Life Rebalanced Live 2026

HOPE IN INNOVATION:
EMERGING THERAPIES FOR CHRONIC DIZZINESS

0:00:00.6 Abbie Ross: Good morning, afternoon, or evening, depending on where you're tuning in from today. And welcome to the first day of the Vestibular Disorders Association's sixth annual Life Rebalance Live. I'm Dr. Abbie Ross. I'm a Vestibular Physical Therapist, founder of Balancing Act Rehab and the Dizzy Reset, co-host of the podcast Talk Dizzy to Me, and a proud board member of VeDA. I'm so, so excited to be here with you all today to kick off this year's virtual conference. We have an awesome week ahead of us. I'd like to begin by thanking our sponsor who has made this event possible year after year. The James D. And Linda B. Hainlen Discovery Fund and the University of Minnesota's Department of Otolaryngology have generously supported Life Rebalance Live since its inception in 2020. A special shout-out to Jim Hainlen, who inspired this event by holding his own vestibular conference in 2018 and in 2019. Having experienced vestibular symptoms firsthand, 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 also to provide a platform where people can connect. Now I'd like to introduce my co-host, not only for this conference, but also on our Talk Dizzy to Me podcast, Vestibular Physical Therapist, Dr. Dani Tolman.

0:01:25.2 Danielle Tolman: Thank you, Abbie, and hello everyone. We also want to say thank you so much to all who have contributed to this conference in some way, including VeDA's donors, staff, and volunteers. With their contributions, we were able to put the live version of this conference on at no cost to our attendees. If you wish to gain lifetime access to the presentations following the live event this week, we will have them available for purchase for $65. Your financial support helps VeDA's continued mission to spread vestibular awareness.

0:02:01.8 Abbie Ross: And before we get started, I'd like to direct you to the poll questions for this session. So if you haven't already, please complete those now. Also, feel free to talk amongst yourselves in the chat and please put any questions you have for the speakers in the Q&A section, and we'll do our best to incorporate as many of those as we can.

0:02:20.3 Danielle Tolman: And just a little reminder, although you will be hearing from healthcare professionals today, none of the information presented should be taken as medical advice. Please consult with your healthcare provider before making any changes to your treatment protocol.

0:02:36.9 Abbie Ross: So today, on day one of this year's Life Rebalance Live, we're going to talk about innovation as it relates to vestibular care. Today's talk will focus on how innovation extends beyond devices, beyond drugs, to include new approaches in communication, education, and even social awareness that empower patients and clinicians alike. We'll gain insight into how today's research builds on the lessons of the past, where progress is being made in understanding and treating vestibular disorders, and how a spirit of curiosity and perseverance continues to drive the search for diagnostics and treatments to support people living with dizziness and imbalance.

0:03:18.8 Danielle Tolman: It's my pleasure to introduce our guest speakers, Dr. Sue Whitney and Dr. David Hale. Dr. Whitney is a professor in the departments of Physical Therapy and Otolaryngology at the University of

Pittsburgh. She is a prolific researcher, author, and one of the most prominent Vestibular Physical Therapists in the field. Dr. Hale is a fellowship-trained neurologist specializing in neurovisual and vestibular disorders and serves as the co-director of the Vestibular and Ocular Motor Otoneurology Clinical Fellowship at Johns Hopkins. Welcome, Dr. Whitney and Dr. Hale. So when we say innovation, it makes me think of words like new and progressive. Dr. Hale, how do you define innovation specifically in terms of vestibular care? Does it always mean new technology, or can it also involve new ways of thinking about patient care and rehabilitation?

0:04:14.5 David Hale: That's a really great question, Danielle. I think that innovation really does have a very broad definition that expands beyond our traditional ways of thinking of it. It doesn't mean just new technologies, it doesn't mean just new medications, but I think it involves new approaches to diagnoses as well as the way that we're teaching about them as well, especially from a clinical perspective. When I think of innovation, or innovation, I really think about refreshed perspectives on how we approach vestibular diagnoses, like working in a multidisciplinary team rather than in a siloed approach. I think about the new diagnostic criteria that we have that allow us to name diseases and then develop appropriate treatments for them, and also understanding the impacts that the vestibular diagnoses have on our patients in a psychosocial manner as well. And I think by focusing on all of these thoughts as well, we can still view this as an innovation. I'd really love to hear what Dr. Whitney has to say from the physical therapy perspective as well too.

0:05:29.3 Sue Whitney: Yeah. I think there's some really exciting things going on. For example, there was a recent paper that actually talked about why people don't do their exercises. Because as a physical therapist, my medicine is exercise, and that's what I ask people to do. But there was this key paper that came out of the UK, out of London... Not London but England, that actually described why people don't do exercises and what might motivate them to actually do them. So even that alone is something that's kind of exciting. And it's just asking people their perspective. So people on the call who live with dizziness are now being asked about their lived experience, which is very, very exciting. And that's really somewhat novel. We've even done an interesting study recently with people with mild brain injury or concussion. And one of the things that we've found is that... Because people normally ask people after a concussion and then they get dizziness, "Do you have ringing in the ears?" And often people will say yes. It's a pretty common thing. Well, what we've done is we've followed these people out six months as part of one of these physiotherapist dissertations. This is Rebecca. What she found was that people who have this ringing in the ear, it takes them longer to get better. So we're starting to ask more questions, we're starting to follow up and really learn more about the lived experience and are starting then to try and figure out if we can do something about these things early so that people don't have long-term consequences.

0:07:32.0 Abbie Ross: I love that you brought up lived experience because the second half of Life Rebalanced Live, we'll hear from people who have lived experience, and I think it is such an important part that helps us treat moving forward. How do we care for our patients? Well, often we learn best from our patients, so of course we want to hear from them. Let's talk about clinical practice guidelines a little bit and how they help translate research into real-world care by developing roadmaps for us to follow as clinicians. And for those who might be unfamiliar with clinical practice guidelines, how do they ensure that emerging treatments are both safe and evidence-based? And maybe, Dr. Whitney, we'll have you start to talk about clinical practice guidelines and what that means.

0:08:17.6 Sue Whitney: Sure. So clinical practice guidelines are really... I had somebody describe it to me: they're trying to take a 12-lane road and make it four lanes. It's not that you can't deviate a little bit, and it's not that there's only one way to do something, but it at least tries to get the variants, variations in care a little bit less. So if there's evidence that says that this works, hopefully people won't be over here trying treatments that aren't going to help you get any better. So that's really part of what clinical practice guidelines do. And I can still remember a patient of mine who came in recently and he said, "Well, I want to know why you're doing what you're doing, because the clinical practice guideline doesn't say that." And I got a little offended, of course, and I said, "Did you look at the authors on that clinical practice guideline?" And he said no. And I said, "Well, I helped write that document. I'm third author on that paper." And I said, "Here's the rationale for why I didn't do what's in that guideline." So even if it's in the guideline, it's not always necessarily the right intervention. At least it wasn't, in my opinion, the right thing for this man to do.

0:09:39.6 Sue Whitney: So we're all going to go off a little bit on these guidelines, but it gives us some rules. And what I think is especially helpful for people when you know that you're in an area where there isn't a Dr. Hale, a good neurologist to go to that's right around the corner, or there isn't somebody who's a highly experienced vestibular physiotherapist to see, someone who has less experience can pick up that clinical practice guideline and hopefully provide you with at least the beginning care that you need. And if that doesn't work, then you can find somebody who's more experienced. But just one other thing I want to say is that these guidelines are approved not just by, for example, for the guidelines I helped with the American Academy of Head and Neck Surgery's BPPV guideline, the benign, the loose crystal guideline, and also for the Vestibular Rehabilitation Treatment guideline, we included people not just who were physical therapists, but we included doctors who specialized in neurology and doctors who specialize in inner ear problems and audiologists. So these documents are not written just by one profession. They're usually written by many, and they all have to approve it. So it's kind of like in America we call it the good housekeeping stamp of approval. It's like, this is pretty good for just about everybody. And when you see those guidelines, that's really what they are, and I think they've improved care globally because they're often cited around the world.

0:11:23.0 Danielle Tolman: And maybe something similar to that, and I'm going to throw this over to you, Dr. Hale, but in therapy we have the clinical practice guidelines, and in a similar way, I feel like in the evaluation diagnostic side of things, we have those diagnostic criteria. Could you maybe talk a little bit about that, Dr. Hale? Hale, about what kind of that would look like from the evaluating and diagnosing side?

0:11:45.4 David Hale: Yeah, and I'll just echo that I think starting with clinical practice guidelines, it provides an immediate authority that people can look to for an answer in the same way that diagnostic criteria exist to help frame a thought process for a diagnosing clinician and sometimes then that leading to a treatment plan as well. It's important to know that we need diagnostic criteria to be able to provide a name for a disease so that we can correctly study and learn more about the patients who are experiencing those symptoms and group them appropriately based off of their diagnosis. The Bárány Society, or the International Society of Neuro-Otology, really provides a lot of very clear guidelines for many of the vestibular diagnoses that I use every day, and I know that we all are using every day in our practices to put patients into the right category, if not more than one. But just as Dr. Whitney said that clinical practice guidelines provide that rigid structure and guidelines for people to be understanding, a diagnostic criteria sometimes is showing the most average person to capture that person perfectly. So I always remind my patients that you may not check every single box 100% for this. And that's okay, because there are gonna be extremes on both ends of the spectrum where someone can still have symptoms that are similar to the most commonly described diagnoses, like vestibular migraine or persistent postural-perceptual dizziness, just as an example. And those overlap with so many of our vestibular diagnoses as well, which we don't have overlap diagnoses, but you could have more than one. And it starts off by providing the correct framework that we then can apply clinically. And the best part about that is once we start to apply these frameworks, we can track patterns over time and learn more and more about, well, maybe this treatment didn't work well because we didn't categorize the person in the correct way and didn't make the correct diagnosis in the first place.

