends on the level. But I've done meditation. If I could switch from the earplugs to the earbuds and put meditation on, if it's-- if I think it's more like anxiety kind of thing on to do some breathwork, that helps me. If I-- back then, when it was-- my first flight, I used to have a rescue med that used to help, but that's more like if it's really intense. And it's-- no turning back. That's a last minute resort. But I would usually try other things first before that to tone things down. But--

HEATHER DAVIES: And what about you, Brian?

BRIAN PLATZER: I mean, I've struggled speaking with a vocabulary of flare ups because my symptoms are so constant and steady that it's more slight shifts to the worse. And once I start shifting to the worse, it pretty much takes the rest of the day where I know I'm going to be going to be bad. And then I hope that the nighttime is enough of a reset to get me back to something closer to baseline in the morning.

So I have, I think, become somewhat better over the years and not adding anxiety and frustration and anger to the feeling of-- feeling worse in that moment, where especially in the first few months dealing with it, I would double the suffering just because I would feel like, Oh, no, it's coming on. And like, Oh, today is the day where I have to do this. And now the whole rest of the day is going to be ruined. And I thought I was going to look forward to this, but I won't even be able to do it. And that would increase the symptoms as well as the anxiety.

So I've tried to come to terms with the fact that, today is going to be one of those painful, awful days. And hopefully, it'll only be a day or two as opposed to more than that. But I think that it's-- I didn't mean this to be as depressing an answer as I realize it's sounding now. There is some--

HEATHER DAVIES: It's real. That's all part of this, believe me.

BRIAN PLATZER: And that's the thing--

HEATHER DAVIES: Believe me, we understand.

BRIAN PLATZER: --that leads to solace in just understanding that the chronic nature of the condition is that-- the expectation is that life will be hard, but trying not to punish myself for then enduring the hard day or month. Month is too long, but day or a few days has let me at least relax a little bit and come to terms with the fact that this is the life I'm living as opposed to constantly being disappointed.

I remember in the beginning, constantly checking, am I feeling a little bit better? Am I feeling-- is it coming? And I would like close one eye and then open the other, and see whether there would be some fuzziness or some haze. And if it was a little bit less, I would say like, OK, maybe I'm on the right trajectory. I think just a little bit more of realizing that it'll slowly get worse and then hopefully, better, and not worth the constant verification and checking and all of that has, at least, let me settle into a more stable routinized behavior.

PATRICK PARKINSON: Yeah, I find that approach so important because the natural instinct wired this way is to want to control the symptoms. And that's what I spent the first, I mean, decade plus, really trying to control all the symptoms when they came up. As soon as I got stressed, I was like, Oh, I need to-- I need to figure this out. I need to-- but to Dr. Steenerson, when she was saying earlier, that just hypes us all up and gets our system even more on high alert. So--

BRIAN PLATZER: For sure. I got something--

PATRICK PARKINSON: I agree, that kind of allowance helped me as well. Go ahead, Brian.

BRIAN PLATZER: I completely agree. And just something related to this, if not exactly the same thing, is how to discuss and perform one's suffering in front of other people, where in the beginning, it felt just so lonely and so infuriating that I think I had an instinct to always want other people to know the extent to which I was suffering. And I-- especially because of the invisible nature, sometimes, of what we're all dealing with. It can feel like the people-- from loved ones to strangers, there's a continuum, but there's that sense of just like in the beginning, I just desperately needed everyone to know how hard life is at all times.

And there still is that equation of how to articulate, and how to explain it, and how often to and what situations and all of that. But I do feel less of a need to make other people aware of how difficult life is all of the time because I felt that that-- I think in the beginning that I was incorrectly thinking that that could limit some of the loneliness or some of the desperation. But now, trying to suppress the need to perform my suffering, I think, has helped me-- yeah, I think has helped me get out of the cycle of anxiety that you're discussing, Patrick.

HEATHER DAVIES: Yeah.

PATRICK PARKINSON: Sure. Sure. Yeah, but that--

DARILYS: Yeah, that mindset shift that Brian and Patrick were talking about of not trying to control the symptoms. How you're always feeling is really-- it's definitely true. That really-- it helped me too once I made that switch because I was-- again, I was like that too.

