Life Rebalanced Live 2026

WHEN CONDITIONS OVERLAP:
PPPD, VESTIBULAR MIGRAINE, AND OTHER COMORBIDITIES

0:00:03.9 Abbie Ross: Hello and welcome to the final day of the Vestibular Disorders Association 6th Annual Life Rebalanced Live virtual conference. Final day, somehow we made it. 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 here at VEDA. Before we dive into our last day, I'd like to again thank our sponsor one last time. The James D. And Linda B. Hainlin Discovery Fund and the University of Minnesota's Department of Otolaryngology have generously supported Life Rebalanced Live since its inception in 2020. A special shout-out to Jim Hainlin, a fellow patient who inspired this event by holding his own vestibular conference in both 2018 and in 2019. Jim cares so deeply about supporting people on their vestibular journey, and it was important to him to not only educate people about vestibular disorders, but provide a platform where people can connect. 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.

0:01:12.2 Dani Tolman: Thank you, Abbie, and hello everybody. Happy Friday and final day of Life Rebalanced Live. 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're 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.

0:01:49.1 Abbie Ross: And before we get started with today's conversation, I'd like to direct you to the poll questions for this session. If you haven't already, please complete those polls now. Also, feel free to talk amongst yourselves. You guys know the drill by now, and please put any questions you have for the speakers on today's topic in the Q&A section, and we'll do our best as always to incorporate as many as we can.

0:02:10.9 Dani Tolman: And just a little reminder, although you'll 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.

0:02:25.2 Abbie Ross: Today we're going to explore what happens when vestibular conditions coexist, such as 3PD or persistent postural-perceptual dizziness, vestibular migraine, and BPPV, or benign paroxysmal positional vertigo. We'll talk about how this can emphasize the need for a multidisciplinary, whole-person approach, and our speakers will share clinical insights on diagnosis, treatment, and care coordination while emphasizing realistic expectations.

0:02:54.5 Dani Tolman: Such a big, huge topic and very exciting day. So it is my pleasure to introduce our guest speakers, Dr. Shin C. Beh and Dr. Kristen K. Steenerson. Most people know these two guests as the vestibular migraine experts. Dr. Beh has published numerous papers and has authored several invaluable books for our community while also operating a clinic out of Irving, Texas. Dr. Steenerson is the clinical associate professor of otolaryngology, head and neck surgery, and neurology and neurological sciences at Stanford University, where she directs the Vestibular Balance Disorders Program. Welcome, Dr. Beh and Dr. Steenerson. All right, we got to get right into it because this is a big topic, big day. I know a lot of people are gonna be watching and very excited to hear from both of you. So many people present with overlapping symptoms. Dr. Beh, let's start with you. Where do you begin when trying to differentiate between 3PD, vestibular migraine, and other comorbidities in your diagnostic process?

0:03:57.3 Shin C. Beh: I think the first part is, of course, history. Right? In every condition, but in any vestibular disorder, you have to start with the history and the pattern of the symptoms, what triggers the symptoms. Based on that, you can tell what's going on, whether it's vestibular migraine, whether you have 3PD, whether you have BPPV, whether it could be Meniere's disease. And I think from there, then you look at the tests that have been performed so far, and you go to your exam... This is a very broad overview, obviously. And then based on all of that data, you can make a diagnosis.

0:04:32.3 Abbie Ross: Can you tell us a little bit about the differentiating factors, specifically between vestibular migraine and 3PD? Maybe symptom presentation, timing of symptoms, triggers of symptoms? Dr. Steenerson.

0:04:47.2 Kristen K. Steenerson: Yeah, this is a great question and it's a little bit controversial. So first I'll talk about the information that we do have, where the diagnostic criteria for 3PD recommend that the dizziness has a continuous or chronic timing. So it's there the majority of the time, at least 50% of the time. And classically, it starts with an inciting event. Sometimes you know what the event was, like you had BPPV or a first ever vestibular migraine attack or a panic attack. And ever since that event, you feel this persistent rocking or floating or dissociation sensation that is worse when you're upright, worse in complicated environments. Whereas vestibular migraine is classically an episodic event. So this is something that comes and goes, but usually has hypersensitivity symptoms that go along with it. So lights are too bright, or sounds are too loud, or smells are nauseating. Motion is overly sensitizing. Light touch might be painful. And these episodes can last anywhere from five minutes up to 72 hours. But we know that there are inherent problems with both of those sets of criteria... That they're purposefully limiting how many people can be diagnosed to ensure that we are diagnosing the most people correctly. But in order to do that, we're actually purposefully eliminating the more overlapping of syndromes to try and give people as clear a diagnosis as possible. But that means that we're not diagnosing everyone with those conditions.

0:06:16.9 Dani Tolman: It's so challenging when we have those overlapping symptoms and presentations, especially because it's not uncommon for different diagnoses to co-exist. Are there overlapping physiological or neurological processes that explain why these disorders might overlap or occur together? Dr. Beh, I'll kick that over to you first.

0:06:40.5 Shin C. Beh: Absolutely. So I think first of all is, of course, genetics, right? How we are born, we can't change that. And how we are born determines how the brain is also programmed. So generally, broadly speaking, a lot of patients who are more vulnerable to getting migraine or 3PD tend to have early indicators like history of motion sickness, a little bit more prone to anxiety, tend to be a little bit more type A personalities. Those are the folk that are a little bit more predisposed to developing vestibular migraine symptoms and 3PD. There's this hormonal component to it too. So a lot of patients who have migraine, who have vestibular disorders, tend to be women. And so there is a link between estrogen, maybe progesterone, and a lot of these vestibular disorders. We also see the hormonal link in the time when they develop these conditions. So a lot of times we see, again, these general patterns that a lot of patients with 3PD with vestibular migraine tend to develop the symptoms a little bit later in life, so closer to the perimenopausal state.

0:07:50.7 Abbie Ross: Dr. Steenerson, did you have anything to add to that?

0:07:54.6 Kristen K. Steenerson: One thing that is interesting is looking at the neuroanatomy, or the pathways in the brain and the nervous system that overlap between what we think of as traditional migraine pathways and 3PD pathways, which is why I think it can be so challenging and confusing... Because you might actually highlight both of those pathways that get activated and therefore have so much overlap in terms of symptoms. And those different pathways, they have really technical terms, but we think of like the trigeminovascular system, the trigeminocervical system, and then a really important pathway is through our fear system, so through the parabrachial nucleus. So we have a lot of anxiety that gets activated by vestibular disorders. But that's also why our fight-or-flight system can become hijacked and really challenging to control when we get a vestibular problem, that can feed into the development of 3PD. So there's a lot of really interesting but really frustrating overlap in the neuroanatomy.

0:08:52.1 Shin C. Beh: Absolutely. And to piggyback on that, I think the neurotransmitters too. You have issues like serotonin, norepinephrine, dopamine related to all these conditions as well.

0:09:02.5 Abbie Ross: Yeah, such a good point and such a good segue into our next question, actually, about psychological stressors. So anxiety, depression, just stress in general... Could these be considered causation or amplifiers to symptoms, or maybe even both in some cases? Dr. Beh, why don't you start that one?

0:09:23.5 Shin C. Beh: Ah, you give me the tough one. So stress is a huge problem for a lot of patients with both migraine and PPPD. It can be many different things. So for PPPD, of course, a lot of times it is the inciting event. So a very highly stressful event can bring on PPPD. You could experience a vestibular episode with a lot of stress, that could also bring on PPPD. We have patients who... Now to segue a little bit... With MDDS, they can travel without any problems, but if they travel during a time of very high stress, that could also bring on MDDS. And of course, with migraine, stress can initiate the first presentations of migraine, vestibular migraine, and also be a trigger for a lot of the episodes. So I think the relationship there is very complex. I wouldn't say that stress would be the cause of these conditions. For migraine, for PPPD, yes, it could be the cause of the provoking event, but migraine... I think the initial event is more of an unmasking of the migraine issues, and then later on it becomes a trigger for it.

0:10:35.5 Dani Tolman: I think what frustrates me while working with patients are those who are coming in with this guilt or the shame of feeling that their doctor is telling them, "You're just stressed, you're just anxious. Your symptoms are just related to that and you just need to relax. You just need to take this medication." I really don't want that guilt on patients, but it's really not coming down to as simple as that. I wouldn't say that, as you had mentioned, that these symptoms are caused by, but maybe have a difficult relationship with. Dr. Steenerson, how do you talk to your patients about this and maybe kind of unpack that with them... That while stress plays a role, this is not the cause of what's going on?

0:11:17.9 Kristen K. Steenerson: Yeah, it's a great question. I think of stress as... First of all, I think we should make it a more neutral term... That we need stress to grow. We need stress to push ourselves, we need stress to learn new skills. We need stress physiologically for our bones to be strong and for us to prevent fractures as we get older.

We need to do weight-bearing exercises. So stress is not necessarily a bad thing, and in many ways it improves our resilience and our overall tolerance of the world around us. But we know that stress is dose-dependent, meaning that if you have too much too quickly, or in a setting where you're not prepared for it, it can be overwhelming. And so as a result, I think the threshold model can sometimes be a helpful way to think about this. So we all have a threshold of tolerance of certain amounts of stimuli that we can take, or certain amounts of information that we can take. But if your threshold is very low... And that could be because of things that Dr. Beh brought up, like hormone fluctuations or sleep deprivation, or there's another vestibular disorder that is going on... All of this has made your threshold very low, so you're very susceptible. Now suddenly stress can become too overwhelming for you to maintain your homeostasis. And so you break through that stress tolerance level, and that's where you'll get an episode. So the underlying cause is still related to this complex interplay of environment, genetics, and other predispositions medically, but stress is potentially making that threshold so much easier to overcome in an unhelpful way. So if we can try and modulate our stress responsiveness, our resilience, emotional regulation, that could help with, first of all, improving that threshold, but then also reducing how often we're surpassing that threshold.

0:13:00.0 Abbie Ross: Such good explanations from both of you. I also want to touch on two other diagnoses before we transition maybe into management and treatment. How do we identify Meniere's disease and BPPV? Dr. Steenerson, why don't we start with you this time?