0:14:08.6 Danielle Tolman: And similar to those clinical practice guidelines, would those diagnostic criteria potentially evolve over time or be updated as we have better understanding of these conditions?

0:14:23.5 David Hale: Yes, they certainly are. And the clinical practice guidelines have multidisciplinary committees, just like Dr. Whitney mentioned... Sorry, the diagnostic criteria have multidisciplinary committees, just like Dr. Whitney mentioned for clinical practice guidelines, of experts in their different fields that come together to create these diagnostic criteria that then do evolve and change over time as we have new diagnostic methods and we have new tools at our disposal to help make these diagnoses. I believe a Ménière's disease update will be coming out soon, and we'll have more information on what that will look like with each new iteration, essentially.

0:15:09.8 Sue Whitney: It's really exciting because before we didn't necessarily have diagnoses for some of the conditions. And the other thing that's really exciting is that we talked about, for example, in Berlin about 10 days ago, to update some of these Bárány Society diagnostic criteria. There are new diagnoses. So a lot of you say, "Oh, maybe the doctor didn't know what this was." Well, it may not have actually been described before. So some of these diagnoses are new. And you think, "How could something be new?" But people have lived for thousands of years, but we're getting so much better at trying to figure out what someone's problem is. And then once we know what it is, then we can figure out what's the best way to treat that problem. So a lot of you think, "Oh, they can't figure it out." Well, we are starting to figure out some of these things, and it's very exciting.

0:16:10.8 Abbie Ross: It really is. Am I echoing? No? Okay. You talked about lived experience again before, and I want to come back to that because my question is, how are we anticipating that patient feedback and lived experience will contribute to the direction of vestibular research? I just want to expand on that a little bit. Is it through registries? Is it through your anecdotal patient experience in the office? Dr. Whitney, why don't we go with you since you brought that up earlier?

0:16:44.9 Sue Whitney: Well, I can tell you that at the Bárány meeting just a week ago in Berlin, we talked about lived experience. And we also started to talk about, for the diagnostic criteria, getting feedback from people who live with the disease, too. So it's not just a bunch of neurologists and physiotherapists and other people sitting together. We're actually talking about trying to find out more from people when we even write these diagnostic documents. And I have the honor of being asked to write a document about rehabilitation for people with acute conditions. So the group is branching out, so we're not just talking now about how to make the diagnosis, but we're also talking about what's the best care for people who have specific conditions. And I think with kind of this lived experience, we're doing a better job, for example, developing questions or specific questions to ask others. So one of the things that Devin McCaslin from the

University of Michigan is leading is a group of us who are looking at, is there a questionnaire that we could ask everybody on the planet about vestibular disorders to get an idea of how it's affecting their lives? And then we can compare data from Dr. Hale at Johns Hopkins to Sue Whitney at the University of Pittsburgh. So that's really exciting. But we also are looking at making sure that they're the right questions. So we're gonna go back after we've got these questions and work with people who live with these problems to see if we're asking the right questions. So we don't want to develop this wonderful questionnaire that we think, who don't have the problem, think is great and we totally missed the boat. So there's I think a lot more interaction. And actually VeDA as an organization has really been forthright about saying, "Hey, have you asked people who live with this condition? And if you haven't, we have people who can give you advice."

0:18:59.5 Abbie Ross: By the thousands, as a matter of fact. And also maybe a little plug, we do have a registry as well where you can input information about your lived experience. Maybe someone can put that in the chat if it hasn't made its way there already. I want to also talk about, from a social media standpoint. 10 years ago, 20 years ago, certainly there was not as much information out there as there is now. And I think probably all of us on this call, we've talked about vertigo, looked up dizziness, things related to the vestibular world, and maybe we've even been targeted by algorithms for certain, or I should say potential, snake oil solutions, quick fixes that often over-promise and perhaps under-deliver to our audience listening today. So how can we responsibly evaluate these types of new treatment approaches that are being pushed out this way, especially to sometimes a very vulnerable patient population? Dr. Hale, what are your thoughts?

0:20:07.3 David Hale: I think that's a great question and something that is a blessing that we have ease of access of information. But when people are really experiencing symptoms and it's impacting them, they are looking for a quick solution and can unfortunately be taken advantage of by our social media and advertising. I encourage my patients to always just ask not only me but all of their providers in their care team if something comes up because there might be an idea that we haven't thought of or a different perspective that we can take, and that can be taught to us through social media or something that a patient has learned and I always appreciate that perspective. But I always try and frame the perspective of going back to, well, let's critically analyze this treatment. Is it something that has been studied? Is it something that is recommended by our large societies like the American Academy of Neurology and International Society of Neuro-Otology and the Head and Neck Society as well to know, are these treatments that are safe, effective, and worth our time, money, and effort? Believe it or not, I try to say to patients, if it's something where someone's asking you money for, or a product you have to buy, we should raise our flags and critically appraise it before we go forward with it.

0:21:41.0 David Hale: But it is difficult. I was reviewing a paper for a journal recently as a reviewer, and the paper was very creative and it was looking at what is being taught about different vestibular diagnoses and treatments across different social media platforms and the accuracy of the information. And I think in a very positive way, it determined, based off of looking through different social media platforms, that about 80% of the information that they found when they were using certain search words and keywords was correct. But what was a little bit concerning in the review is that things that were incorrect often had the most views or often had the most wow factor. Just like you mentioned that with someone is... Something that's attention grabbing or something that is really pushing people toward a certain way when they're looking for a quick fix might be what gets shared the most or viewed the most. I think just viewing everything with a critical lens is very important, just as we do in our clinic with medicines, therapies, and tests that we're recommending. We should view our social media content with that same critical lens.

0:23:04.5 Sue Whitney: I'd like to add something, and that is that around the globe people can get on something called PubMed. It's P-U-B-M-E-D. And you don't have to understand everything, but if you were to put in a certain new intervention, and a couple keywords, and you saw nothing come up, or if it's a product and you see nothing come up, I would say, "Hmm, that's not, there's not good data there." I also want to warn you that ChatGPT is stupid related to vestibular disorders. Okay? I can tell you that ChatGPT acknowledged that I had written... They made up a citation, they said that Sue Whitney wrote a paper, and Sue Whitney had not written that paper when I looked at it. So it has to get smarter. So if you use AI, people are talking all over the world about AI and we all use it, I use it too, but please be very, very cautious about using information from AI about vestibular because, at least the programs that I've tried it in, because there's different places that you can go, they're just not smart about vestibular disorders. So I would caution you severely about thinking that that is a truth unless you substantiate it in another way. Okay.

0:24:30.0 Danielle Tolman: That's a really great piece of advice. And maybe one way that you could utilize that is actually taking the paper that you're trying to read and understand and using that reference in AI to kind of summarize key points and to make it easy for a patient to understand. Giving it the correct prompts to pull from the correct information may be a great way to access all of the good stuff like what Dr. Whitney is writing and understand it in better terms. So kind of building off of that, we want to be really excited about the new stuff that's coming out that's gonna be helpful, but how do we balance that enthusiasm for new treatments with the caution required to make sure that we have patient safety and ethical care? What are those ethical considerations that we want to think about when introducing experimental or cutting-edge therapies to patients who are desperate for relief? Dr. Whitney, I'm gonna throw that over to you first.

0:25:28.5 Sue Whitney: I'm not sure I have a great answer, but I'm always worried about whether someone might fall down because of something that I do or some new intervention. So I don't want anybody to break any bones and come away intact. I think also if something... If you're pretty sure something's gonna fail, that's so hard too for me to say, "Maybe that's not the thing to be doing," because when you fail a bunch of things in terms of trying to make yourself better, that's not very motivating. So I like sure wins. And so like Dr. Hale, I try and encourage people... I don't discourage people from trying anything, but I'll say, "Have you looked at this?" because I always say, "Maybe it'll work for you. I haven't had success in the past, but maybe this will work for you. It doesn't cost much money. You can give it a try." But if it's something that's a serious medicine that has side effects, then I'm gonna behave a lot differently. And I might actually say, "I really..." Then I kind of say, "Whoa, that I haven't seen any direct evidence of this. There are potential complications of doing this, so you might want to really consult with a couple physicians or more than whoever's gonna prescribe this because there's not super good evidence." So I do sometimes get a little bit more aggressive because I don't want any harm to come to the person who's sitting in front of me. Dr. Hale, you deal with this, I'm sure, all the time. What do you do?

0:27:06.5 David Hale: Yeah, that's exactly right. I think what I always remind my patients with everything is that new does not mean better. It just means that it's something that we don't have as much experience with. And I give patients that same perspective, like we mentioned earlier about, we have learned new things in the last 20 years, but there are some constant things that have been reliably successful for the last 20 years as well. So I say, let's try things that are more likely to provide us with success up front, and we will cautiously approach trying something new. Of course, if something has harms, that's when my flags raise and I say, "Well, we've really got to be cautious with this. It's not something that I recommend personally." But if there's something new and it seems that it's safe and there's the potential for it to be effective for that individual, then I help make a plan that I think is very reasonable with that person. And just remember that our patient experiences and what our patients tell us can help shape what we recommend for the next person, but it may not apply to their unique situation because they'll ask me, "Well, what do other patients do?" Or, "What was this scenario like?" But each person's scenario and case really is so different that we have to tailor it to that individual's other medicines, their other treatment paradigms, their other diagnoses outside of the realm of vestibular to make a plan that is, like we asked or like this question said, balancing something new and exciting with being safe, cautious, and effective.