And I had-- my doctor had this tracker in an app that I always had to daily track my symptoms and how high they were. And that was supposed to help me. And I did it for so long until I noticed how it was impacting me. And I'm like, this is making me feel worse, it's-- because I'm constantly, again, throughout the day, checking how bad is it. It's making me constantly aware of it.

And I finally said, you know what? I'm like, I'm not doing this part anymore. I think it's making me worse. And ever since I stopped, again, it was that shift in mindset of like, I'm not-- it's always there, but I'm not going to give it that attention like that anymore. And it feels a lot better. It's not as intense anymore as back then. And it's really helpful.

HEATHER DAVIES: It takes a lot of practice, doesn't it? [LAUGHS]

DARILYS: Yeah, it wasn't overnight. It's--

HEATHER DAVIES: No.

DARILYS: --a lot of work.

BRIAN PLATZER: And for anyone listening out there, I definitely haven't mastered it. There are a lot of-- every day, there's a moment where I am furious and then trying to calm myself down. But I think the mindset of acknowledging and moving on even through the anxiety, or fury, or disappointment, or whatever emotion one feels is healthier than the spinning down into the self-pity of it.

HEATHER DAVIES: Right.

PATRICK PARKINSON: Absolutely. Thanks so much for chiming in on that. I know that that's a hot question for a lot of people.

HEATHER DAVIES: Yes.

PATRICK PARKINSON: Yeah. And acknowledging that frustration, that's natural too. We have a right to be frustrated and allowing those emotions as well. So anyways, thanks for the insight.

HEATHER DAVIES: Well, while we're talking about lifestyle changes, because this is definitely a lifestyle change having a vestibular disorder, what has been most helpful for you finding your new-- and I know it's overused, new normal? Brian, what has been most helpful for you?

BRIAN PLATZER: Yeah, I've found that what's most helpful for me is articulating the boundaries to those around me, to the extent where they could understand it. Where, I think, what was really awful was pretending that it-- that I could push my way through it or that it wasn't a big deal.

I just tell my friends, I would love to see you but I can't have dinner at a restaurant starting at 8 o'clock because I'll be miserable the whole time. And then the next day, I'll have to be in bed. And instead, initially, again, I would

be in that mindset where I'd say like, how about lunch? And they'll say, well, no, we don't want to do that. And say, all right, 6 o'clock would be better. And they'll say like, what do you mean? What--

So just like-- just articulating exactly what I can endure versus what I can't has been incredibly helpful. And that's within my family, telling my-- the fact that my eight-year-old knows now that if it's a birthday party at a loud bouncy ball VR bowling alley place, he knows I won't be able to attend that. So we would have to go with a friend.

And just explaining-- and at work, I teach and telling the head of my department that I need a break between classes in order to find some equilibrium again. I just find, the more honest and explicit I can be about what I need, and the less I feel shame or pretending I'm not dealing with something severe, the easier life has become.

And it was difficult, initially, too because so few people really understand it. And they say, Oh, yeah, my aunt was dizzy. She drank water. Have you tried drinking water? That made her feel-- everyone has-- the word dizziness doesn't have the severity to most people as it does in our lives, but just being more confident to be explicit about exactly what parameters within which I could live was definitely the--

HEATHER DAVIES: Yeah, I love that.

BRIAN PLATZER: --the best thing.

HEATHER DAVIES: The boundaries are huge.

BRIAN PLATZER: Yeah.

HEATHER DAVIES: Yeah. And how about you, Darilys, what lifestyle changes have been most helpful for you?

DARILYS: Yeah, definitely, sleep was a big one. I never had-- I never--

HEATHER DAVIES: Did you say sleep?

DARILYS: Yes, sleep was--

HEATHER DAVIES: Sleep.

DARILYS: --a big one. I never had a, quote unquote, "curfew" before for myself. And I was-- I always weirdly suffered from insomnia before. It's not until I started taking those vitamins and supplements. I don't know what the connection was. I don't know if it was because I did it together with the sleep routine and I started taking the vitamins and supplements at the same time. But when I started that, it was like the first time I ever slept through the night. And it's been a lot better ever since.

HEATHER DAVIES: May I ask, have you ever had a sleep study or anything like that?

DARILYS: I had not.