0:13:16.7 Kristen K. Steenerson: Yeah, these are great questions. So Meniere's disease is an inner ear disorder where we think the underlying mechanism is related to too much production of endolymph, which is this fluid inside our ears. It's really complicated and controversial even if that's the underlying cause, but that's what a lot of people agree on at this moment in time. And so as a result, if there's too much fluid buildup in the ear, that will cause fluctuating hearing loss, so low-frequency hearing loss. It will cause fullness in the ears. It will usually cause a loud, roaring, whooshing, jet engine-like tinnitus on one side. And those symptoms should be time-locked, so simultaneous with vertigo episodes. And we have strict criteria for that. You should have 20-minute to 12-hour long episodes that have these time-locked hearing symptoms that go along with it, and a documented hearing test that shows you have a low-frequency hearing loss. And migraine can have a lot of overlap with that because people can have hearing symptoms that go along with it, and so it can sound a lot like it when someone's talking to you in the clinic. But you really have to get that objective measurement with the hearing test, and ideally some vestibular function testing, because we'll usually see some signs of deficit in the vestibular side just like the cochlear side. So it's really important to get extra testing to be able to get the diagnosis of Meniere's disease, and also recognize that 50% of people with Meniere's disease have vestibular migraine, and that vestibular migraine is at least 10 times more common than Meniere's disease. So a lot of people are over-diagnosed with Meniere's and under-diagnosed with vestibular migraine. And then BPPV is a mechanical problem where we have crystals that are supposed to be stuck in one compartment, but they can fracture and fall out of place down one of three tunnels on each side. And so when we move our head in the plane of that tunnel, that causes the crystals to fall out of place and causes your eyes to jump, and it causes you to feel a horrible spinning sensation for usually 15 to 60 seconds. So that's a mechanical problem that we can check by placing your head in different positions, looking to see if you get vertigo and nystagmus, or the jumping of the eyes. So we can check that in the office. But it's tricky because it's a dynamic problem. So if it just so happens that that day you're getting checked the crystals are in place like they're supposed to, you won't trigger the symptoms. So it's really critical for the patient to tell me that, "No, it's not happening like it usually does," so that I can say, "Okay, well, this test just isn't valid today because we're not getting the representative attack," to try and pair that with your diagnostic accuracy. But that too... You have two to three times higher likelihood of developing BPPV if you have vestibular migraine, and vice versa, much more likely to have vestibular migraine if you have BPPV. So there's a lot of overlap between those, but it's really important to bring that up because they do have different treatments available. So you really want to know if someone has multiple diagnoses that you're dealing with, because you may be undertreating them.

0:16:17.4 Dani Tolman: You're making our jobs a heck of a lot easier because all of my follow-up questions you hit on the next thing that you say, which is perfect. I mean, you're absolutely... It's really good to know that there are a lot of these overlapping diagnoses, but having one of these diagnoses also makes it more likely to develop a secondary condition of BPPV, or it might complement another diagnosis that aligns with that. Dr. Beh, do you have anything to add?

0:16:43.0 Shin C. Beh: Piggyback off that too. So hearing is the most important one in Meniere's disease. If there's evidence of asymmetrical low-frequency hearing loss on the test, then that supports the diagnosis of Meniere's disease. I think the complicated part with Meniere's disease is, like Dr. Steenerson mentioned, the overlap with migraine. So anything that gives you vertigo can trigger a migraine attack. So you potentially could have a Meniere's disease attack that causes a migraine attack, and so you develop the light sensitivity, sound sensitivity afterwards. So that can be slightly confusing, but the hearing test would be key to making the diagnosis of Meniere's disease. For BPPV, the attacks usually are a bit shorter. So you have positional vertigo, positional dizziness brought on if you put your head in a specific position, lasts a few seconds, never more than a minute, and you really don't have the associated migraine features: light sensitivity, noise sensitivity, visual aura, headache, all that good stuff. Right? And so that bit of history can help us to differentiate these conditions.

0:17:51.0 Dani Tolman: I think history is huge, not only for you guys in the diagnosis and trying to figure out where to start with this patient, but I feel like it also opens a conversation for education. I think that where patients struggle is putting language to what they're experiencing and how to accurately report that to their healthcare providers in order to paint a clear picture. And then I have found that when patients better understand their symptoms and their diagnoses, then they really take a step back and they're doing a much better job of distinguishing what their symptoms go to when something's flaring up. Is this more of a BPPV issue? Is this more of a migraine issue? If I'm having a migraine, do I need to be on the lookout for BPPV? So I think that not only does this create a conversation and create a good history for you guys to be able to help them, but also starts the conversation to educate that patient when it goes into treatment and management of these diagnoses. So let's start to morph into the treatment and management strategies that we have with overlapping diagnoses. Dr. Steenerson, where do you start? What does it look like for a treatment approach when it comes to working with somebody that has multiple diagnoses that may be overlapping?

0:19:10.2 Kristen K. Steenerson: Great question. So when I am suspicious that someone has underlying diagnoses, I want to understand if there is a potential trigger effect, like Dr. Beh was talking about. So does this person have recurrent vestibular symptoms on top of their more chronic vestibular symptoms? So for example, if they have BPPV, that's really critical to understand because that can act as the retriggering for PPPD to really maintain that chronic state and keep you in that fight-or-flight state. So that's usually my top priority... To understand first, do you have an episodic vestibular syndrome on top of your chronic vestibular syndrome? Because we need to make sure that's as managed as best as possible to try and reduce that overall retriggering effect that happens with the chronic vestibular syndromes like PPPD. So that's usually a critical part of the treatment plan: addressing triggers. Then, of course, a lifestyle inventory. Are your basic brain health needs being met? Are you getting enough sleep, and is it quality sleep? Are you eating healthfully, nutrient-dense foods? Are you getting enough exercise... Cardio and strength training, and vestibular-focused? Are you drinking enough water, getting enough electrolytes? Is there any autonomic dysfunction that might be adding on to the challenge of your dizziness? And then what's your stress management like? Do you have stress management tools? Are there other stressors that we could reduce, or improve your coping with? And then from there, of course, physical therapy to help with getting moving again and focusing on the right types of vestibular therapy... Which you guys are way more experts than I am... But making sure that we're not just doing a hypofunction approach. We're not only thinking of this as a vestibular neuritis, and we need to think about habituation and desensitization exercises, exposure therapy, and combining that with some type of emotional regulation like mindfulness or meditation, cognitive behavioral therapy practices, and then finally medications if needed. Huge answer.

0:21:12.0 Dani Tolman: Yeah. Let's break it down even further. Dr. Beh, can you talk specifically... What are you recommending to your patients about sleep, for example, or stress management or hydration?

0:21:25.0 Shin C. Beh: So those are very important, I think more on the migraine side, PPPD, MdDS. BPPV, less clear from what I understand regarding that. Sleep is very important when it comes to many different neurological conditions, and the key is to have some regular pattern of sleep. I think it's too simple to say, "Everyone, you must get eight hours of sleep." Some people need a little less, some people need a little more. It depends on what your physiological needs are. So getting that amount of sleep that your body needs is important. Not sleeping at irregular hours, not taking naps when you're not supposed to take naps... I think that goes a long way to help prevent the migraine symptoms from flaring up and can also help with stress management. And then it gets important when it comes to PPPD and MdDS. The diet part... I know everyone pays a lot of attention to diet. We have this tendency to think that the diet will solve a lot of our problems, but it's not as simple as that. It can help for sure. So big takeaways I tell all our patients with dizziness: make sure you don't consume too much caffeine. So no more than the equivalent of one about 10-ounce cup of coffee per day. Limit your alcohol intake to no more than one to two cups per day. Limit processed food intake as well. Those three things are very important. If you drink too much caffeine, consume too much alcohol, too much processed foods, that can worsen migraine control, that can aggravate a lot of conditions as well, like anxiety and depression, which has a link to PPPD and MdDS too. When it comes to limiting the migraine trigger foods, that also can be quite useful in some people. The tricky part is, of course, not everyone has the same triggers. Some people may find that chocolate will do it, some people bananas, some people avocados. The key is to find what triggers your attacks. If you avoid every single food that is known to trigger migraine, you're gonna have a very boring life, unfortunately... You won't be able to eat very much. Sugar intake is an interesting one. So excessive sugar intake can trigger migraine attacks. Too much sugar also can worsen depression, can worsen anxiety. Salt, of course, for Meniere's disease, that's the big one... To limit salt intake from that standpoint. Salt in migraine is an interesting concept too. So some people who eat too much salty foods can trigger a migraine attack, and some people who are about to have a migraine attack find that if they eat something really salty, that can actually abort the migraine attack. Salt also has a role in anxiety too. So excessive salt intake can also worsen anxiety, and that may worsen PPPD control. If you want to adhere to one particular diet, I usually recommend the one that has the most evidence, which would be the Mediterranean diet.

0:24:14.7 Dani Tolman: I love what you're echoing about diet and looking at food because even 10 years ago, 11 years ago, when I first started working with this patient population, I found that even just talking about the diet aspect was a big stress inducer. People were diving in and going directly into the elimination diet or the Heal Your Headache, and man, is it stressful... Because you take a huge change to your life and now you don't know what you can eat, you don't want to go out to restaurants. You completely take your world and shrink it down and make it so stressful. And I think that a lot of people watching today are probably very relieved with some of the tips that you gave, because those are really easy things to make a gentle shift towards to see some improvement on. So those lifestyle modifications, looking at trigger avoidance, are all huge. What about that multidisciplinary team? We kind of mentioned some things in terms of physical therapy and mindfulness. Could you guys talk about what that multidisciplinary team might look like? Who might be involved with those approaches? Dr. Steenerson, I'm gonna throw that over to you first.

0:25:21.5 Kristen K. Steenerson: Yeah. And I think you can think about this in terms of degrees of influence. So I think that the highest degree of influence is the vestibular physical therapist, the vestibular neurologist, or the vestibular neuro-otolaryngologist. This is something that we're treating all the time, very comfortable with, can really address the most vestibular-specific questions and needs. But then we think of the vestibular-adjacent problems that can either be directly related to, or a consequence or cascade effect of, dealing with the vestibular disorders. And so in that realm, I think of cardiology, for example... Are you developing some autonomic dysfunction or postural tachycardia syndrome? Autonomic neurology, same question. Psychiatry to help with medication management if anxiety or depression are really severe because of the vestibular disorder. Psychology for non-medication management of those psychological problems that can occur as a result of the vestibular disorder. And then sometimes nutritionists can be really helpful. I'm usually seeing people who have become really restrictive in their eating and now their life has gotten really small, and they've become really fear-avoidant of food and situations. So having a nutritionist or dietitian in addition can be really helpful. And then sometimes an exercise physiologist or a personal trainer if they're beyond the physical therapy, but they just need to get exercising more and get more movement. Those can be kind of farther out, but still potential teammates to work with or work alongside.