0:28:55.7 Danielle Tolman: Yeah. And it reminds us all how individualized this type of care really should be. And across the board, I mean, you may have experienced someone with the exact same diagnosis and you think this one treatment is gonna work, or this one medication, or this one device, and then they have the opposite effect of what you anticipated. So even as clinicians, we're always learning, and I think that's probably why we're all in this field, because there's so much to learn even every single day. Now, let's talk too about... We've mentioned a little bit about research already. Both of you have provided some things that are exciting and up-and-coming. But is there anything else in terms of research or projects or products, devices that you feel might make a meaningful difference for patients living with dizziness in the future? Dr. Whitney, why don't we start this one with you?

0:29:48.1 Sue Whitney: Sure. So one thing that does work, it's more fun than what I do anyway, is virtual reality. So there are a lot of people who are doing virtual reality around the globe. It's much cheaper. When I first got into the virtual reality realm about 25 years ago, we built a whole room to be able to do this. Now people can buy an Oculus Rift, or you can drop your cell phone into a piece of cardboard and people are using that. So there's all kinds of opportunities, and also opportunities where you can share what you're experiencing with your doctor. So there are apps that you can put on your phone, for example, that really do a great job. You can hold it out here, for example, like this, and it can just look at your eyeballs.

And then you can send that recording or show it to your doctor when you go in. And then they have a better... With more knowledge, the physician then can make a better decision about what's going on with you. So there's all kinds of technology, especially with the cell phones, that is helping us better manage people.

0:30:59.3 Sue Whitney: And there's even some people that will use the cell phone and even a Zoom link, for example, to help make the diagnosis. So telehealth, some of you are familiar with where you can see your doctor and talk to them just like we're talking now. And when you do that, you sometimes can give people a better idea of what you're having trouble doing in your home. So I think there's ways that we can now interact with people living with dizziness that we can better understand what they're having trouble with and also have a better understanding of what's actually happening, especially with their eyes and with their walking, when we can actually see them in different environments. So I think those kinds of things are really exciting. The ability to... I'm sure some of you have already been asked to do this, but I have people count their steps. One of the best ways that I manage people is to get them to move. And if you show me your phone and you took 400 steps today, I'm gonna be like, "What kind of day was that? You sat too much." "We need you to move."

Because people with vestibular disorders can sometimes stop moving, and we know that movement is one of the keys to getting better. So things like technology can help me better understand how you're living, and they can also help you to help me understand what your problem is. So that's what I wanted to say. Go ahead, Dr. Hale. Sorry I took so long there.

0:32:36.8 David Hale: No, that was great. And I am also so excited about all those same applications. And I frequently have patients use that application that records their eyes. And then in my inbox, I receive a lot of really nice, high-quality videos that have been very diagnostically helpful for seeing patients who might be asymptomatic at the time of my visit, but their episodes are happening outside of the clinic time. I think something else that really excites me, and this might be a little bit of a different perspective or an indirect application, is that how excited people are to learn about vestibular disorders. And one of my goals is to teach other clinicians and people in training about dizziness and vestibular disorders, and having the view that if we can have more people recognize and diagnose these conditions accurately, it means that more patients can have answers faster than they would otherwise. So I'm leveraging technology in that way by giving virtual lectures as often as I can to neurology residents all over the country to make sure that they're aware and have access to the same vestibular education that I've been lucky enough to have myself, that I trained at a hospital where I had really great mentors. But I think that we should be able to expand that to not just the walls of Johns Hopkins or another big academic institution where Dr. Whitney is or others, but that this is accessed in many places. And technology breaks down that barrier or that wall and allows us to kind of spread or multiply. And along those lines, I think sooner rather than later, we'll have phone applications that could allow clinicians to train on different technologies and resources that are often hard to understand to make diagnosis easier. So that's an innovation that I'm really excited about and very passionate about.

0:34:48.0 Sue Whitney: Yeah, I just wanted to add a little bit too, especially for some of you who live in less developed areas. All right, so what The Bárány Society, that's an international group of people from different disciplines, is getting together, we've been working on this now for about three years. We're trying to develop exactly what Dr. Hale talked about, which is a bank of lectures and material for people who might care for you in your country or in your state to access these materials for free. And Dr. Gold, who works with Dr. Hale, has a library of materials like that related to eye movements that's at the University of Utah, virtually, in their library. And what we're trying to do is provide materials for therapists around the world and for doctors so that if you live in sub-Saharan Africa and there's not anybody who... The doctor doesn't have access to a Johns Hopkins, they can go to this site that will be free to learn more about vestibular problems so that hopefully when you go in to see them as someone living with dizziness, that they might have more knowledge and could help you more effectively. So we're trying to improve the world and improve the world's knowledge of dizziness so that people get the care when they need it and the right care.

0:36:22.8 Abbie Ross: And you're doing a great job, Dr. Whitney, I have to say. I also want to mention maybe a shift in the way that healthcare professionals and patients think about healthcare as a whole might be happening. And we've kind of touched on this too, but I like to tell people to think of yourself as my teammate. Your feedback is guiding my care, whereas before maybe healthcare used to be, "I'm going to the doctor and I'm going to listen to what the doctor tells me." But we actually are listening to you as well, and it's allowing us to make informed decisions about your care. So just generally speaking, start to think about your own health and well-being as something that you are very much an active participant in. If something's not working, we want to know. If something's going really well, we want to know. And also when we were thinking about diagnostics before, when you were talking, Dr. Hale, I think another thing that can be really helpful is for patients prior to an appointment, if you're still seeking the cause of your symptoms, usually understanding the timing of your symptoms and what's triggering your symptoms can be very helpful for your provider to understand what's going on and then what's the best way to help you. So going in prepared with those two pieces of information in particular can be very helpful in giving you a successful session. Now, we've talked about some research and what's upcoming. What would you say are the biggest barriers that slow the adoption of innovative therapies or medications or technologies in vestibular rehab and in neurotology practice? Dr. Hale, why don't we start with you on that one?

0:38:08.2 David Hale: Of course. And I'll just give a plug that the Vestibular Disorders Association website has a really nice questionnaire that helps guide patients through the timing of their symptoms, potential triggers, and when patients come to clinic with that filled out or our own clinic questionnaire, it's exceedingly helpful. And that leads me into my next barrier. I think one of the biggest barriers that I commented on already is diagnosis. And that if patients aren't receiving a diagnosis, then it's hard for them to receive treatment. So even though we have great diagnostic criteria for many of these disorders, like vestibular migraine and Persistent Postural-Perceptual Dizziness, and I'm thankful this isn't an experience I have on a regular basis, but I know it is for some of my colleagues, that I still get comments about, "Well, it can't be vestibular migraine because there was no headache," or the dizziness was, quote, "all in someone's head" in reference to outdated thinking regarding functional neurologic disorders. And I think those barriers of diagnosis and understanding and correctly naming a disorder prevent us from implementing the therapies and the technologies and the treatments that we can use to make someone better. I know that everyone in this room and the people watching are always up to date, of course, but that's not the case sometimes outside of these walls. And I think that's a barrier that we're going to need to address to raise awareness so that patients can get the help that they need, essentially.

0:39:57.4 Danielle Tolman: Dr. Whitney, do you have anything to add to that?

0:40:01.6 Sue Whitney: If I remembered the question, I could do it.

0:40:05.3 Danielle Tolman: We were talking about potential barriers that might slow innovation that we're seeing in terms of developing therapies and rehab.

0:40:14.6 Sue Whitney: Yes. What I wanted to say was money. We are a kind of a small niche, and the agencies around the globe that give money, they don't give enough money to support vestibular research, which is a real problem. And I do think that that slows things down significantly. There aren't really foundations for us to go to to get money to do small projects. For example, we've tried for years. 25 years ago, we tried to see what was the best medicine that we could give people with vestibular migraine, because vestibular migraine is incredibly common across the globe. And we tried to get money from the National Institutes of Health to do a trial to look to see which drug would work better. But drug companies don't want to support us because they don't perceive they're going to make any money on it. And the National Institutes of Health says, "Oh, well..." They just don't get it. So I think that there's not enough money to support vestibular research for us to answer some really important questions that could probably help a whole lot of people. So that's a limitation that I see. And if there was more money, then maybe we could help more people. So to do drug trials especially is a big problem. Have you seen that also, Dr. Hale?

0:41:40.8 David Hale: Yes, it's certainly been a barrier, and it's a topic in healthcare now, I think, not only just vestibular but across the healthcare field as a whole. But we are a small number of providers in comparison to other diagnoses, despite how common dizziness is and how many people it affects. There's a small proportion of people thinking about dizziness and caring for dizziness on a daily basis, which really does impede our ability to get forward. But I think we have done remarkable work as a field and despite those barriers and limitations. And really, that's people like you, Dr. Whitney, as I'm so young in my career.

0:42:26.2 Danielle Tolman: I think what really excites me about everything upcoming in our field is how much things are improving and growing and becoming more accessible, even in the last 10 years. So as both of you had mentioned, having these technologies advance, whether it's for diagnosis or for therapies and treatments, one thing that is for certain is that people are taking charge of trying to help make this more visible. We see this on social media and access to these educational materials and just lived experiences and people who are sharing what they're feeling. So many people, I feel, have underreported or have been hesitant to share what they're experiencing out of fear that they won't be believed or people might think that they're crazy or it's all in their head. And even in a short amount of time, even the last five years, I will say that I've seen a huge difference in what patients are bringing in to ask questions about or what they're telling me they're experiencing when they're coming in for their evaluations or treatment sessions, which is just, I think, so important. It lends to this barrier that you both had mentioned about not having the research, not having the funding for the research, because people who are providing the funding aren't sure this is actually something that they want to put money into.