HEATHER DAVIES: I know you mentioned sleep a couple of times.

DARILYS: I had not. And I had actually thought about having it done a long time, but it's just since-- I didn't do it just because it went away after I did that. And I'm like, if I had known, all I needed was like vitamins and a sleep routine, I would have done it a long time ago. But that was a big change for me because it does need-- like Brian has mentioned, you need to stick to it. And for this condition, every-- an hour later, a couple hours later, it makes a big difference.

And I also agreed with him in terms of boundaries was also something that, for the first time in my life, came up with this that I had to learn about them for, I think, the first time and learn how to apply them. And that-- it's also helped me just with also my stress and my anxiety triggers with this condition. But also just to not push-- again, not push myself. And it takes a lot of work because it's not something easy to do. People, again, like you

mentioned, don't understand, but it's something that we just have to do for ourselves.

And I don't know. I think it's taking me a lot to get to this point. I know a lot of people are not quite in the grateful stage of this condition because it is horrible, but it has made me grow a lot. And it took me a long time to get to this stage.

If you had asked me that even just maybe seven months ago, I would not have been happy with that because I would have been in the-- just in a different mindset than I am right now and would have been thinking, it's the worst thing that ever happened to me. And-- but--

HEATHER DAVIES: Do you find that flexibility-- having flexibility in your current life, in your day to day has helped also? I mean, I find that huge. I have to be really willing to listen to my body and adjust my schedule through the day. Do you guys find that?

DARILYS: I don't have a-- I'm still working so I don't have as much flexibility. Luckily, I have-- I've had the opportunity to had somebody at work who understands and I can get off work early if things are too bad so that has helped-- that has been helpful throughout this. But-- and in my off time, that is something that I definitely do have to do. I was very much a planner type person that scheduled everything down to-- and-- yeah. And now I just-- I'm more like, if it happens, it happens. If not, this is room to see how it goes, and if not, then it's all right. So it definitely changed me.

BRIAN PLATZER: Yeah, I find that I need to have downtime scheduled into each day, which is a luxury I have, based on how I've created the architecture of my professional life. So I have a couple hours in the early afternoon most days, where I'll be able to try to recuperate a little bit. Ironically, it means that weekends are really hard because I'm with my kids all weekend and I don't have that same break. So during the work week, I'm

able to schedule things out where I have some of that time. But the lack of flexibility that comes with parenting makes it incredibly difficult. And I can't disappear or I can't schedule time away to the same extent. So it's a challenge.

HEATHER DAVIES: Did you have a question, Patrick? Sorry.

PATRICK PARKINSON: Yeah, one question that came up here, and both of you, Darilys and Brian, you mentioned the need to set boundaries with people and advocate for yourself, especially in things-- in places like work. And one of the questions is around, how do you do that when people don't really understand your condition, they can't really see what you're going through? Do you all have any specific tips for what helped with that?

BRIAN PLATZER: It's funny, I've been thinking a lot about this lately because I find that when I try to tell people my symptoms in an honest, straightforward way, they don't understand and it feels less significant or they don't-- words like "Brain fog" or "Disequilibrium," it just doesn't resonate. So I find I have these shorthand ways of trying to explain it to people, which is, sometimes, a lie and sometimes, true. But I'll say like, when things are tough, I lose all vision in my right eye, which is sometimes, the case. And people understand what it means that you can't see out of one eye and how disorienting that will be. Or I'll say like, if I-- I'm nervous about standing up right now because I think I might fall over, even if it's not the case. And I-- it's-- I mean, I guess, the answer to your question, what do you do? You lie to make people understand is the honest answer.

I try to get something relatively close to what I'm feeling and say it in such a way that a normal human being will understand the-- just how hard life is. So it ends up going to, I just can't see right now. My vision is blurred. Or I'm scared if I stand up, I won't be able to maintain that. Even if that's not exactly right, I just-- it's a shorthand to try to explain to a colleague or a supervisor

or a cousin who's in a bad mood, just like, it's not that I don't want to go out with your kid to play in the park, it's that if I do, I might fall over.

And I find that that-- it's, again, a little lonely and very frustrating, but at least, that's a general vocabulary that the whole world can say like, Oh, that is really bad, as opposed to the subtleties of how we all experience the highs and lows of various brain and inner ear tricks, which I think are very complicated to figure out a way to explain with any degree of specificity that can be understood.