0:27:03.1 Abbie Ross: And I think one thing this stresses is that there is not a silver bullet to any of these conditions, and that's why a multifaceted approach by a multidisciplinary team is so, so important. But I know one question that our audience often wants to hear about are the meds. And we heard Dr. Steenerson mention meds last in her list of treatment and management approach, and I loved that, because I think it's important our audience knows that there's a lot of self-agency over their care. There are things you can do to help outside of medications. But if we get to the point of medications, or if we think medications are appropriate, what's the approach there, Dr. Beh?

0:27:46.3 Shin C. Beh: So first thing would be to figure out what we are treating, right? If it's more along the lines of PPPD, if it's more along the lines of vestibular migraine. I think the important point that I emphasize to a lot of patients is that it's not their fault if they have to take medication. I think the trouble is a lot of people start to feel that, "Oh, if I try hard enough, if I exercise hard enough, eat well enough, eat clean enough, do all these things, I can overcome this." And sometimes we are just slaves to our genes. Some people do really well with the supplements. Some people do really well with diet control, exercise, all that good stuff. But often we may need some medications... It's none of your fault. We cannot will away diseases as much as we try. We may need glasses, yeah. Not our fault. All the positive thinking in the world cannot make our vision better. So sometimes medications are needed. If you have an overlap between vestibular migraine and PPPD, my experience is as you help reduce the number of migraine attacks over time, PPPD also gets better. If it's just PPPD triggered by, say, a very stressful event, or an isolated vestibular event like BPPV or vestibular neuritis, the treatment is also different. So on the migraine side, you have a ton of different possible treatments. You have, of course, the antidepressants that are commonly used. You have the old ones like the tricyclic antidepressants. You have the newer ones like the selective serotonin reuptake inhibitors and the selective norepinephrine reuptake inhibitors. You have, of course, the anticonvulsant medications that are involved. You have the blood pressure medications, you have Botox, and of course the new class of medications that are calcitonin gene-related peptide inhibitors. Is there one magical class of treatment? Absolutely not. Can anything cause side effects? Absolutely. Can we predict side effects? We cannot. Can we predict which medication will work best for you? We cannot. So what we do is we try to figure out what would be best for each person based on if they have any other comorbid issues. So, for example, if they have high blood pressure or high heart rate, we could potentially consider beta blockers. If somebody has trouble with insomnia, we could choose medications that could help them fall asleep at bedtime. If they have trouble with fatigue during the day, then we perhaps could choose medications that would be a bit more activating and they can use during the day. If a patient has constipation, then we avoid medications that could worsen constipation, and so on and so forth. When it comes to PPPD, the mainstay of treatment I believe that most of us use would be the antidepressant therapy, usually the newer antidepressants, the SSRIs and the SNRIs. Now, of course, there are some who have a lot of trouble tolerating these medications, and so that's where we have to maybe explore other options as well. Like beta blockers can be useful in people with anxiety. Some of the anticonvulsants may also be helpful in this patient population. One thing I forgot to mention would be neuromodulation, where you use devices to alter the brain's activity. In migraine, you have the Cefaly, or the trigeminal nerve stimulator. You have the vagus nerve stimulators. I think you have the SAVI as well, which is like a TMS device. You also have the combination of the trigeminal and occipital stimulator and the Nerivio device as well. So all of them can potentially work in migraine. I don't have as much experience with the Nerivio in vestibular migraine. I'm not sure if Dr. Steenerson has experience with that. When it comes to PPPD, there was one study from Europe that showed that the vagus nerve stimulation could potentially help with PPPD. So I think it's very... It's impossible to say, "This is the treatment that everyone needs to follow." It has to be individualized. It depends on each person, their experience, what they're aiming for, what other issues that they have.

0:31:47.1 Dani Tolman: I guess a follow-up to that... A lot of my patients end up having, or they assume, is: "I don't want to go on this because that's another medication add."

Is there a chance, or what does the likelihood look like, that they can come off of these medications? If they start them, are they on them for life, Dr. Steenerson?

0:32:05.9 Kristen K. Steenerson: So I approach this very similar to how we approach people dealing with chronic migraine, where I think about the timeline in terms of months to years. And so if someone has an appreciable improvement responsive to their medication, I'll recommend staying on that for at least another year to try and help create a steady state. Let's remind your brain what it feels like to be able to modulate the vestibular system in a helpful way and to feel like you can have more predictability. And then at a year, we can decide if you think that the timing is right to try and come off the medicine to see if you still need it. Because it's possible that there was something going on at that point in time... There are hormone fluctuations, you're in perimenopause, excessive stressors happening in your life, there's some other endocrinologic or other medical comorbidity that has now subsided. And so maybe the medication isn't needed anymore. And then patients are really, I think, savvy at being able to say, "Yeah, it's a good time. I think I want to try it." Or, "You know what? I can tell it's not right, so let's do this next year." So I really try and set these year-long check-ins to determine if you really do need it lifelong. Some people might, and so that's a possibility, but it's always up to you if it really is worth it to stay on the medication long-term. And thankfully, we have a lot of great literature from our psychiatry colleagues showing that most of these medicines are probably safe to stay on long-term, as long as you're connected with a physician to monitor.

0:33:36.5 Dani Tolman: I like that you said it's always up to you, because I stress to patients... When you're working with your neurologist or whoever is managing your medications, you really are part of the team. They're relying on your feedback to make adjustments. Dr. Beh, can you talk to us a little bit about what that looks like? If a patient comes to you and says, "I was projectile vomiting after starting this," or, "I had this other adverse effect," how long are you allowing them to stay on that medication before changing it? And also, talk to us a little bit about dosing. Is there anything you consider when it comes to dosing for patients who might be more sensitive to meds?

0:34:13.8 Shin C. Beh: So all our patients, I think, are more sensitive to medications in general. People with migraine, vestibular migraine, PPPD tend to have generally more sensitive constitutions. And so I start at the lowest dose of whatever medication that we choose... The babiest dose that we can find... And slowly work our way upwards. Much different from, say, when we look at the antidepressants: the psychiatrists often start at higher doses and move more quickly, whereas they laugh at the neurologists like us who start with little baby doses and very gingerly titrate up the dose. So the goals are different. In the psychiatry world, of course, they are trying to get depression and anxiety under control more quickly. For us, it's a balancing act. We are trying to get things under control, but at the same time avoid bad side effects and give the body a little bit of a chance to get used to the medication. When to give up depends on the side effects. Of course, if it's a really bad side effect, then I'm not going to have them continue taking the medication. For example, if we start an antidepressant, even at the low dose, if they told me that they started to have thoughts of hurting themselves, I'm like, "Stop. No more." If it's just maybe feeling a little strange, a little bit weird, slightly more dizzy than usual, a little bit anxious, I'd say try to put up with it. Generally speaking, as you build up the dosage, that tends to get better as you build that tolerance to the medication. As for that target dose, it's impossible to predict. So how I approach my patients is: we're slowly going to build up the dosage. It'll take a little time for us to see whether it's helping you or not. But once we get to a dose that you tell us that you are happy with, that controls your symptoms well, then we can stay at that dose, barring, of course, any bad side effects.

0:36:09.5 Dani Tolman: This is something I have patients that are asking, actually something that I'm kind of interested in knowing more about too. But how much are you guys seeing patients' medications that you are prescribing being determined by insurance coverage or what the insurance is willing to cover? So we talk about some of the ideal things to put patients on and what we really want for them, but what are you guys seeing in the clinic when it comes to prescribing those meds? Are patients getting the support and help that they need? Do you have any recommendations for how maybe people can advocate for themselves to get that taken care of? I want to hear from both of you, but Dr. Steenerson, let's start with you first.

0:36:56.9 Kristen K. Steenerson: Yeah, it's an emerging problem. We're a little bit behind the migraine headache literature in terms of studies and research that have been done for vestibular specific. However, really interestingly, in the last 2023, there was a really lovely study looking at triptans for vestibular migraine and found that they were essentially ineffective for vestibular migraine symptoms. But if we try and prescribe a migraine-specific medicine like CGRPs, for example, the gepants... Maybe you've heard of Ubrelvy, Nurtec… Those will be rejected by insurance companies because the patient has not tried a triptan, since those are considered first-line migraine headache abortive or rescue therapies. And so we're finding ourselves in this conundrum where we have evidence that shows triptans are not effective for the vestibular symptoms of vestibular migraine, but insurance is requiring us to prescribe them to attempt to see if they'll help this person, even though I've never seen it help people, in order to kind of jump through these hoops to get access to CGRPs, which we do have evidence showing they can be helpful for the vestibular symptoms of vestibular migraine. So a lot of times I have patients that are just good team players and they're like, "Okay, just write me the prescription. I will try it once and see, and then I can report back that it's not helpful." But medically, that's really uncomfortable. Why would we prescribe something that isn't indicated or makes sense? But this is, unfortunately, an unhelpful system and a system not geared towards patient care that we work in.

0:38:34.3 Dani Tolman: What's frustrating to me is that some patients will just get really frustrated with having to jump through all these hoops and kind of throw up their hands and be like, "I'm done with this. I don't want to try this anymore because this is pointless. Why are we doing this?" And it hurts my heart because I want them to get to the point that they need to get to. It just is so frustrating. Dr. Beh, what do you have to add to that?

0:38:55.8 Shin C. Beh: Insurance companies are the children of Satan, definitely born of the devil himself. So the thing is they're in it for money, right? They're not there to help patients. So they do everything that they can to deny care to patients, everything, even with generic medications. So that's the frustrating part. I've had patients be denied generic medications which, if you use the Mark Cuban pharmacy, GoodRx, or Amazon PillPack, you could get it for really cheap, but they get denied by insurance companies, which is just insanely frustrating. Of course, with the newer medications, the CGRP blockers, then that becomes a big hurdle. For the most part, I don't try to be too specific when I submit the diagnosis. Right? I don't have to tell the insurance company that it's vestibular migraine. I just say migraine. Right? We're not lying. We're just not being too specific. So usually, sometimes with that, we can get approval for some patients. It depends on which medication is covered. Whether there are three injectables, sometimes they cover one, sometimes they cover none, sometimes they cover more than one. The gepants, sometimes they cover them, sometimes they don't. So it depends. And sometimes the copay is really high, but sometimes we will try. My experience with the triptans is slightly different. I found that they do work for quite a few of my patients, so I do prescribe the triptans. In patients in whom they're contraindicated or they don't work, then we try the gepants, of course. I try as much as possible when it comes to especially the rescue medications because they may cover one of the gepants, right, this year, but next year, if they don't get a good deal with the manufacturer, they may decide they don't want to cover it. So you could be left out in the cold. So if you have multiple rescue medications or multiple medications that you know could potentially work, that way we can cover all our bases.