0:43:46.2 Danielle Tolman: So it leads us into our next question that I have about really encouraging people who are watching and listening to partake in things like the patient registries. But could you talk about how the impact of these data collection tools, whether they're wearable sensors, the telehealth platforms, or the patient registries or AI, on helping to advance that clinical educator innovation and improving those treatment guidelines? Dr. Whitney, I'm gonna throw it over to you first. What can you say about that?

0:44:17.9 Sue Whitney: Well, I think that knowledge is power. And it's really important for us to validate the lived experience of people. So you can say, "Boy, people walk less steps." And there's a paper that recently came out that said that people with chronic vestibular disorders walk less steps over time. And that came out within the last couple months. So the more we know, the better we can care for people. So some of these wearables, some of these technologies are really making a difference. And right now, some of the best work is coming out of China. I used to say it was South Korea that they were writing, but somehow China as a country has really woken up to the fact that people are dizzy in China and are really doing some amazing work. So we now know that after rehab, there's a spot in the back of your head that lights up differently with vestibular migraine. Now, we never knew that before. I now know from some work that we did here that when people who are really bothered by visual motion, if you put them... If you put something over their head, we can figure out where their blood goes. And we thought that my idea was that when people who saw lots of motion, what would happen is that this area of their brain here would light up on fire because their brain was working so hard. Well, it didn't. It went, the blood went down. And in people who don't have those symptoms, the blood went up. So what we're learning is that some of the assumptions that we have from all these innovations are totally wrong.

And hopefully once we know what really is happening in people's brains, we can help people get better. So some of these innovations to me are just so exciting because... And we just completed a study with these amazing athletes who are what are called US Army Rangers. They're the top of the line. And the Department of Defense funded us to look at these people before and after rehabilitation. And we put them in a scanner so we could see how their brains worked. And what we found is that in this area over here, that is kind of where we think a lot of inner ear vestibular kind of stuff is processed, it changed how it worked. It works differently after rehabilitation.

0:46:48.7 Sue Whitney: So we're starting to have some real evidence that rehab and therapy and things like that work based on science. So it's really kind of pulling things together and validating especially some of these things like persons with PPPD. That's a tough, tough diagnosis to have, which is that Persistent Postural-Perceptual Dizziness. Those are the people that we're learning that their brains work differently than others. I mean, it's the same brain, but their brains actually maybe formed a little differently, and that's probably why they developed the problem, and they work a little bit differently. So to me, that means that their therapy and their drugs may need to be a little bit different too. So there's lots of things that are exciting, I think, for anybody living with a chronic vestibular condition.

0:47:38.2 Abbie Ross: If we look at just, again, the last, I don't know, what is it, 2026, 40 years ago or something like that, when Dr. John Epley came out with the Epley maneuver, I mean, how long did it take us to really implement that widely across our practices for Posterior Canal BPPV? It took a long time. These things do take time, but hopefully that means that by the time it is widely accepted, it actually does work for us. Now, I want to get into some audience questions here because somehow we are approaching our hour mark already. And I like this question: "What is the current research or where is the medical literature pointing to regarding advances in understanding how to address hormonal impact on vestibular symptoms?" Maybe, Dr. Hale, we'll start with you. And I'm thinking more about vestibular migraine with this, but please take the question or take the answer wherever you wish.

0:48:34.1 David Hale: Of course. I think that's a good question, and I'll start off by saying that I'm certainly not an expert in hormones or the hormonal cycle, but we do know that, as you mentioned, Abbie, that there is a link between migraines and hormonal cycles, especially around ages 40 to

60 in people who are going through menopause or the perimenopause and postmenopause stages. And it is often a reliable trigger that can sometimes be helpful and give a diagnostic clue for the clinician if symptoms are happening in a cyclical manner, for example. What it says to me when I'm evaluating a patient is that I am concerned that there could be a hormonal trigger for their vestibular symptoms, which most commonly is vestibular migraine in that case. And it wouldn't change my treatment of that patient's vestibular migraine per se. I would still treat them in the same exact ways that I would treat other patients, but the difference would be that I'd want them to work with their OB-GYN or their GYN provider to discuss about what does it mean to have this hormonal link. Would that person be appropriate to be on a medicine that could change their hormonal cycle, which is a determination that should be made by their endocrinologist or their OB-GYN. But I have had patients who have had better control of their migraine symptoms when they are having better control of the hormonal fluctuations that they're experiencing.

0:50:14.7 Danielle Tolman: Let's dip into some other questions that we have that are popping up in the chat. I'm seeing a lot of questions about wearable devices. Now, this is gonna have a pretty broad range, but Dr. Whitney, I'm gonna kick this over to you. Could we talk about some of these devices which I think are very appealing to patients because it's going a non-medication route, which I think a lot of people try to steer clear from initially. So could we maybe talk some things? There's some questions about neuromodulation devices or apps, or we have the BalanceBelt mentioned, or anything that helps with rehab. Could you maybe talk to some things that you're seeing popping up in the rehab side of things that patients are seeing success with that are hitting the market?

0:51:00.5 Sue Whitney: Sure. Well, the BalanceBelt is Herman Kingma's out of Maastricht, and that I don't think that's yet approved here in the United States, but it certainly is approved in Europe. And when I've talked to Herman, he's said that that's a belt that you put it on like a belt and it buzzes. All right, so it has a little buzzer in it, and it lets you know where you are in space. "Oh, I went too far." I came back and it stops. That's one mechanism that it can work by. We've done some work here in the United States on a BalanceBelt that we had built too with the University of Michigan and Harvard. So there's data that they work, but not for all people. And Herman will tell you that he doesn't understand why it works for some people but not others. And that's been primarily used for persons with inner ear loss on both sides. Okay, so that's one device that's out there. That was one, and then you talked about...

0:52:02.2 Danielle Tolman: About neuromodulation devices like the CEFALY or Truvaga, like vagus nerve or trigeminal nerve stimulation?

0:52:09.2 Sue Whitney: Yeah, I haven't seen too much evidence that that works, so I don't know much about it. I get almost all of my information from PubMed. So when I see that and I read it and I buy it. And galvanic stim is another one that's out there. People have tried that for 34 years now; that hasn't worked too well either. I'm not against new things at all. I'm a new adapter, but I have to have something to grab onto to really believe that it works. There's a device that you can use for your exercise called Vertigenius that a friend of mine developed in Ireland, and that is for sale and available at least in Europe and in the United States, and that helps people do their exercises, their eye-head exercises. We've developed an app that I should have disclosed, I guess, that I'm on the patent for that we use eye and facial recognition software to figure out if and when you're doing your exercises and if you're doing them correctly. And the take-home message is no matter what I ask people to do, even if I pay them to do it in the study, they don't do what I asked them to do. So that was quite revealing. So we're kind of halfway through this large study and learning about that. So my exercises obviously are boring and people don't do them as much as they want. There's some other apps that are out there. The one was sponsored by the Department of Defense for older adults who are dizzy that has some little games that you can play. So there's just all kinds of cool things that are available plus apps. But you probably, if you're someone with the lived experience, you probably should ask a healthcare provider about what's the best app to use because you can find all kinds of things on your phone, and some of them could hurt you.

0:54:13.1 Sue Whitney: All right, so if you heard Dr. Hale talk about vestibular migraine and how common that is. And that's often people have that plus other things too sometimes, if you, for example, get online or get on your phone or your tablet and you start moving these patterns by real fast that are black and white, you may be trash for a day or two. So I usually advise people that if they want to try something like that, they should probably check with their provider to find out how it should best be used because there's absolutely no instructions when you go online for a lot of these new technologies. So I just warn you that some of them will work great for you. But the dosing, it's the timing and the dose and the intensity and frequency that are really important. And that's where a healthcare provider can help you figure out what might be best for you to try.

0:55:08.3 Abbie Ross: Yeah, we actually had Dr. Meldrum on last year, I believe it was. So if you want to go back to those recordings and learn more about that wearable device, please do so. Dr. Hale, did you have something to add?

0:55:22.1 David Hale: Yeah, I just was gonna quickly add some thoughts about the migraine-specific and vagus nerve stimulator devices because I get asked a lot in my clinic. So it's something that I've recently done a literature review on. Devices like, just saying names in no specific order, like CEFALY or the Nerivio devices, which have been used in prevention of migraine, just as we apply other migraine treatments to vestibular migraine often, they can be used as an abortive or a preventative for migraine treatment as a medication-free way. That doesn't mean it's going to work for everybody, though. But in some patients who have inability to take medicine or in patients who might become pregnant, for example, it is something that we do have to try because we don't have other options. Regarding vagus nerve stimulators, there, I have recently investigated this a little bit more trying to have better information for my patients. There are just a very small number of studies that have looked at vagus nerve stimulators in the moment of a vestibular migraine, and there is some potentially promising results, but it's done on a very small scale. And I found one where people were using vagus nerve stimulators in the setting of Persistent Postural-Perceptual Dizziness and didn't find great results for those patients specifically. But that doesn't mean that it's not a good device. It just might not be being applied in the correct format or for the correct person yet, which is what I think we need to understand more about these devices. I'm always hesitant to recommend something that's really expensive or out of pocket when I don't have proof or, like Dr. Whitney said, PubMed evidence that it's going to be helpful for people. But those are... I just want to add those thoughts in.

0:57:22.7 Abbie Ross: Thank you. Yeah, when we talk about innovation, we have to start somewhere. So of course we're gonna be in this space of time where maybe we don't have the evidence that we're hoping for yet and it will take time to get there. Or maybe it shows, yeah, this is not going to help at all, or this maybe only helps a very select few and probably is not worth it for everyone. There's also a couple questions before we, we have one final question that we also want you both to answer, but I want to touch on this because I saw a couple questions in the chat. What about any research in terms of treatments or therapeutic approaches for people who have developed vestibular issues post-COVID? Do either of you have thoughts on that?