PATRICK PARKINSON: True. True. Thank you. Yeah, you're bridging that gap, which makes perfect sense.

HEATHER DAVIES: Darilys, you're at a work conference right now. How-- can you share how your employer does-- do they know about your vestibular migraine? And any-- did they make accommodations for you?

DARILYS: Yes. So yeah, my employers know and-- but they-- employers are the only ones that know. And I don't typically share, at work, more than that because like we talked about, not many people understand. Luckily, one of my employers has more of an understanding with them, so I got just lucky with that. And so yeah, so they just understand a bit more about that.

But yeah, so they-- when I need a bit more-- when I need to go early, when things are a bit more bad for me, then I can, and things like that. But as to the other question with sharing with colleagues or people, I just leave it as-- since again, the language of them not understanding, I leave it as I have a vestibular condition or a vestibular neurological condition because again, we all know this that as soon as you say vestibular migraine, they think it's headache. Sometimes, I say a balance disorder, just-- it really depends.

And sometimes, I have my walking poles, sometimes, I don't. It really depends on the day. But I try to say less. And if it's extended family, I may say like, if you really want to know more, we can talk about it. You can ask

me questions. But otherwise, I just leave it at less is more. Because a lot of the times, people don't really-- they're just asking to ask. And the more you try to help them understand with the language that we know but they don't understand, they'll just--

I think, at some point, we give up. And it's more frustrating for us to try and explain, so I just don't. But I am willing to say that if you truly do want to understand, then come talk to me. And the ones that are actually sincere in wanting to know, those do actually call back and want to talk to me about it.

HEATHER DAVIES: Yeah. And they can definitely tell a difference too.

DARILYS: Exactly. So--

HEATHER DAVIES: Darilys, are you wearing light-sensitive glasses?

DARILYS: Yes.

HEATHER DAVIES: All right. Can you tell us about those?

DARILYS: Yeah. I found out about these last year through the vestibular support groups. These are the indoor ones. They really help me with my light sensitivity. And especially for computers, like for this meeting and just in general, I use it almost every day. For work, especially, I use it. And it helps me-- or just with screens. So since I use also my phone a lot, then I just use it more. If I'm not going to use any screens and if I'm at home, then I don't need them.

And I have the outdoor ones also. I took about a day and a half of wearing them all day before I notice a drastic back then, like I-- my dizziness reduced so much that I felt it just from the-- you have this level always of how dizzy are you when it's PPPD because it's all the time that you notice those shifts in it. And a lot of people have talked about them. And I-- they're not the most budget-friendly so I was set on returning them. And as soon as I felt that, I'm like, OK, I'm going to-- I'm going to keep them. They're a good investment.

HEATHER DAVIES: And they're working. Yay. And you look sassy with them. That's so nice.

DARILYS: I got used to the color. They're not my favorite color. But now it's worth it if they make me feel better.

HEATHER DAVIES: Oh, good.

DARILYS: So--

HEATHER DAVIES: My goodness, we're coming up to the end. Can you believe it? Patrick, did you have any other questions before I ask our final one?

PATRICK PARKINSON: There are several questions. I just don't know if we have time to get to all of them today, but we've got the full week. So--

HEATHER DAVIES: The rest of the week, yeah.

PATRICK PARKINSON: --I'll be keeping track of these. And yeah, yeah, but I want to make sure you can wrap up, Heather.

HEATHER DAVIES: Sure. Sure. Well, Brian, what would you-- what would you tell someone starting out in their vestibular journey towards recovery?

BRIAN PLATZER: Yeah, I would tell people a few things. One is not to necessarily correlate the certainty with which a medical practitioner speaks with the confidence you should have in that medical practitioner. There are a lot of doctors from primary care all the way to the most prestigious brain people in the world, to acupuncturists, to herbalists, who will speak with certainty that they'll be able to be the magic cure. And that doesn't necessarily mean that they'll find the right answer.

So I just-- the self-advocacy piece, the need to, if it's not working for you, try to push forward. Ask if something can change. See if there are other practitioners out there. Just find the right doctor. Don't be embarrassed or

nervous or hesitant to try a different doctor if your doctor isn't working. Find the specialist. Travel for specialists, if necessary.