0:40:57.2 Abbie Ross: We have some questions too about nutraceuticals or supplementation. And for those people who say, "No, I don't want to try medications yet," let's talk about the diagnoses specific in the title of this talk, maybe vestibular migraine, PPPD. Dr. Steenerson, do you have any recommendations for nutraceutical support?

0:41:18.3 Kristen K. Steenerson: Yeah, there's some relatively strong evidence showing that certain vitamins and minerals might be helpful for migraine prevention. It's unclear about the direct impact on PPPD with the evidence that we have so far. But if there is a comorbid migraine story with someone who has PPPD, I think it's absolutely reasonable to try them. The top three that I will use are magnesium, riboflavin, which is vitamin B2, and coenzyme Q10. There are several other vitamins that have some research to support them, but those have the highest level of research and usually the highest level of tolerability, especially the B2 and the CoQ10. Magnesium can be a little bit more challenging for certain people, but those can be a great option. It's really critical to make sure that you're taking high enough doses and that you're trying it long enough, so it can take two to three months for it to become effective. So patience is required.

0:42:13.2 Abbie Ross: And for the magnesium, there was a specific question too from our audience. What form are you talking about? More of a magnesium complex?

0:42:21.6 Abbie Ross: Yep. So usually glycinate and threonate are the easiest to tolerate and may have the most penetration into the central nervous system. But if you have problems with constipation, then citrate, oxide, those might be helpful in another way and still potentially helpful for migraine.

0:42:43.3 Dani Tolman: Dr. Beh, do you have anything to add to that? Because I know in your wonderful book, you've got a whole chapter on supplements I love referencing.

0:42:52.0 Shin C. Beh: To add to the magnesium part, sometimes gluconate also could be potentially useful, malate also. So basically the organic salts of magnesium are better absorbed and less upsetting to the GI system compared to, say, magnesium oxide, which is the cheapest form of magnesium and sold in many products. I think to add to what Dr. Steenerson said, vitamin D is a big one. I think in the migraine world, potentially in PPPD, and definitely in BPPV. So low vitamin D has been shown to be related to increased number of BPPV episodes. So supplementing with vitamin D can be very helpful there. From the PPPD standpoint, we have to, in a way, extrapolate some of the data from the psychiatry stuff that's used for anxiety, for depression, could potentially be useful in PPPD. We don't have studies to prove that they work, but based on what we use in PPPD in antidepressant therapy, these nutraceuticals could potentially be helpful. So there's, of course, like folic acid, B12, B6, that may be helpful. Vitamin D also has an effect on the mood too. Low vitamin D can cause more issues with anxiety, more issues with depression. Certain herbs that have been possibly could help with mood too, so like Ashwagandha potentially could be very useful in some patients. I worked with a psychiatrist when I was at UT Southwestern who often recommended Rhodiola. That could also help with patients with PPPD too.

0:44:22.1 Dani Tolman: Dr. Steenerson?

0:44:23.0 Kristen K. Steenerson: Just one more thing to emphasize. Unfortunately, in the United States, we don't have any regulation of vitamins and supplements. So just always a word to the wise when you're purchasing them. There's no way for us to know for sure that what you're getting is what is advertised or that it's the pure version of that. So it's an unfortunate circumstance, but I always want to make sure that we emphasize buyer beware because we don't want to create any medical problems additionally.

0:44:51.8 Dani Tolman: There's something else that I want to hit on before we go, because we're already coming to almost an hour here, which is absolutely insane. And this is something that is kind of popping up in the chat and questions in various ways. I kind of want to give it more of an umbrella topic. We talk about these overlying conditions and we've kind of kept it to vestibular-related conditions, but what about outside of that? Looking at questions in terms of having and managing these conditions with POTS or Ehlers-Danlos or fibromyalgia. I don't think it's too far-fetched to say that some of these more complicated other diagnoses that also aren't maybe well understood sometimes overlap with other issues like this. Would we be able to touch on that a little bit and kind of talk about what that might look like, especially working with this patient population? Dr. Beh, let's kick it to you first.

0:45:47.7 Shin C. Beh: You bring up a very interesting one. So POTS, definitely there is a link between POTS and migraine. So people with migraine have a higher chance of being diagnosed with POTS and vice versa. The key I think in POTS would be to make sure that we don't put people on meds that could potentially raise the heart rate too much or put them on the blood pressure meds that drop their blood pressure too much. So there's a little bit of a balancing act there. I think the tricky part also in POTS is you do have a lot of overlap in symptoms like brain fog and the other thing and fatigue especially. And so treating that can be a bit challenging. You also have to make sure in POTS that you consume more sodium, take measures to make sure that the blood pressure stays up. Working with a good cardiologist, autonomic neurologist who is an expert in POTS, I think, can be very, very important. Ehlers-Danlos also, the hypermobility disorders also have a very high overlap in patients with migraine. In this situation, I think the problem comes in with the pain. A lot of times neck pain, back pain, that can be a trigger for migraine. A lot of people with migraine can experience neck pain as a manifestation of migraine. A lot of people with dizziness tend to stiffen up and so develop neck pain. And people who have neck pain, like from Ehlers-Danlos and all that, can, when the neck pain flares up, trigger their migraine attacks. And so helping manage that is important. I often have... It's difficult to find. Vestibular therapists are hard to find already. Neck therapists are also very hard to find. So working with a good physical therapist who's familiar with neck therapy can be very important as well in these patients. Sometimes we may have to also prescribe medications like the muscle relaxants or non-steroidal anti-inflammatory drugs to also help address the pain. It depends also a lot on... Fibromyalgia is also a big one that has a lot of overlap with migraine. The brain is essentially more sensitive to pain in fibromyalgia. I think with this condition, choosing say a medication that could potentially help with both could be important, more from the antidepressant world or even the anticonvulsant world. Exercise could be also a really important one in a lot of these conditions. So with POTS, weight-bearing exercise, resistance exercises are very important. In patients with Ehlers-Danlos, finding the right exercise that could help their symptoms without aggravating their pain would be important. And the same thing also with fibromyalgia.

0:48:28.3 Abbie Ross: That was great. You mentioned something about fatigue, which reminded me of a question that we had from our audience. Dr. Steenerson, can you talk about why fatigue might be so prevalent especially when there's coexisting conditions?

0:48:42.2 Kristen K. Steenerson: Yeah, definitely an evolving understanding, I will say, but I like to think of it like you have transitioned from automatic processing to manual processing. So your automatic mode in your car versus the manual. When your vestibular system has become dysfunctional, it's much harder for you to do classic things like standing up and walking across the room without micromanaging. When I stand up, am I going to get dizzy? Am I going to feel like I'm going to fall? How complicated is the environment that I need to navigate to feel safe? Now you're suddenly asking yourself all of those questions that typically you would never think of. And that's exhausting because now you're having to spend energy on each one of those micro functions instead of the global function which comes so automatically and reflexively to you when you feel normal that you don't even notice it, and therefore require very little energy expenditure. Not to mention the psychological aspects. So feeling constantly anxious, having your fight or flight system on 24/7 or more often than you're used to, is also a huge energy expenditure, which can be really frustrating. And then along those lines, when you are constantly tasking yourself with the basic needs of just standing and walking, that makes it really hard for you to function cognitively because your brain has decided that it needs to spend its energy on the most potentially dangerous activities. So it's going to focus energy and thought processes on that, meaning you don't have that energy to complete higher challenging cognitive things like recall and memory and keeping multiple things in your mind at the same time, like walking into a room. Why did I come in here? Oh no, what was I going to say? What's that word that I keep looking for? None of those from a neurological perspective are worrisome. We are not worried about your actual brain functionality. That to us is an attention problem. Your brain is distracted because you're having to focus on something else. But it's really distressing to experience that, especially if you're not a neurologist. Why would you know that? And so that also can be energy depleting, making people feel fatigued on a physical aspect, a cognitive aspect. And then those like to feed into each other, giving people an overall sense of brain fog and like they have very little energy to expend.

0:50:58.1 Dani Tolman: Dr. Beh, what do you have to add to that?

0:51:00.8 Shin C. Beh: Fatigue is a complicated one. Like Dr. Steenerson said, those are a lot of the direct effects of your brain expending precious resources having to deal with balance, deal with dizziness. But I think there is also the issue like say with sleep, for example. So a lot of these conditions are associated with poor sleep quality. And so if you're not getting adequate sleep, guess what, you're going to be fatigued the next day. Medications too, some of them can cause fatigue. Like some of the benzodiazepines, some of the anticonvulsants, the blood pressure medications, sometimes even the antidepressants may cause fatigue. And so ruling those out could be very important. We've talked about the perimenopausal state, which can be associated with these conditions and can also cause brain fog and fatigue. And of course, a lot of the other stuff we have to look into. Long COVID is also a fairly important one. We do see patients in whom these like PPPD, vestibular migraine can be triggered after they catch COVID. And I think differentiating whether the fatigue, the brain fog is coming from long COVID versus say vestibular migraine or PPPD can be a bit challenging in that population.

0:52:10.0 Dani Tolman: I want to look forward and I want to pick your guys' brains and see if there's anything that you are both excited about, whether it's research that's being done or emerging treatments or different medications. What is something that you guys are looking forward to that's coming down the pipeline? Dr. Beh, let's start with you first.

0:52:33.1 Shin C. Beh: That's a lot. So that's the good part there, right? I think the... As Dr. Steenerson mentioned, we are just starting. We've been lagging behind a lot of the other subspecialties. So we are starting to get a little bit more research into vestibular migraine and the treatments that can help. Starting to get some clinical trials in vestibular migraine and so we get more data, right? A lot of what we have is personal experience, anecdotal data, which is pretty important, but having clinical trials that can prove which medications work, which don't work, can be extremely helpful, especially when we're dealing with insurance companies. I think along the devices also, more devices are emerging that could be also very helpful in patients with migraine.