0:58:08.2 Sue Whitney: I see it all the time and it sure looks like they have, it can be in the inner ear, I'm sure you've seen it there too, but it can also be some kind of dizziness in the brain. And boy, we just don't know a whole lot about how to best manage. Dr. Hale, do you have... 'Cause I'm sure you're seeing the same thing I am.

0:58:30.4 David Hale: Exactly. And I am seeing, just like you said, sometimes I have seen cases of post-COVID vestibular neuritis. And with patients who have long symptoms from COVID, termed Long COVID, they often can develop migraines even outside of the vestibular realm. So aside from their long COVID, you have to have a high index of suspicion of does this person also develop vestibular migraine and the symptoms that can go along with that? And in some ways, I think of it as we might approach a patient with concussion, of we know that something happened, let's make sure we're not overlooking anything else or the effects have led to a different problem that we have to make sure we're addressing down the line.

0:59:19.3 Abbie Ross: Now, just to wrap up, we've got maybe 15 to 30 seconds for each of you to answer this question. Looking ahead in the next 10 years, what changes do you both hope to see in the vestibular world? Dr. Whitney?

0:59:32.4 Sue Whitney: I think some answers for people so that they truly know what's wrong with them and then we come up with some good interventions that have evidence. That's what I'd like to see.

0:59:46.2 David Hale: And along with that, I really want to see that we have a huge group of providers who are very excited to evaluate and treat patients with dizziness and have a great understanding of it.

1:00:00.0 Danielle Tolman: As a fellow vestibuloholic, I can wholly say that I'm very excited and hopeful about that, too. Not only that people feel supported and seen, but that we have an army of clinicians at the ready to treat patients anywhere that they need help. If you'd like to learn more about Dr. Sue Whitney and Dr. David Hale, check out the information in the banner below as well as in today's agenda. Thank you so much to both of you for joining us today and sharing your expertise on emerging therapies for vestibular conditions. And now we'd like to pass the baton to Heather

Davies and Cynthia Ryan, who will be facilitating our patient panel. Oh, and what a great day one. I am just so pumped for this week. I feel like this week is gonna be absolutely amazing. Hi, Heather. Hi, Cynthia. Happy first day of Life Rebalance Live.

1:00:47.1 Cynthia Ryan: Hi, everybody. Good to see you.

1:00:49.7 Heather Davies: Yes. Thanks, Abbie and Dani again. So much information. I just want to go back and replay it now. The PubMed thing is gonna be a huge game changer.

1:01:00.7 Cynthia Ryan: I'm Cynthia Ryan. I'm VeDA's Executive Director, and I'm here with Heather Davies, who I'll let introduce herself in a minute. And we just got off of the session with Dr. Hale and Dr. Whitney, and I just love how they bring the huge topic of vestibular research and innovation down to the simplest level, things that we can really understand and put into practice because it is a big topic, and it's very frustrating that research takes so long and that there's so many things out there that maybe there's some research on, but it's not conclusive yet. So how do we know? We're gonna talk a little bit about that in a minute. Heather, let me pass it off to you to introduce yourself, and then we'll get going with our patient panel today.

1:01:50.7 Heather Davies: Sounds good. I'm Heather Davies. I am host of the Ménière's Muse podcast. I'm also a Ménière's patient, as well as vestibular migraine. And today we are welcoming our patient panelists, Neil Canham and Alicia Wolf.

1:02:05.6 Cynthia Ryan: All right, let's bring them on.

1:02:14.9 Heather Davies: It's gonna be a technical day.

1:02:16.2 Cynthia Ryan: No, I'm gonna bring them on. Neil and Alicia, welcome. Good to see you.

1:02:18.8 Neil Canham: Hello. Hi.

1:02:20.6 Alicia Wolf: Hello.

1:02:21.7 Cynthia Ryan: Hi.

1:02:22.5 Heather Davies: Hello. Well, we are just gonna jump right in. I'm sorry.

1:02:28.3 Cynthia Ryan: Go ahead. You get us started, Heather.

1:02:32.5 Heather Davies: Well, we're gonna jump right in with the discussion questions. Do you guys have feedback?

1:02:41.9 Cynthia Ryan: Tell us what you thought about what you... Were you guys listening to Dr. Hale and Dr. Whitney? What were you thinking when they were talking about what's worked, what hasn't worked? Alicia, I know that you're really involved with some of the wearables. Tell us what you were thinking while they were talking.

1:03:03.9 Alicia Wolf: No, what they said was totally true. The studies that have been done were really small. Actually, it was my neurologist and a couple of the neurologists I've worked with at UT Southwestern before who have done the small studies on both CEFALY and gammaCore, which is the non-invasive vagus nerve stimulation device. And so because of that, I have had a lot of experience using some of these, as I seem to be closer to it just having them as doctors previously. So I've had a lot of experiences with some of these devices, and I totally agree with what they've said. It's kind of hard 'cause the research that we have on vestibular issues is just so limited.

1:03:50.8 Neil Canham: Yeah, I felt the same way. I thought I was really quite pleased to see a degree of not skepticism, but just giving the data as it is, really. And I think that's quite valid. I think the title of our session here, Hope in Innovation, is great, and I think it's wonderful to have healthy hope through innovations. And we just need to be careful sometimes it doesn't turn into false hope through exploitation, which is what unfortunately happens a lot in chronic diseases. We see it rather too much. So it was good to see that balance, I think, from them.

1:04:30.6 Heather Davies: From that standpoint. I'm sorry, I'm still having technical issues, so bear with me.

1:04:40.3 Cynthia Ryan: Oh okay.

1:04:40.6 Heather Davies: I wanted to ask Alicia, at the beginning of your vestibular journey, what were you hoping to find in terms of answers and treatment, and how has that changed over time?

1:04:53.4 Alicia Wolf: That's a really great.

1:04:56.2 Cynthia Ryan: I know it's a big, a big question.

1:04:58.4 Alicia Wolf: I think at the time that I was one of those patients, kind of like you all discussed in the earlier hour, I was one of those patients who didn't want to rely heavily on medication. I was 30 years old. I was hoping to have a family soon, and so that made me even more limited as to the treatments I could try. When I first started this journey, there were none of the Gepants, there was none of the anti-CGRP medications, there were none of the devices. It was the classic migraine medications. And so I've been through this vestibular migraine and PPPD journey just trying to figure things out for myself, and a lot of times we as patients have to trial things with our doctors, and there's just not a lot of, "Oh, yes, this will work for you." And that's what's kind of been the story of my journey as shifting into a vestibular migraine advocate. Now I have a lot of access that patients don't always have because I am able to go to some of these conferences or I'm able to speak to some of these doctors who have more education in vestibular disorders, and that just is really hard to find throughout the country. And so I try to take all that information and try things out myself to see, okay, is this really working for me? Is it worth the expense? Is it worth the money? Is this something I wouldn't spend my money on? And so throughout my journey, I've found things that maybe haven't had a lot of research behind it, but they were incredibly helpful for me and what I was trying to do with my vestibular migraine treatment. And then there have been other things that have come out new on the market, things like migraine glasses, things like these neuromodulation devices that have been really helpful for certain points in my migraine treatment. So I'm excited to talk to you guys about some of those today.

1:06:53.4 Heather Davies: Sweet.

1:07:08.7 Cynthia Ryan: Well, now I want to touch on what Dr. Hale was saying right at the end about those neuromodulation devices that Dr. Whitney was saying there's not a lot of conclusive evidence, and Dr. Hale supported that and said that he will try them for people who other things don't work for. So I think it's important when there isn't a lot of evidence out there to check with your healthcare provider and work with them on whether it might work for you instead of just trying it on your own, because there are so many things that you can get over the counter. And I think Heather's still having technical issues. She's gonna come out and come back in. But, Neil, I'm gonna pass it off to you to answer that question as well.

1:07:59.7 Neil Canham: Well, in terms of treatments and how things may have changed, I think... I mean I've had Ménière's disease for 17 years, and right from the beginning in the UK, when I lived in the UK, doctors had always been really quite honest about the possibilities for treatment. And I think I've been quite glad about that, and I don't think that's changed very much. And for me personally, I'm not really looking for or expecting much in the way of treatment. I'm very, very keen to understand and promote any research that might help others who are potentially in earlier stages. The way that Ménière's tends to go, I think the longer it is, the less likelihood there is of interrupting the cycle and the process. But I almost dissociate myself from the condition and try and look at it from the outside, and that's my coping mechanism in a way. Yeah, sometimes I feel terrible, but the rest of the time I'm researching and reading and writing and talking to researchers and understanding what's going on so that other people might benefit, really.

1:09:01.4 Cynthia Ryan: Yeah, I think that that's what a lot of... And Alicia, you were saying this too, because you become an advocate, you are doing a lot of research. And, Neil, you also have a blog where you post the research that you've looked into and ways that... And what I love is that you guys take this information and distill it through the patient experience into ways that other people can understand and have it applied to them. So I think just calling out to everybody who is asking, "Where can I get information on research?" Dr. Whitney very rightly referred everybody to PubMed as the ultimate place to find research, but that can be really hard to look through. It's really complicated. I know I put... I take a paper like that and I put it through AI and I say, "Make this accessible," but then you have to review that and make sure that it didn't correct anything. So I love that you guys and probably other vestibular advocates out there who have platforms are also doing something similar. So check the science, check with your healthcare provider, and follow vestibular advocates like the two of you, I think is a great place to start. So let's talk about some of the emerging therapies or lifestyle adaptations that the two of you have made or tried. Now, Alicia, I know you tried a lot of stuff and you post about supplements, you post about neuromodulation devices, and you just mentioned the migraine glasses. Do you want to talk about those a little bit and what your experience has been, how you go about that process?