Just make it as full time a job as you have energy for because the big difference between the folks I know in our community who have found some relief and those who haven't are the ones who have given up due to despair and just said that this is my life and I'm going to sleep and drink my way through it, even if it increases symptoms versus those who keep on trying. So I know that's a little bit like rah, rah cheerleadery, but I do think it's important to say that those of us who do keep on trying and who keep on changing until they find a quality of life again are the ones who find a quality of life again. And it really is important.

The other side of it is not to underestimate the loneliness aspect of this, which I brought up a couple of times. But just like I don't think I realized that I was depressed until I-- it was pointed out to me. And I've seen a couple psychologists and therapists. Those who didn't understand chronic illnesses tended to be not very helpful. But when I found somebody who specialized in talking through what it meant, I was able to wrap my head around just a little bit better, what it means to try to live with a chronic condition.

So those would be the two main pieces of advice that I would have. One is just keep on trying things, keep on going. If you don't like your doctor, it's not your fault. Find a different doctor. If you need to, again, travel, or ask for recommendations, or keep on searching. Find a medical practitioner you like, who respects you, whom you trust. And two, don't undersell the psychological side of it because it can be incredibly devastating in ways that even when I was enduring the worst of it, I wasn't fully aware of.

HEATHER DAVIES: Right. And there's so much out there, especially with VeDA, with community groups, online, in person, then there's personal coaching therapists. There's so much out there that-- and you don't have to go through this alone. You just have to find your people and hold on to them.

[LAUGHS] But thank you so much, Brian. It's so true in so much of what you said. And Darilys, what would you like to share with someone who is just starting out in their vestibular journey?

DARILYS: I think, also similar to what Brian mentioned, don't give up. I think that's the main part. We start off, I think, at the worst. And again, we-- I think a lot of us fall into depression. I was one of them. The isolation, even if you have people around you, is real because they cannot understand what you're going through, only people that have similar conditions or maybe other chronic invisible illness can understand what you're going through. So the isolation and that despair is real.

And it-- falling into that trap of despair, this will be forever, especially when you can't get help, which, with the lack of awareness, it took me two years and a half to find a doctor who knew anything about vestibular disorders. And even then, it wouldn't-- I was like, Oh, finally, I found somebody. And they decided not to treat me. So I was like-- that sent me into a little bit of a downward spiral because I thought I finally had something and it got taken away from me. But it was still an answer. I got my diagnosis, which was very helpful.

And just-- I think what kind of gave me hope was that even when I was in a darker mind frame, I used that because I got so angry at all the doctors that dismissed me. And I was in that depression that I was thinking, these doctors don't care about what I'm going through. They don't care, as if I'm not worth anything. And I got so angry at one point that I'm like, but I am worth something. I know I am. So if I give up, I'm letting them win.

So I think that fueled me to keep trying and looking for other specialists because just out of spite-- out of spite, I was like, well, I'm not going to give up because I know that-- I know how much I'm worth. And I'm-- just to prove all of the ones who've not helped-- wanted to help me, that I'm going to find somebody who will.

And just-- I think even if what seems to be like the wrong reasons, as long as-- if it helps you, just don't give up on yourself and just try to remember how much your worth and just try to think about, I don't know, just self love and all of that. And in the midst of whatever you're going through, that it's going to be tough but it doesn't have to be-- you're not going to be in that black hole forever, that you can get out of it and things will get better. But you have to keep trying.

HEATHER DAVIES: That's perfect. And I'm very happy, Darilys, you didn't give up. We're happy that you're here. Thank you, guys, so much for sharing so much of your journey. Oh, my gosh, we could talk forever. What a great first day. Thank you, Brian, and Darilys, and Cynthia, and everyone behind the scenes.

BRIAN PLATZER: Thanks for the opportunity. This has been a wonderful conversation.

DARILYS: Thank you.

HEATHER DAVIES: Awesome. And as a reminder, you can purchase lifetime access to the recordings and transcripts of the 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 I also want to extend another thank you 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 wonderful conference.

HEATHER DAVIES: Thank you guys for joining us. We'll see you tomorrow.

PATRICK PARKINSON: Thank you all so much.