PPPD side, of course, we want to see more research into that. The field is wide at the moment with medications, devices, therapies. All that is very exciting. From jumping back to the migraine side, of course, everyone is focused on the CGRP side of things at the moment, can potentially be very helpful. And so seeing more data would be useful. I think emerging from the headache world, they are looking at PACAP as another migraine therapy. So of course looking at the application in people with vestibular migraine would be extremely exciting. Botox, some data is coming out for Botox in vestibular migraine. So that could also be a very exciting development in the field.

0:54:06.5 Abbie Ross: And I want to also go back to something that we touched on a couple times in this talk, but we also have more questions in the chat on this. Specifically with migraine again and menstrual cycles, can you talk a little bit about why symptoms might ramp up at certain times of the month or certain periods of our lives and then also what can we do about that, Dr. Steenerson?

0:54:29.6 Kristen K. Steenerson: Yeah, this is a great question that I'm super interested in, but the literature is very limited, so I'll start with that. But we know that women are more likely to have vestibular disorders, as Dr. Beh pointed out. We also know that you're more likely to develop vestibular disorders around hormone fluctuation periods. So that means around perimenopause, that means around the period. So as estrogen drops right before you get your period or start the menstrual cycle. And then we also can see this in artificial estrogen drop periods, like you have to have your ovaries removed or you suddenly withdraw your contraceptives, or there's some type of interruption with that cascade of the hormones. So there seems to be a connection there. What is probably a more interesting question is why is it that that doesn't affect every single woman? So who is it that's more sensitive? Why is their threshold lower? What genetic susceptibility do they have? And so along those lines, that means we also don't know who benefits from hormone interventions. So who benefits from continuous estrogen to try and limit how much the estrogen is dropping? So, for example, continuous oral contraceptives or birth control. Who benefits from menopause hormone treatment? So as you get to perimenopause, who should be started on estrogen ASAP, and will that help modulate their vestibular symptoms versus... Not have an effect on? We don't have great answers to those. Clinically, I follow their other hormone symptoms. So if someone has really challenging periods or has other menopause symptoms like hot flashes or significant anxiety or sleep problems that are coexisting with the vestibular symptoms, I will recommend talking to their gynecologist to think about some hormone treatments to try. But the evidence is too limited right now to say definitively, you, I can tell based off your symptoms that you will benefit from hormone treatments at this point.

0:56:26.7 Dani Tolman: Did you have something to add, Dr. Beh?

0:56:29.6 Shin C. Beh: It's a complicated topic. Estrogen is a big one that we all look at. It affects the inner ear as well. So estrogen is involved in the health of the otoconal plate in the ears, microvascular circulation in the ear. So as the levels start to fluctuate in perimenopause and drop, that may account for why there's an increase in incidence of BPPV. In the brain itself, it's involved in so many things, vestibular function, neurotransmitter levels. And so that can explain potentially why as you're getting towards perimenopause, these things start to increase. And why during pregnancy, everything is stable for most patients. Once you deliver, the symptoms can flare up, and then the symptoms flaring up around the menstrual cycle. Progesterone, I think, also plays a pretty big role as well. Progesterone mostly, if you think about it, mostly a calming effect on the brain itself. And so patients who have more issues like with anxiety, sleep issues, especially around the perimenopausal state, could potentially benefit from some progesterone. Testosterone is an interesting one, even in women. Brain fog, fatigue, especially in the postmenopausal state, can also be related to low testosterone levels. That's maybe also why some women who go through surgical menopause tend to have much worse symptoms compared to those who undergo natural menopause because there's still some testosterone that could support certain functions. So we definitely need a lot of research. Jumping back a little bit, I think we forgot to mention one member of the multidisciplinary team would be our good friends in gynecology. I think extremely important for them to be helping our patients too, because sometimes, of course, hormone replacement, birth control are not without risk. So working with them to manage those risks is extremely important...

0:58:22.8 Dani Tolman: Let me throw this at you guys real quick, because this is something that I've just been seeing and I'm personally interested in hearing more about it. But maybe people who never had migraine symptoms and then all of a sudden start hormone replacement therapy. I feel like my social media feeds, which are making me starting to feel a little bit older, are filled with weighted vests and hormone replacement therapy options for going into that early perimenopause. But I am feeling like I'm seeing patients come in with typical migraine-like symptoms who don't have a classic history of that, and then all of a sudden they have these symptoms that come on, which happen to also come on shortly after starting some sort of a hormone gel or cream or replacement therapy. Dr. Steenerson, is that something that you've been noticing as well, or am I crazy?

0:59:09.8 Kristen K. Steenerson: No, definitely, you're not crazy ever. But no, it's a pattern that I've seen as well, especially in patients who are undergoing hormone therapies for breast cancer, say. And I like to think... There is no, as far as I know, there's no great research suggesting this, this is my own theory, so please beware... But I like to think of it like the threshold, that this might be enough of a threshold irritant to drop your threshold that now you're suddenly having migraines when you weren't. But I also like to think about, did you really not have migraines or was no one calling them migraines? So we think about the migraine equivalents, right? Could you read a book in the backseat of the car when you were a little kid? Nope, I got motion sick. That's migraine equivalent to me, or at least a high likelihood of migraine. Did people have Meniere's disease in your family? Did you have unexplained abdominal pain as a kid? Did you have sleepwalking or sleep talking or growing pains? There's all these nervous system hypersensitivity syndromes that we call different names that are linked to migraine that might mean, oh, no, you actually did have the genetic susceptibility to migraine this whole time, but not the classic migraine as the manifestation. Just two thoughts.

1:00:15.0 Abbie Ross: Well, I was wondering, maybe my last question will be, do you guys want to hang out for another few hours? Because we have a lot more questions.

Anyway, both amazing. Thank you so much to Dr. Beh and Dr. Steenerson for coming on today's talk. Also, audience, if you want to work with them, I think they're both accepting patients still because I've sent them some. We should have a banner popping up here or something in the chat to contact their offices. We're going to transition now to our patient panel led by Cynthia Ryan and Heather Davies.

1:00:54.4 Dani Tolman: Hey, guys, I feel like I need a few more hours with both of them.

1:00:58.7 Heather Davies: Yes, we could have just kept them on for the patient panel also.

1:01:03.4 Cynthia Ryan: There were definitely so many questions that we couldn't get into and I'm sorry for that. We'll try to fill that in later. But thank you so much to both of you for leading a great week of interviews with some amazing specialists. I just feel so thankful that we have so many wonderful people in our community who are willing to share their expertise with us.

1:01:29.0 Dani Tolman: This has been a great week. Thank you so much for having us as moderators for our expert panels.

1:01:35.0 Abbie Ross: And have a great last session.

1:01:36.7 Cynthia Ryan: Thank you. So this... I know, like I said, there were so many questions, and this topic I've heard from so many people, the pylon effect of having multiple conditions or figuring out which condition you have, or if you know you have more than one condition, what's this symptom saying? Does this come from my vestibular migraine? Does this come from my Meniere's disease? It certainly complicates the vestibular experience.

1:02:08.8 Heather Davies: It does. It does. And you hear it so much in the community of the overlapping symptoms and diagnosis more often than you can imagine. I'm Heather Davies, and I host the Meniere's Muse podcast, and I am a fellow Meniere's and vestibular migraine patient.

1:02:26.6 Cynthia Ryan: And I'm Cynthia Ryan, executive director of the Vestibular Disorders Association. And my mother has vestibular migraine, Meniere's disease, and BPPV.

1:02:39.8 Heather Davies: Oh, wow.

1:02:40.5 Cynthia Ryan: We've got it in the family. And some of the things that Dr. Steenerson was saying at the end made me think, huh, I guess I have the equivalent, even if it hasn't been diagnosed. So I learned something about myself today. So let's bring on our panelists.

1:02:57.5 Heather Davies: Yes. Today we'd like to welcome our patient panelists, Judi Rosenthal and Kayla McCain. Welcome, ladies.

1:03:04.8 Judi Rosenthal: Hi.

1:03:05.5 Kayla McCain: Hi.

1:03:06.4 Cynthia Ryan: Good to see you guys.

1:03:08.3 Heather Davies: Yes, we're just going to jump right in. We'd like to understand a little bit about your journey. So many people with vestibular disorders have a long and confusing road to diagnosis, as we've heard all this week. What was your journey like, Judi, in realizing you had more than one condition?

1:03:25.5 Judi Rosenthal: It was long and very confusing. My situation began when I was 12. I got sick when I was 12, and it was mono, mononucleosis, Epstein-Barr, and viral pneumonia at the same time. I was home from school for a month, and I went back to school and something had changed. It was just different. I was seeing things differently. The lights were bright. I thought that my vision was blurry. That's how I perceived it at 12. So my mother took me to an optometrist who checked my eyes, and he said to my mother in front of me, "Your daughter has a very good imagination." And so it began. Things... I'm gonna try to capsulize this because obviously I'm a lot older than 12, so this went on. By the 10th grade, when I was at a friend's house watching TV, I got my first true spinning vertigo attack, and it was terrifying. Went to the ENT. He said I had tonsillitis, gave me an antibiotic, but the whole balance situation was bad. By the time I was in 12th grade, I had to have a friend walk me from class to class because I couldn't navigate the hallways. I'm just going to read off the timeline because this would take three hours to get through. So sometime in my 20s, I had pressure in my left ear and fullness, and it felt like there was something stuck in it. I was diagnosed with a perilymph dehiscence in my left ear. I was at a hospital in Manhattan. My roommate was Judy Blume, the author. I didn't know it then. She was so nice. She kept walking me back and forth to the bathroom all night because I was too dizzy. And then later on, it didn't resolve anything. I thought at that time there was a magic surgery, a magic pill, where I would be fine again. I went to the Cleveland Clinic. I was diagnosed with Meniere's, and I did have a vestibular nerve section. I had a complication from it after I was discharged in that I had a spinal fluid leak, and it was very severe. Moving along, I was getting mystery fevers, 100. I always had a 100 fever, and it wasn't high enough to be worrisome, but I didn't feel well. My neck was hurting. I was aching all the time, and I was so off balance.