1:11:05.3 Alicia Wolf: Yes. So my neurologist is Dr. Shin Beh. He's been my neurologist for 10 years now. And so he's speaking later this week on Friday with Dr. Kristen Steenerson. So that'll be a great episode that you guys should tune in for. But I've had a lot of information passed on from him. And as we started this vestibular migraine journey together, he was very open to trying some of these smaller studies. He's very like, "Okay, let's just see if it works. I'm seeing this work for other patients. Let's just try it out." And so as long as I was on board, it was something that we would test out together. So that's where a lot of this experience in trying neuromodulation devices and different types of migraine glasses came from, his encouragement to try some of these things. And then I would go to him, "Is this safe for me?" and he would approve it. We originally started with the gammaCore device, which was something they were studying through UT Southwestern, and that has also had a small study for vestibular migraine as well. It showed some promise with vertigo attacks. But the big reason why we started it was I was going through pregnancy. I had a high-risk pregnancy with IVF. And so I was working with him and a maternal-fetal medicine doctor, which for all the women out there who have vestibular migraine or any of these vestibular disorders, find a maternal-fetal medicine doctor because they are trained to help you get through some of these extra illnesses that you may have that you have to continue medication for. They're not gonna tell you, "Hey, get off all your medication," because we are dealing with a serious neurological vestibular disorder. And so that alone, we shouldn't be pulling patients automatically off of medications just for pregnancy. So that's a good doctor to factor in if you are looking to get pregnant and want to have a good treatment plan set up. And so I would run everything by her and Dr. Beh to get their opinions. And so we did neuromodulation with vagus nerve stimulation. Started with the gammaCore device because we thought that it could help with my nausea. I was having hyperemesis gravidarum, which is shortened for HG, and that was causing me to have lots of nausea, vomiting, and that in turn was triggering a lot of my vestibular migraine symptoms too.

1:13:45.5 Sue Whitney: I haven't discovered if there's a connection there, but I do talk to a lot of people with vestibular migraine and vestibular disorders who seem to have that issue throughout pregnancy. And so we thought since there is... Your vagus nerve is basically responsible for your gut-brain connection, we thought maybe it could be a little calming and helpful from that nausea, vomiting perspective. So I do find that stimulation to be very helpful for that kind of thing. I use it a lot during more vertigo episodes or a lot of high nausea days, a lot of really dizzy days. I try to use it every night before bed to help with sleep, that sort of thing. I wouldn't say that it was as much of a game changer for me as medication was, but I will say it was really helpful to have as a part of my treatment plan. And now there are devices. Truvaga is basically owned by electroCore, which owns gammaCore. But it's considered a health device, so not meant to treat any sort of illness, which is why you can find it over the counter versus having to get a prescription for something like gammaCore.

1:15:06.9 Sue Whitney: And there's also Pulsetto, I think, out there. The main feedback that I hear from patients about Pulsetto is it's a wearable. So I find it kind of tricky to find where my vagus nerve is. I have my Truvaga with me. So you have to move it around to get in the right spot to trigger your vagus nerve stimulation. And I find that can be different for everyone. So I think that wearing this device around your neck where you can't really move it around and customize it could be a little more difficult for patients. I also like that Truvaga was the same company as gammaCore. So you're getting a lot of that same research behind gammaCore.

Whenever I was later on in my journey, after I had my daughter, I started experiencing more pain with my migraine attacks, which I realized was... Which I had never had pain with my attacks before previously. So went maybe seven or eight years without pain, and then all of a sudden I started getting really painful headaches included with my migraine attacks. And so we decided to try the CEFALY device, and that for me was incredibly helpful with pain. I noticed that it was maybe less effective for specifically dizziness, but when it came to pain, it's just almost immediate relief. And that works on your trigeminal nerve. So it's a device you just kind of wear on your forehead. What makes this one tricky is you kind of have to lay down with it. So I think part of its relief is that you have to lay down, take a break. You can't be moving around with it, and it's sort of a mindful activity. So I have found that to be really helpful from that perspective. There hasn't been any one device I'm like, "Oh, yes, this is way more effective than medication." But these are just tools that you can help along with your whole treatment, like you mentioned, the supplements, the lifestyle changes, the dietary changes, the medication.

1:17:33.3 Cynthia Ryan: Right. Well, thank you for that because I know that there were a lot of questions about wearable devices.

1:17:40.9 Alicia Wolf: I noticed.

1:17:41.2 Cynthia Ryan: There was also a question about pregnancy and using them during pregnancy, so that was really helpful, and I'm glad we got to spend some time on that. I think that Heather is back online, so we're gonna welcome her back into the studio. Hi, Heather. This is the life of the traveling Ménière's Muse. Neil, I wanted to ask you because I know that you do a lot of research on research. So, and people we were talking about looking for information about new treatments online. How do you decide which sources to trust when you're evaluating something new?

1:18:20.8 Neil Canham: Yeah, that was another aspect of what was mentioned before that I was really happy to see. The idea that AI can give you good answers on health is very dangerous, and it's unfortunately impossible to avoid. I run a couple of Facebook support groups with 10,000 members each, and it's extremely common to see somebody simply post a screenshot of an AI response as a mic drop answer to a particular problem. These things just want to tell you what you want to hear. And so if you phrase a question with "Is something true?", it'll say yes more than no, even if that's got no basis in fact. And they've even quite happily made up references that just don't exist. They know what a reference looks like, what the format should be, and so, "Oh, it would be really great if this guy sees a reference. Right, here's a reference," but there's no underlying paper. So that's the first thing is... AI, having said that, is a fantastically useful tool if you use it right. So as other people have mentioned, maybe summarizing papers. The deep research tool that Google's Gemini has is extremely useful, but every single thing that comes out of it needs to be carefully read and the ultimate sources need to be found because they may not exist.

1:19:54.1 Neil Canham: Then, so that's the first thing is to really try and follow things back to the studies. And we've talked a lot about studies, and previous panelists also were talking about studies. But this is actually an increasing problem to a degree that access to studies is fantastic, and it's wonderful that everybody can go to PubMed or to Frontiers or whatever it happens to be and read research. But not all research is created equal. There's a huge problem now in the research community that the number of papers that are being produced is absolutely astonishing. And I'm a member of the Cochrane Collaboration, and I volunteer through their crowdsourcing platform to help read abstracts and assign them to buckets to determine whether they're clinical trials or whether they're observational trials. And you can go online and you can actually just do that as a crowdsourcing thing. And it has to be done like that because there's so much research that's being done, and it's of hugely varying quality. So somebody will come along and say, "There's a study that shows X," and that doesn't actually tell you very much. You could probably find a study to tell you pretty much anything if you look hard enough.

1:21:18.3 Neil Canham: So I think what's... What I've ended up doing is to do some learning about research and to study. I mean I was a research scientist many, many years ago, but understanding research in health and in clinical medicine is really, it's a really challenging topic. And there's a huge spectrum of types of evidence, ranging from anecdote at one end, which is you will hear people say anecdotes are not evidence. That's not true. Anecdotes are just not particularly good evidence, but they are a certain starting point. Somebody experienced something. We need to find out about that. But you go up from that, you get to case studies and observational studies and build and build and build. And gradually there's a pyramid of, I've got it on my wall just over here, a pyramid of studies structures that give better and better evidence. And right at the very top, near the top, you've got placebo-controlled blinded trials, and then above that you have meta-analyses and systemic reviews, which bring together lots of studies. And then you get that's like the gold standard, is to take as many studies as you can find and try and see if we can level the evidence and get to that point. And that's what the Cochrane Collaboration actually does. So I think that's really key. It's not just saying I want to read studies, but it's understanding, is this a good study? Has it been done well? Is there a meta-analysis that looks at all the studies in this topic? And that's a massive problem for a condition like Ménière's or any rare condition, because there aren't enough studies. There isn't enough data to pull it all together, and that creates a huge problem. But to answer your question, that's my process really, is looking at the research, chasing it back to the studies, and then saying, "Okay, where does this study sit in the levels of evidence?" And then taking that a bit further. Now what I've been very, very lucky to manage to talk to and build relationships with some of the foremost researchers in Ménière's, so then I can actually read their studies and ask them questions and dig even deeper so.

1:23:43.9 Cynthia Ryan: I love that. It's super helpful. It's a real learning curve to understand the research, and we're fortunate...

1:23:53.1 Neil Canham: I should just add one thing actually, because the Cochrane Collaboration, for people who are interested, they actually have astonishingly great free learning materials, which is where you can go and learn about this stuff. So it's really good.

1:24:06.9 Cynthia Ryan: Well, let's put that in the chat after the session so people can access that. And I just want to piggyback on that. Even I, and I'm not a science person, but I've been in this role working with VeDA for 14 years, I've read a lot of vestibular research, but when I see a paper, I'll share it with my medical advisors and I'll ask for their input. And there have often been papers that I thought sounded really robust that they poked holes in. So again, it is, as you said, it's really hard to know what is quality research. So I think part of the message is to not just hang your hat on everything that you read, but to be curious, but be skeptical, and make notes of questions that you have and bring it to your healthcare provider.

1:25:07.6 Alicia Wolf: Yeah. I mean, I've had to do research more recently on actually low iron, low iron deficiency diagnosis from low ferritin. And I found out that was really contributing to some of my dizziness and attacks later on after I had had my second child. And I've noticed that even taking some of this information, I'll find good quality studies, but even taking some of this information to my doctors or my primary care doctor, there's been a mismatch there. And they're not totally always informed about this. And so that led me to eventually seeing a hematologist about it. And I think this is something that commonly happens with vestibular patients, is you will bring something that you see online to your doctor and they may not always know about it. And so, and like Neil had said, sometimes the studies are really small or may not be the most reliable, but it's all we have to go off of. So I get frustrated as a patient because I do want... It's kind of like you have to balance both things of how much do you actually advocate for yourself as a patient and then how much of the studies go into that. And it's this tough balance where the patient is kind of stuck in the middle, unfortunately.