1:06:46.2 Judi Rosenthal: Somewhere around then, TMJ was like a really big thing back then. So I was diagnosed with TMJ. I had conservative treatments. I went to Mount Sinai Hospital in New York City, and I needed two surgeries for TMJ. I'm like, maybe that will get rid of the dizziness. It didn't. So, and all this time, I'm like, these aren't related. They can't be. It's just different, strange things that are happening to me. I started having bad menstrual cycles. I had stage four endometriosis. I was told by my gynecologist that if it's cancer, they're going to do a total hysterectomy. It was terrifying. It was not cancer, obviously. And then in my 30s, the GI problems hit, and I was misdiagnosed with ulcerative colitis. It was not ulcerative colitis. It was Crohn's. So I went to various doctors over the years. And then from the ulcerative colitis diagnosis, I was being treated with a biologic. Didn't take care of the balance problems, but my ulcerative colitis doctor retired very suddenly. I went to NYU, and within one day, I had all the answers. I had Crohn's, and he had to do an abdominal CT just to check. And my sacroiliac joints were both completely fused together. And he said, "I'm sending you to a rheumatologist. You have ankylosing spondylitis." And I didn't know what that was, even though I was a medical transcriber for 31 years. And that was the root problem of everything. There was no internet back when I was younger, so I sort of cross-referenced everything. Meniere's more highly likely in AS. It's an inflammatory systemic disease. So everything that was inflamed was because my body was inflamed. So I'm on a higher dose of the biologic. Unfortunately, I would break through if I wasn't on low-dose chemo oral. And with as much as I went through, the vestibular problems were the worst, the absolute worst. Pain is easy to identify, or even the Crohn's, which I almost died once from it when the inflammation went to my heart. But vestibular just made you feel different, like you were on a different operating system than everyone else. Things were just weird and blurry. And then I got involved with VEDA, and it's where I am now.

1:10:07.6 Dani Tolman: Wow, that's quite the story. I mean, first of all, it started so early, but one of the things I heard was that you were diagnosed with so many things, and some of them were accurate and some of them weren't. I think a lot of people can relate to that. And then at some point, you're like, "All these things that I was diagnosed with that I didn't have, do I list those? Are those my diagnoses? Are they not?"

And the other thing that you said is you didn't think that they were all related, but they probably are. The inflammation affects so many things in our body. So your story really encapsulates so much of what people who have multiple conditions, vestibular and non-vestibular, deal with.

1:10:57.4 Judi Rosenthal: And for the vestibular, the misdiagnoses were hypoglycemia, allergies, stress. They always throw the stress under the rug and see if it sticks. But considering what I was going through, I'm gonna say yes, I was definitely stressed.

1:11:20.3 Dani Tolman: Kayla, do you want to tell us about your diagnosis journey to figuring out? Because I remember knowing you before when you had one diagnosis, so discovering that you actually have more than one.

1:11:36.8 Kayla McCain: Yeah. For me, it was nine years ago, and it was on Halloween night when this happened. It's a day you're never gonna forget. My husband and I were watching a scary movie, and at the time, I was laying on his lap. During the movie, I started to feel kind of these dropping sensations. And I was like, "Am I just feeling nervous from this scary movie? I don't really know what's going on," until it felt like I was literally melting into the couch. And I felt like I was having a stroke. I remember I'm 27 years old at the time, being like, "I'm too young to be having an issue like this." I remember sitting up and starting to panic, and I remember telling my husband, "Do we need to go to the ER? Am I having a heart attack? Am I having a stroke? What is going on?" And he was like, "Just calm down. Let's just turn off the movie. Let's just try to go to bed, and maybe you'll feel better in the morning." Okay. Somehow I managed to go to sleep. The next morning when I woke up and I was driving to work, I remember gripping the steering wheel. I had about a probably 20-minute commute, and I live in Dallas. I remember being on the busy highway going downtown and holding on to my steering wheel thinking, "I don't feel right right now. It feels like I've had a couple glasses of wine. I just don't feel normal." I remember getting into my office and same thing, kind of walking in the hallways and everything was floating, and I just felt like I couldn't stay balanced. This went on for a few days. At the time, I didn't have a doctor that I regularly went to, so I went to Walgreens, the Minute Clinic. I remember that doctor at the time was like, "Oh, it probably is just allergies or sinus issues. So here's some allergy medicine, and you're on your way." So I took that. Nothing changed. And then a few days later, I remember being at work and just resting my head on my desk because I just felt terrible.

1:13:30.6 Kayla McCain: And my best friend at the time was like, "You don't look well. You should go to the ER or go see a different type of doctor." So I remember I went into the ER, and I had a fever at the time, which was a precursor of something else that I didn't find out till later. They took a CT scan of my head, realized I didn't have a tumor, gave me some meclizine, and sent me on my way without really any answers, which I know so many people can relate to. Then after that, I still just wasn't accepting these various things these doctors were telling me. So I kept going and seeing doctors until I finally kind of got a clue that it must be something going on with my ears because every time I was having an attack, I could feel it in my ears. So I finally got into the Dallas Ear Institute, where they told me that I had vestibular migraine. And that kind of led me onto the journey where I actually found Dr. Beh, who we just had on.

He's my neurologist. And this was probably six or seven months of searching for doctors when I finally saw him, and he kind of got me on a treatment plan. During that time over the last nine years, I've had two babies and living my life. I didn't do medication at first. I got on medication after the fact of having kids, which significantly changed my migraine journey. And I was honestly doing really well until two years ago when we moved across the country and I had a horrible, horrible vestibular migraine attack, which led into another panic attack, kind of similar to when I first got diagnosed with vestibular migraine. And I remember calling Dr. Beh and being like, "I don't feel right. I'm having a series of bad attacks again. My medications aren't working. Nothing seems to be helping." And I remember at the time, we did a couple different medications to see if we could just get past this attack, and we would meet again in a couple of weeks. And then after my update with him and explaining the symptoms I was having, including when I had vestibular migraine... It was like the walls, when I'm walking, it was kind of this floating, dizzy sensation or kind of feeling like I'm spinning or melting. With PPPD, which I got diagnosed with right around this time, my eyes would bounce, and it was constantly bouncing, and it was worse at nighttime. And I just felt like I was kind of outside of my body. So there's a lot of different types of feelings I was having. And that is also why I was confused at the time, because surely this didn't feel like vestibular migraine, but I didn't even consider that something else could happen at this point. I just thought that was my diagnosis with vestibular migraine, nothing else. Surely I can't have another one. But anyway, long story short, he did determine that I also have PPPD. And kind of going back to what I said too, when I was in the ER, when I did get diagnosed with vestibular migraine, they think the fact that I had a fever and just based on what I was going through, there was probably a component of vestibular neuritis at that time too. So, long story short, that is where I'm at now.

1:16:45.7 Dani Tolman: I think vestibular migraine and PPPD are some of the most difficult ones to have together because it's really difficult to differentiate what symptoms are what. And then some of the treatment overlaps, and some of it is different. For your treatment, how did your treatment change when you were diagnosed with PPPD?

1:17:11.2 Kayla McCain: Yes. So what's interesting is kind of what I said before is when I first got vestibular migraine, I really wanted to go the natural route of any way that I could, whether that was doing supplements, seeing a counselor to help with stress and anxiety, exercise. I didn't want to take medication because I was planning on starting a family. Then after I started a family, I took medication for migraine, which helped, but I never responded great to any kind of antidepressants or SSRIs. It just wasn't for me. And I know a lot of people in the community feel that way. We're all so sensitive to medications that the idea of starting anything, it's scary. With PPPD, this time in my life, I was in a different place. With vestibular migraine, I was newly married. It was just me and my husband. I'm navigating my 20s. This time around, I have two small kids. I couldn't really afford to not be more willing to try medication. And I knew that just because I needed to feel normal quicker is how I felt. So I did trial several medications, and I failed some of them. And it was discouraging. And then finally, kind of like what Dr. Beh was just talking about in the session before, he always starts at the smallest dose and is always working with his patients to get them to a place that they can comfortably tolerate a medication. And for me, I finally got on one where we started off with a droplet. We did a liquid form, and we built up my tolerance. And after failing a few other SSRIs, this is the one I've tolerated, and it's changed my life.

1:18:50.7 Abbie Ross: What about you, Judi? How have you learned to manage your symptoms day to day, especially when the different conditions require different approaches?

1:18:59.7 Judi Rosenthal: Yeah. Well, the Crohn's is in remission with the biologic. I still get nervous every time I go for an infusion because it's a medical procedure. But that works, and that's what I stick with. So I manage the symptoms. I mean, it's now basically the vestibular. Four years ago... I couldn't remember all the diagnoses. I was also diagnosed with bilateral vestibular hypofunction, which, if you go back to the beginning, I think that's what the mono did. And there are studies that show that mono can lead to these autoimmune issues. So it was like, "Oh! Oh, that was it! Oh, my gosh, I wasn't crazy!" Because you kind of feel like you are. It's such strange symptoms. So I manage the vestibular. I started walking. I started doing steps. I have my Apple Watch. And that's what helps me. At first, it was so hard to do, but I sort of have a walking track. It's down the hallway. And at first it was impossible, and I would build it up another 500 steps per week. And it would be... I don't know if other vestibulaholics have this... But it would be like step, step, marshmallow step. Ah! And that would throw me off balance. And I make a startle sound. And now the startle sound is lower and less frequent. And that's what helps. That's what helps me. I know there are so many modalities. I know that people go for vestibular therapy. I went for 19 months of vestibular therapy, and I was grateful for it because that's where I got the diagnosis of vestibular hypofunction bilaterally. And that was like the last piece in the puzzle that, oh, my gosh, I have nerve damage. Got it. Now I get it. But I think also understanding what your symptoms are was pivotal for me. If it's a rainy day, a cloudy day, a dark day, I know I'm not going to be feeling as great. It's just how it is. I've had lots of time to learn about this. And then on a sunny day, it's like, oh, my gosh, I feel so much better today. And I grab my husband... And yes, throughout all this, I've been married for 31 years, go figure... And I grab my husband and I'm like, "Let's go out. We're doing something." He's like, "Sure."

1:22:08.0 Dani Tolman: That's awesome. I'm the same way. I'm like, "Let's go do something." But that weather is a big trigger for me as well. I can tell when the clouds are changing and the sun's not saying hello, I'm gonna have a rough day. Kayla, I know you mentioned medication. Do you have any other ways of managing your symptoms day to day?

1:22:27.8 Kayla McCain: Yes. Stress is a big one for me. So it's easier said than done trying to manage stress, but I do try. And this is something when I first got diagnosed with vestibular migraine... I think a lot of people can relate to this... You are in such a state of anxiety and you kind of hide in your house. I didn't want to leave, and I'm an extrovert, I'm a big social person, I love to exercise, and I stopped doing all of those things, which only made things worse for me. So when PPPD happened for me, the thing I knew not to do was to stop exercising. I knew exercising helps me manage my stress. I know it helps just with my vestibular therapy. It's kind of what I learned when I went through vestibular rehab. And so, yeah, exercising is non-negotiable for me, and that can just be as simple as even just going on a walk. It doesn't have to be anything crazy. I try to do meditation. It's kind of like... When I was going through PPPD again... It's so funny, you learn so much when you go through your first diagnosis, and then when it happens again, it's like, "Did I not learn anything?" because I'm right back on the message boards, I'm on Reddit, I'm on TikTok, I'm doing all the things. And I'm pretty involved in this community, so it's like I'm relearning it all over again. And I remember not letting myself go too deep into the stuff that scared me of what people were talking about. I had to remove myself from that because that would cause more stress. But by doing that, I also found some different tools I'd never used before, like some cool guided meditations on YouTube that actually helped me, doing some more yoga. And yeah, I have my medication component, but it's definitely the stress part of it too, just trying to bring that down to baseline.

1:24:11.9 Abbie Ross: Kayla, there are a couple of questions in the Q&A about the liquid medication you mentioned. Can you extrapolate on that a little?

1:24:22.3 Kayla McCain: Yeah, I'm fine to talk about medication because it's my own personal journey. Okay, so just to give a little context, when I first got PPPD, the first medication we tried was Effexor, and I only made it three days. I had horrible side effects. It was not for me. So we got off that. And because previously when I had vestibular migraine, I did try amitriptyline way back when... Again, had a bad reaction... So I was like, "I don't know if SSRIs or antidepressants are for me." I was very freaked out by them, and I know in the community a lot of people feel that way. So then Dr. Beh was like, "Well, let's try a different medication." I am blinking right now... Gabapentin. And I hated that as well. I felt even more dizzy, I felt even more of a fog. It was a terrible, terrible experience for me. So I got off of that. It was about a couple of weeks that went by where I was like, "I just think I'm throwing in the towel and I'm going to have to figure this out naturally like I did with vestibular migraine. There's just nothing clearly working for me." A couple of weeks went by and I'm like, "Okay, nope, I can't do this. I just can't handle this." And so I asked Dr. Beh again, "Is there something we can try that might be not as aggressive for me when we're getting on the medication?" And he said, "Yes, actually. Typically we start with Effexor because studies show that it's better for PPPD." He goes, "But we can't rule out things that work for everybody," like he did talk about on his session. So we did Zoloft, and we started with the liquid kind because it's the easiest way to almost titrate onto it. And I remember he goes, "Grab a water bottle and just put one drop in it." I said, "One drop? Like, what dosage is that?" He's like, "It doesn't matter. Just put one drop in it." And then when you feel like it was okay, a couple days go by, put in two drops. I'm like, "Okay." And we continued to do that until I got up to just kind of a standard dosage. And even still, we're kind of still tweaking it, and now I'm on the actual physical pill. But we started off with the liquid, and it was like the first time I was ever able to tolerate a medication like that. And I think it's because I'm so sensitive to medications, it was a very easy way for my body to adjust.

1:26:42.8 Dani Tolman: That was a great explanation. And just another call out to everyone, everyone reacts to medications differently. So as Kayla said, this is her experience. Other people, the SSRIs work for them. So work with your healthcare professional to find what is going to work for you. But I loved that doing the smallest dose you could, especially for someone who is sensitive to medications. What do you think is the most difficult part of navigating overlapping conditions? Because there's the physical part. You've got, obviously, and you mentioned this, Judi, you've had lots of different kinds of vestibular and non-vestibular conditions, and the vestibular physical symptoms are some of the craziest and hardest to manage. But there's also the emotional part, and then there's the whole navigating the healthcare system. Which parts of those do you think were really the most difficult? Judi, do you want to start?

1:27:53.2 Judi Rosenthal: Well, for me, when you go to a specialist, if you go to a gastroenterologist, they're just gonna stick with what's on their end. If you go to a gynecologist, it's on their end. If it's a rheumatologist, it's what they're focusing on because that's what they're trained in. There was never anybody that was putting the pieces together for me, except that with ankylosing spondylitis, Crohn's is like a cousin. It is a known complication of it. So I wasn't even looking at this point for everything to be pieced together. To me, it was this odd bunch of illnesses that I had gotten that were completely separate of each other. It never occurred to me that they were connected. And by the time I was diagnosed with ankylosing spondylitis, not only were my hips, my sacroiliac joints fused, my neck vertebra is fused from C2 or 3 all the way down. And I did end up with a spinal deformity in my upper back because from all the inflammation over many years, it pitched my spine forward. So that's another balance situation because I can't sit up straight. And if I'm walking, I'm sort of pitched forward, actually. Mick Mars of Motley Crue has ankylosing spondylitis. I wrote to him. He never wrote back. But most people just get this kind of one, even with AS, you get the bone and joint situation. I got everything that could possibly go with it. I don't know why, but I was just lucky.

1:30:02.4 Dani Tolman: So it sounds like for you, a lot of the structural changes were the most challenging and that they actually affected your vestibular stuff as well. Kayla, how about for you? How much does the emotional part weigh versus the physical part?

1:30:26.0 Kayla McCain: I think with anyone who struggles with a vestibular disorder, it's hard because it was kind of like what Judi was talking about with pain versus being dizzy, is that you don't have a broken bone. You're not walking around being like, "I'm broken, I'm hurt." It's all in your head, and I think that's a big emotional part for anybody suffering with a vestibular disorder is that nobody's truly understanding how you're feeling. I mean, you can tell everybody and describe the symptoms, but when people don't get it and they can't understand why you're canceling plans or they can't understand why you're just feeling terrible but they don't see it, that's just really hard on the person going through it because you can only describe it so much for someone to understand. I mean, I had some experiences with some friends who would end up getting BPPV or have some sinus pressure and they're like, "Oh, I had a bout of dizziness. I kind of get it." And some part of me was sad that that happened to them, but kind of relieved to be like, "Oh, yeah, this is my world. Like, you understand that." So, yeah, I feel like when you feel misunderstood and you're going through it in the beginning and you don't know what's going on, that level of anxiety that you carry, the whole thing is extremely emotional. That's honestly, I think for a lot of people, the hardest part because especially when you're not understanding what's happening to your body, it just puts you in such a fight or flight state until you can really start getting some answers.

1:31:54.4 Dani Tolman: And I imagine that's made even worse by the fact that you're young. Well, you were in your 20s, right, Kayla, when you first were diagnosed? And Judi, you were even younger. When you're young, you look like nothing can be wrong. You're supposed to be healthy.

1:32:14.8 Judi Rosenthal: Yeah, definitely.

1:32:17.2 Kayla McCain: Yeah, exactly. I remember I was at a part of my life where I'm in my mid-20s, I'm living the downtown life and my friends suddenly didn't understand why I didn't want to go out. I feel like there was a really just gap of trying to explain that because of the part of my life I was in. And I think that's where I struggled too because I'm like, I'm only 27 years old, like, why is this happening to me? And you kind of go through those whys too, like why me? And I remember part of it in the beginning too, you have that self-pity moment. Just for me, it's how long can you stay in that moment though too? I'm a doer. So I had my cry and then it was like, okay, I got to get better.

1:33:02.4 Judi Rosenthal: And there's always a big stigma with canceling plans because if you can't... I always tried to do things and then as it got closer, it was the last-minute cancellation and people just didn't understand that.

1:33:21.6 Dani Tolman: Yeah. It was hard for me too when people stopped inviting you. I'm like, no, keep inviting me. I might surprise you and show up. So just please keep inviting me. That's really tough. It really is. What role would you say, Kayla, plays in pacing and resting and stress management? Does that play in keeping your symptoms under control? And I know you said you had children too. That adds an entirely different element to keeping things under control.

1:33:52.8 Kayla McCain: Oh yeah. I have an almost six-year-old boy and a three-and-a-half-year-old boy. So there's a lot of wrestling and craziness that happens and I'm like sometimes, how do I function in this environment? I love them, but they're crazy sometimes. Yeah, I'm very hormonally sensitive too. So I do know that I can have more of a spike in my symptoms around my cycle. So with that, I try to be mindful and maybe even look ahead and know that if I'm not gonna be feeling great this week, maybe I'll schedule a massage or maybe I'll make sure I put some more time to myself or ways that I can squeeze in that little moment to take care of myself. My kids are in school some of the week. My oldest is full-time and then my other one's in preschool. So it's a hard balance because I also work. So I'm finding time where it's working, taking care of my kids, and then taking care of myself. And I try to be mindful on some of those days where no one's there to at least even carve out maybe one or two hours where I can just rest and do nothing and relax. I try to be super mindful of that each week to at least find some time for myself.

1:35:01.1 Dani Tolman: I love that. It's really hard to do, but you really have to find it, whether it's just a couple hours in the morning or just wherever you can grab it. How about you, Judi? How about you with any... What have you found that works for you to help keep symptoms under control?

1:35:21.4 Judi Rosenthal: It depends on the day and how I'm feeling. Sometimes it's rest. If I've done something the day before that's out of the norm, I will be exhausted. And I do sometimes feel guilty about just having to rest. I'm telling myself I shouldn't have to do this, but I do have to do it and try not to beat myself up about it. I can be my own worst enemy. And keeping up with the exercise. There really hasn't been any dietary changes. I once went to an allergist and he told me I was allergic to everything except turkey and brown rice. I don't think so. I lived on turkey and brown rice for two months. It didn't make any difference, but I lost 10 pounds. But some of the things were pretty strange, but I was willing to try anything. I was like, okay, I'll try that. Thank goodness it didn't make a difference. I would hate to be living on turkey and brown rice my whole life. But it is pacing. I know that if I do something one day, the next day it's probably gonna be a pretty quiet day. And the key for me is just giving myself permission to do that.

1:36:54.4 Dani Tolman: Yeah. Sorry, I wanted to mention something. Do you sometimes... I'm pretty bad about this. Like, all right, I want to do this, but I know I'm gonna feel bad. So sometimes the trade-off is worth it. I want to go to this concert, but I know I might... I just have to have an outlet and an escape plan so I can still enjoy my life. You just can't just think of the what-ifs and just not move. I think that's a big thing that a lot of people need to hear out there that, yes, sometimes the trade-off is gonna be in bed the next day, but I'm living my life. Do you feel that way...