1:26:40.1 Cynthia Ryan: Yeah, that actually relates to something I was just thinking about, is how do you balance the excitement that comes with trying a new therapy with the uncertainty of what that, is it gonna work? Is it something that is going to lead... Could there be unintentional consequences? Do either of you... Have either of you... Can you kind of relate to that?

1:27:13.7 Neil Canham: Well, actually, I suppose in a way I can, because I've tried for many years, I've been through the sort of very standard non-destructive suggestions that are always made: dietary changes, salt, caffeine, these kinds of things, and betahistine, which is an extremely interesting mixed evidence base. And in no case was anything in my case effective. But then you start to look at things which involve some kind of actual intervention. And because I've been a musician for most of my life, anybody fiddling with my ears has always been a bit of a nightmare to me. I've always thought the last thing I wanted was to lose my hearing, which of course I am losing. I have hearing aids now but. So therefore rejected some of the things which do seem to have some potential evidence of helping for some people, like steroid injections through the eardrum. And because I've got Ménière's in both ears, for years no doctor has wanted to do anything destructive, because you lose the balance in the ear that's giving you problems, and then the other ear is also giving you problems, and then you end up losing the balance in both ears and you're in real trouble. So I haven't actually ended up pursuing very many treatments at all, but I do try and find out about them. And there is a massive problem with treatments, researching treatments for Ménière's, because, and I think it's a bit of a black joke in the research community that two-thirds of patients will get better whatever you do to them, even if you don't do anything to them over a period of a typical study, which makes it almost impossible. In fact, some studies have been shown to be not particularly reliable because they said in their non-treatment arm only 8% of people got better. And most of the researchers looked at that and went, "Well, that's not normal. There should be a lot more than that in the placebo control arm actually getting better." So, yeah, it is one of those things you have to choose for yourself what you're willing to accept, what risks you're willing to accept, what damage. And many people go for destructive treatments if they're unilateral, because some of them really... If you take the whole inner ear away, you're not gonna get bad vestibular signals from that ear.

1:29:51.9 Cynthia Ryan: Right. Those are really good points. I hadn't even thought about the treatments that you mentioned. And now that you say it, I can think of other situations also where, like for example, my mom has, she has Ménière's disease, vestibular migraine, hearing loss. She's older, obviously, and because of... One of her audiologists at one point recommended, because of her hearing loss, cochlear implants. And because of her age and her problems with balance, severe problems with balance, and the chance of getting a cochlear implant and accidentally damaging the vestibular nerve, that could have a detrimental effect on her balance, which could cause her to fall. And so, great example of how a treatment might be a godsend for some people but contraindicated for others. And you have to talk about that with your healthcare provider and make decisions on your own. So I was wondering is, what gives you guys hope for the future? We've talked about a lot of stuff that's really frustrating, but is there anything out there right now that you think is really innovative and could really make a difference in, for you, Alicia, vestibular migraine, for you, Neil, Ménière's disease?

1:31:30.9 Alicia Wolf: As far as vestibular migraine, so I just finished updating an article for Migraine Again on vestibular migraine treatments. And so we have some new information that's been done, that's been posted in the past year, really. I think some of the biggest takeaways from it is that triptans seem to be less effective than we once thought for vestibular migraine symptoms, so specifically vertigo and dizziness. And what seems to be showing promise are things like the gepants like Nurtec. 63% of patients had a 50% reduction in one of those studies, and that was nearly two weeks into treatment, so it seems to be really quick. I personally am hearing a lot of success from talking to patients with it, so that's showing a lot of promise for me. We've had a lot of great information come out about the anti-CGRP meds. So those were studied to show a 50% reduction in vertigo. So just having some of these companies look at, and these medications, look at specifically vertigo and dizziness is huge for us, because typically in migraine studies, we're just focusing on pain and not really the vertigo and dizziness part for vestibular patients.

1:32:58.7 Alicia Wolf: Another thing that I found interesting was SAVI Dual. It's a single-pulse transcranial magnetic stimulation device. It actually goes on the back of the head. It's closely linked to visual-vestibular processing, so it may be particularly helpful for people who have a lot of overwhelming visual stimulus, so busy environments, that sort of thing that we kind of deal with. I haven't personally tried it, but this was just something that came up in the research. Nerivio is another option of a device. They haven't really done anything as far as vestibular migraine for it, but I think just some of these studies coming out about vertigo and dizziness specifically, I mean, we know there's some crossover with your general migraine treatments, but it's not... It's when I take a general, like if I were to take a triptan and I don't have any head pain, is that really gonna be worth the side effects for me? Or is there something that I could take that could target specifically the dizziness if that's all I'm feeling that day? And so now we're just getting more information around that, which gives me a lot of hope that there will be more focus on it in the future. I just see vestibular migraine and PPPD more talked about in the last 10 years than I used to. So I think that's also really promising that the more people share and talk about it, the more we will get attention to get these proper studies done.

1:34:38.4 Cynthia Ryan: Absolutely. Yeah. PPPD especially is, and vestibular migraine and PPPD together co-occurring at the same time, Ménière's disease as well, lots of attention on that. As you were talking, Alicia, I was thinking that when we think of research, especially patients thinking of research, we're thinking of what research is out there developing something that can help me, as opposed to a lot of research that's going on that helps to better understand a condition. It might... That research study itself might not be developing a treatment, but that knowledge can help future research. And Neil, I know that you wrote a blog post on some Ménière's research that was talking about the genetics of Ménière's. Do you want to share a little bit about that?

1:35:28.5 Neil Canham: Yeah, I think just to... Because I think it's important to understand, I think we're almost not there yet when it comes to treatments for Ménière's because the mechanism is just so poorly understood. And although it's been researched for so so many years, there's just so many different ideas and so many little silos of research to look into different aspects of what's going on in the ear. And so in terms of actual mechanism, we're nowhere near actually fully understanding that to the point where we could develop treatments, because unless you understand the mechanism, it's hard to develop a treatment. But I think what I find exciting, there's two areas of research, two teams doing research which I've had the pleasure of getting close to. One is the work that's being done by Professor Lopez-Escamez in University of Sydney, and his team has been looking very carefully at biomarkers, the sorts of things you can find in the blood or the genes, which seem to be much more common in sufferers of Ménière's. And his work has really demonstrated that Ménière's is not one condition. There are... He's identified four very distinct subgroups, and one of them is a group that clearly has a genetic component to their Ménière's. So there is a familial connection. I think I will get the percentages wrong off the top of my head, but I think it's around about 20%. Maybe I need to read my own article again. And those people seem to have various changes in certain genes that are in some to that have connection to the structures in the inner ear, for example, the way the hairs actually connect to the membrane above them. And if those links don't form properly, then the hairs don't work properly. And those genes have been identified. But there are others as well.

1:37:47.9 Neil Canham: But there's also plenty of other subgroups that were identified, a very large group with overlapping other autoimmune diseases and that therefore implying that for that particular subgroup there could be an autoimmune element to the Ménière's disease. And another subgroup which potentially seem to have allergic component to the things that were discovered in the blood and therefore some allergic component to their Ménière's disease. Now that's fantastic. And that also speaks to why it's really difficult to research because if you don't know what subgroup of people you've got, you've just got people with Ménière's disease, it could well be that one of those subgroups responds really well to betahistine and the rest don't. And that means that if you take all the Ménière's patients and then you test betahistine on them, you're gonna get a not very good result and say it doesn't work. Whereas there were a bunch where it really worked but you didn't separate them out.

1:38:58.3 Neil Canham: And so I think Antonio Lopez-Escamez is really keen that researchers in future, the very first thing they do is to look for these biomarkers and decide which subgroup they're actually looking at and then they might, might get better results. The other people I've been talking to is David Bächinger in Zurich and he's been part of some work with Andreas Eckhard at Harvard Medical School. And they've been really looking at two things which particularly undermine a very, very strong, well-held belief about what's happening with Ménière's. It's such an, it's become a meme in the Ménière's community that you have fluid in your inner ear, that fluid is getting overpressure, something membrane bursts, fluids mix together, that mixing of fluids screws up the balance system. And this theory has origins over 100 years ago when people discovered glaucoma and there was a kind of whole rush of oh, maybe everything's to do with overpressure in different systems. But the evidence is really not there that that's a working model. But it's so nice, it's so easy. I said it in one sentence. It just caught on like wildfire and it's almost impossible to get rid of the idea that that's what's happening, even though there's virtually no evidence. And what Andreas and David had done is to demonstrate there seems to be growth of the membranes that are getting bigger. It's not pressure that's making them stretch, but they actually, the membranes themselves are expanding and their extra cells are getting in there and there's actually more space for the fluid. And they've also shown that there's degradation or underdevelopment of another component in the inner ear, the endolymphatic sac, which potentially is then driving this overproduction of cells.

1:41:10.8 Neil Canham: Now for me, these things are really convincing and they speak to much more of a mechanism that might be potentially understandable. Then you've got the inner ear trying really hard to keep itself working properly by creating more cells in one place because they've been lost somewhere else. And this eventually the inner ear gets tired. It can't produce enough cells and it can't manage the right amounts of sodium and potassium in the different fluids and the thing breaks down and stops working properly. So it's some really lovely work. And that for me is where my excitement is and that's where my hope is that we will eventually understand what the mechanism is and then we can really look at interfering with it and stopping it.

1:42:06.1 Cynthia Ryan: Right. Yeah, we have to understand how it works and we think we do, but as that was a great example of how there is always more to learn and you have to keep asking questions. So that's totally fascinating. I'm gonna ask a different question and that is, and I'll start with you, Alicia, how do you think, how impactful do you think the patient experience is in research? How important is it for patient voices to influence clinicians and researchers and how do you... Do you have any experience being involved in that?

1:42:55.4 Alicia Wolf: Yeah, I think that is one of the... Since we don't have the research to really support what is and isn't totally great treatments for vestibular migraine and PPPD, I think you really do have to lean a lot into the patient experience and what your patients are telling you. I know that the things that have worked the most for me in my journey do not have strong clinical evidence for them outside of maybe my migraine glasses, but other things like that, like my Timolol eyedrops, very, very small study. It was incredibly helpful throughout my whole journey from prevention to now, my acute medication. Same with neuromodulation, very small studies, but whenever I have a lot of bad head pain, CEFALY is the first thing to go on, or every single night I use my Truvaga device to help, and I found that's just helping me with sleep to improve my symptoms there. So I think there's a lot to be said for the patient experience. And I have found that the doctors who listen and share with me what their other patients are feeling or seeing are some of the best doctors that I have worked with. And they're the ones that when you meet them, you feel really, really excited and hopeful about your treatment. And there have been so many practitioners I've gone to where I just felt left the appointment and I just felt really defeated because I wasn't really given any options. I wasn't really told about things that could or couldn't help. I wasn't really given that hope in trialing different things, and maybe that'll be the key piece. And so I have really enjoyed working with practitioners who will take my feedback or other patients' feedback and let me know, "Hey, this seems to be working for my other patients. Maybe it's safe for you to try. Maybe this would be a good option for you." So I have found some of the most effective treatments that way.

1:45:13.3 Cynthia Ryan: Yeah. Yeah. Neil, how about you? I know you were talking about how you've developed relationships with researchers, and so you do kind of have a direct line of communication with these researchers. Are they open to your perspectives as a patient?

1:45:32.8 Neil Canham: Absolutely, and in fact, one of the things that I was really astonished about is that I asked some questions having read... Well, I started writing an article about the work of David and Andreas, and on the back of an interview that I'd done with David, and I ended up, as you always do, you think you've asked all the questions you can, and as soon as you start writing, you realize there's lots that you don't know. So I fired back with what I had to apologize for being rather a lot of questions. And I was astonished by the feedback that I got, that he took them to the professor he was working with, and Professor Andreas Eckhard, and they actually studied my questions at a conference and said they were really good and came back with really detailed answers and asked me to give them more. And I just found that really fantastic. It's a long way from the idea that they're the experts and we just need to shut up and listen. It's the complete opposite, and I've been really lucky in that regard. I do know from running the support groups, a lot of people don't have this kind of experience with doctors. And as Alicia was saying, some people do feel that their experiences are disregarded and they're not taken seriously. And I think I've just been incredibly lucky. But I'm astonished that the researchers are so open. And one area I was really happy and I'd like to raise it because it doesn't get mentioned about with Ménière's very often is diplacusis. It's a condition where you hear the pitch of musical notes different in each ear. So you might hear an F on the piano in one ear, and it sounds like a G in the other ear, or even worse. And I had this extremely badly for quite some time, and I had to quit playing in bands, and I actually stopped playing altogether for a while and teaching because I couldn't hear my own instruments properly. I would play a scale and it sounded like nonsense. And I've since discovered this turns out to be really common with Ménière's, but it's almost never mentioned., you never see it listed in any symptom lists. So I'd like to work with David... It turned out that David Bächinger is actually chief medic for one of the big symphony orchestras in Zurich. So he's their doctor, and so he's fascinated by the topic of music and hearing problems with music. So I want to actually get involved in that. I even want to try and develop a tool, maybe an app, which you can use to measure the difference in pitch perception between the two ears. And yeah, I was so happy he seemed really enthusiastic about talking to me about these sorts of things and listening to my perspective.

1:48:37.0 Abbie Ross: Well, I wonder if you could get any of the major musicians who have Ménière's disease to support that research.

1:48:46.0 Neil Canham: Yeah, well, actually, I've been talking to a Professor of Music in the UK, a guy called Andrew Hugill, who also has Ménière's, and he has had diplacusis, and he's done some fascinating projects. He actually built a piano which played notes that sound the way they do to him so that everybody else could perceive the strange scales that he's hearing, and then he composed some music for it.

1:49:07.7 Cynthia Ryan: Right. I think that's something that I've talked to many people about, is how can we get other people to understand, experience, not just understand, but experience what we're going through as vestibular patients. Something else that I want to just talk about and share with people is that it is a growing trend in medical research to directly involve patients in the research, even in the beginning parts of the research. Obviously, you've probably heard that patients can participate in clinical trials. You're either receiving the treatment or you're not receiving the treatment, you're a control. That's a really useful way to support research, even if you're not getting direct benefit. Sometimes you see direct benefit, sometimes you might actually have side effects. There are pluses and minuses to doing that, but it's really useful. And VeDA has some articles about how to participate in research and also the benefits and the drawbacks. So please check out VeDA's website or post a question and I'll post the links to those articles. But also, patients can often participate in the research as it's being developed. I know David Morrill, who many of you probably know, he's VeDA's community support coordinator, and he moderates several support groups as well as a very large Facebook group about vestibular disorders. He has participated... His experience, his vestibular experience comes from having had a stroke that was misdiagnosed.

And so he works with a researcher who specifically studies strokes and is involved in evaluating the research study before they actually go into clinical trials to give feedback on what's important to me in terms of an outcome. I think that very often what doctors or scientists think might be, "We want this as an outcome," that might not be what a patient wants as an outcome. So what's important to me as an outcome, what risks am I willing to take? They might be willing to take higher risks than a researcher might have included in the study. And if it's the type of research that involves questionnaires, are those questions, do they make sense to me? So there are a lot of ways to participate in research that's really useful before the research comes out. Additionally, and this is a selfless plug for VeDA's patient registry, it's a fantastic way to participate in research. What a patient registry does is it's a series of surveys that are designed by medical experts. VeDA spent almost a year reviewing the questions in our surveys on the patient registry to make sure that they are asking the questions that we want to ask and getting the responses that we want that are going to benefit the medical community in helping to understand vestibular disorders.

1:52:40.9 Cynthia Ryan: It's, I'm gonna say easy to participate in, in that it's online. You don't have to go to a facility. A lot of research, you actually have to go to that facility, so you can only participate in research that's at an academic center that's in your local area or you have to travel. With VeDA's patient registry, it's online, so you don't have to travel to participate in it. There are downsides, and one is that there are a lot of questions. And so that can be really hard for people with vestibular disorders to be online for a long time. However, you can start, you can finish one survey, you can stop and come back and finish a second survey. You can even stop right in the middle of the survey. You can do it at your own pace. And if you need help, you can get someone else to help you with it. But it is extremely important to collect the information about the vestibular patient experience. We actually, we, at the beginning of 2025 or in the middle of 2025, we launched a new patient registry. We're collecting information from scratch, and I encourage everyone to go to vestibular.org/registry to participate in that. But we had a previous registry that we just recently published a paper in the Annals of Neurology. That is... Now this information that was provided by patients is in the medical journals and can be referenced by other researchers. So it's really important to get the patient information represented in vestibular research. And it's not just about does this medication help? It's about how this impacts your life.

1:54:48.8 Cynthia Ryan: All right, so I digress. I'm gonna come back to some of the other questions that we have. What advice, Alicia, would you give to a patient who is thinking about trying a new device or therapy for the first time?

1:55:08.6 Alicia Wolf: I would just say that you never know if something's gonna work unless you try. And so I think one of the things that helped me the most during my journey is I was very open-minded to any treatment out there. I'm still trying to try new things as I head into perimenopause. I've noticed a lot of hormonal shifts. So I've had to really be open to trying lots of different things throughout my journey as someone who went through IVF and then two pregnancies and then now heading into peri-menopause. It's just a lot of shifting for me. And it's not just like, oh, you find one medication for vestibular migraine and it's perfect. It's something that you always have to navigate through different stages in your life. And I would also say that if you're not seeing results immediately, to give things more time. Like most migraine treatments really require you to spend a solid three to four months of regular use to really be able to gauge if that is going to be helpful for you. I know with some of these monthly injections, my doctor has told me they can take six to 12 months to even see results from. So I would say if you're not seeing results immediately, don't always give up on things right away because I have found that it's really consistency and time that helps a lot with healing the vestibular migraine and PPPD process. And just continuously putting in effort with it and continuously trying some new things has been the most beneficial for me going from chronic to rare episodic now.

1:57:05.0 Cynthia Ryan: Thanks. Thank you so much. And I just realized that we are actually running over time and I kind of let us go on because we got a little bit of a late start. So I'll go ahead and wrap it up. I'm gonna end with this question for everyone, just to think of it in your mind. If you could imagine the ideal future of vestibular care, what kind of innovation or breakthrough would you want to see? So people, go ahead and post that in the chat. Maybe we'll come in and respond to that. Neil and Alicia, thank you so much for sharing your experience and your expertise as well. In a way, you are experts in not only your body but also in your disease from the research you've done on it. So thanks for sharing with us today.

1:57:57.4 Alicia Wolf: Thank you.

1:57:58.0 Neil Canham: Thank you.

1:57:58.5 Cynthia Ryan: And thank you everyone for being here today. If you want to follow Neil and Alicia, we're gonna have their links. Let's go ahead and put their links here. There's Alicia's link, The Dizzy Cook, and Neil also has a blog where he takes research and discerns it into a way that we can all understand. Please check them out. And don't forget tomorrow, follow us for tomorrow's session on living well with chronic vestibular conditions, and we'll see you then.