1:37:32.6 Judi Rosenthal: Sometimes the trade-off for me is large supermarkets are very, very hard for me. I have to keep stopping. The lights are too bright. I get start crashing into the walls a little bit. So we moved to Connecticut 14 months ago, and up here they have really lovely markets, great produce, great stuff. So instead of going to a supermarket, which I know is gonna be triggering, I'll go to the market and it's fine. And sometimes in the back of my head, I'm like, oh, I wish I could do that, but this works too.

1:38:15.9 Dani Tolman: So we've talked about exercise, we've talked about pacing, relaxing, not feeling guilty about relaxing, lifestyle changes, and giving yourself permission to take some time off. What do you think or how do you think your healthcare providers have helped or hindered your progress when it comes to understanding and treating your conditions? And I think we can, you know, we've talked about having a multidisciplinary team, so we're kind of talking about all your healthcare providers, and I would include complementary healthcare providers as well. Kayla, do you want to start?

1:38:59.5 Kayla McCain: Yeah, I think I'm fortunate that I have found a good neurologist earlier on that's been very supportive. And something I like to talk about, too, when you're looking for a doctor is not a doctor that just kind of checks the boxes and gives you answers. I feel like a lot of times you can find a better caretaker doctor if they have curiosity. I feel like that's the one thing that I love about seeing Dr. Beh is that he's curious. I feel like it wasn't just like, "Okay, well, these medications didn't work, oh well." It was like, "Hmm, what if we just tinker with this and we try these things and see how that can help you?" So I feel very fortunate for that. It is kind of interesting, though, even they were talking about in the discussion was how hormones have such an impact, especially for women with a vestibular disorder. And it's crazy because I feel like when you go see other doctors and they're asking you what conditions that you have, and I'm like, "Well, I have vestibular migraine and triple PD," and they're writing it down as if they kind of know. But I'm like, I don't really think you know. You can kind of just get the vibe. And a lot of the times, some of the things that my OB recently was like, "Okay, well, you're having these issues. Let's get you on birth control." I'm like, "No." Like, I literally got off birth control way back when because that is one of the biggest triggers for me with my symptoms. And she's like, "Well, you can try this and this," and I'm like, "No, it's fine." I know she's trying to do what she's trying to treat what she knows is wrong with me in a different way, but she doesn't understand that relationship with your other doctor. So there's that component. But then on the flip side, I went and started seeing a counselor when I first got sick, and she specialized in chronic disease, and I feel like she really helped take everything that the doctors were saying to me and kind of translate it into how I can have it impact my life. So I guess what I'm saying is it kind of just depends on where you're at in your journey.

You will find doctors along the way that will dismiss you or misdiagnose you. As Judi was saying, I was misdiagnosed with multiple sclerosis two times, and I just knew that wasn't it because my neighbor growing up had multiple sclerosis and I knew that I wasn't similar enough to what she had going on. And then I had one doctor when I was trying to find a neurologist in the end who told me that I was literally crazy. She goes, "Yeah, I think it's in your head, but it's psychologically in your head." That doesn't help. It was very dismissive. So I think ultimately it's advocating for yourself. It's finding doctors that will work with you, not accepting if you don't feel like what a doctor told you is right for you, to just move on and find the next one, too. Just continue to advocate for yourself. And when you do find a good team, try to get them in communication or just knowing what your neurologist might say, then that way you can kind of communicate that, too, to your OB.

1:41:55.3 Dani Tolman: Those are great suggestions. It's so frustrating because I experienced this also, and my husband, who's going through a vestibular exploration, is experiencing this. You hang all your hopes on the expertise of your medical team, and then if they tell you something, how do you know whether to take that and say, "Oh, that's right," because they said so, or to move on to another doctor? So that's really challenging. And what you said about... Because Dr. Beh and Dr. Steenerson were saying an OB-GYN should be part of your care team, but what if they don't understand the vestibular part? How do you connect them? And sometimes you have to be the educator and bringing them that information. And also emphasizing the counselor, bringing it all together and helping you just manage that. Judi, how about you? You've obviously seen so many healthcare professionals. How have they supported you? How have you integrated them working together or not?

1:43:15.6 Judi Rosenthal: Well, I agree with Kayla about, excuse me, advocating for yourself because if there was a treatment that I didn't want to try or had a bad experience, I was like, "No, not gonna do that." Whereas when I was younger, in my parents' generation, doctors, they were the authority. You had to listen to what the doctor said. So I got to a place in my life where I said no. I could say no, I'm not interested in that and keep going, keep moving along. And I have worked on myself over the years. I've gone for talk counseling and that's been important because it puts you through so much and so much stress and trauma that you need to talk to someone and you can't really depend on a family member. My husband's great, I have a best friend and he's great, but you have to go to a professional for me. You have to have someone that's separated from your life to really talk to about it. And that's been important for me.

1:44:40.2 Dani Tolman: I love that you guys have spoken so much about counseling and nowadays they offer so much with telehealth that if you can't leave your home, you can still have those options available to you just from your phone. So that's awesome.

1:44:54.1 Judi Rosenthal: And what Kayla was saying about MS, that was on the table for me too, but it was ruled out. But the age and, oh, by the way, I'm reading Christina Applegate's book who does have MS, obviously. And she said her first vague symptom of MS was that fluorescent lights made her dizzy. And I was like... So different situation, but it's interesting that some symptoms can overlap.

1:45:29.5 Dani Tolman: Absolutely. Speaking of symptoms, when they start piling on and they fluctuate, they could be pretty unpredictable. How do you hold on to hope and have that sense of control, Kayla?

1:45:43.3 Kayla McCain: Well, I think with vestibular migraine, it took a while to adjust. Even when I was starting my treatment journey and finally seeing a neurologist, I still wasn't in any way close to being back to myself. And I think going back to counseling is something that my counselor told me and I still, to this day, this is what I preach, is that I'm never gonna get back to Kayla before vestibular disorder. I'm in the search of a new normal. And I know we talk about that a lot in this community, but it truly was finding ways to do the things that I liked again. Kind of like you were talking about, Heather, like you sometimes maybe push yourself a little bit, but I wanted to feel like myself. And with vestibular migraine attacks, it still caused me a lot of anxiety. But I got to a point where I'm a very... And I learned this in counseling as well about myself, is that if I have more information, I do better from an anxiety standpoint. I can understand what's going on with my body. And I feel like I got to a point where once I started learning why these things were happening to me and it wasn't like, "Oh, there's a tumor in my head," or "I have cancer," whatever, and I learned what was going on, I was able to kind of deal with it better when I had an attack, to kind of take a breath, realize I'm dizzy for this reason, take my emergency med and rest. With triple PD, I had to restart that whole thinking all over again because I had vestibular migraine for seven, eight years before this second diagnosis happened. But it was almost like a reteaching moment for me where I had to take a deep breath because I was caught in that dizzy-anxiety-dizzy cycle where anytime I'd have any kind of symptoms, I would freak out again. And I finally just had to get to the point where it's almost kind of like an acceptance. Like when I feel the dizziness, instead of freaking out, I have to accept I feel this way. And I remind myself why I feel this way and it can kind of calm down and help me just be able to cope, I guess, when I'm having symptoms.

1:47:46.5 Abbie Ross: We have a question in the chat I wanted to bring in and someone was asking about with your triple PD, you said that you have chronic dizziness. Does that mean you have dizziness all the time or does it come and go?

1:47:59.9 Kayla McCain: With triple PD, I did. And I won't know now because when I had vestibular migraine, triple PD wasn't even a diagnosis at that time. I mean, it's fairly new. I almost wonder if I was dealing with it then and I just didn't know because I feel like I even have learned a lot from these sessions this week, too, is that with vestibular migraine, it can be up to 72 hours. And I know that you can have recurrent attacks and can continue to feel like you're dizzy. With triple PD, it wasn't like... Let me start with migraine. If I'm walking and I kind of feel like a melting motion, I know that that's migraine related. With triple PD, it was a constant bouncing sensation. I couldn't look at my phone. I have these built-in bookshelves next to my fireplace and I remember sitting there and they constantly would bounce. And I just wanted to be out of my house, which is almost opposite, because I just felt like the environment in my house was almost making it worse than just being outside. But yeah, triple PD for me, until I got it under control, was 24/7, but worse at night.

1:49:04.1 Dani Tolman: We can backtrack to that question and ask Judi the same thing. How do you hold on to hope and your sense of control over the symptoms?

1:49:15.1 Judi Rosenthal: I don't know if it's a sense of control. It's a feeling of hope. If I'm having a bad day, I tell myself tomorrow will be better because I know eventually it will. But there's still that doubt in my mind. I just had a sinus infection. It made my balance so much worse, so much worse. And I actually reinforce to myself, this is real. This is because it's just such a strange feeling. I get the bouncing too from the bilateral vestibular hypofunction, and I believe I have oscillopsia because when I walk, the gyroscope is off. Like, I walk, I bounce, the floor bounces. I've had this for so long, I thought, "Oh, this must be how everyone sees. I just can't deal with it," or something like that. So now that I'll see a video of what vestibular hypofunction looks like or oscillopsia, and I'll show it to my husband or my friend and I'll be like, "Is this how you see when you walk?" And they're like, "No." I'm like, "Oh. Oh, okay. I get it." So I have to keep reinforcing in myself that this is real. It was never what I was told at the beginning because there just were no answers. Vestibular migraine, that didn't exist back then, or triple PD, or even vestibular hypofunction. Years and years and years ago, I went for testing at NYU. It was called a posturography to see how you react to your environment or how your vestibular system... And I did the test and I thought I did pretty good. And I said to the technician, "I know you're not supposed to give me answers and I'll talk to the doctor, but can I have a little hint?" And he said, "I don't know how you're walking." And I was like, "Really? Wow." So knowing that this is a real organic situation is helpful to me because I'll go into that other rabbit hole where I think, "This can't be anxiety. I can't be having all these things." And even when I first started having gastrointestinal symptoms and I went to Mount Sinai in New York City, one of the doctors there called it S7 syndrome. I was like, "What does that mean?" It's just like, middle-aged woman and, "Oh, you're saying it's stress?" Okay, no, it's not. But I didn't know it at the time and I was like, "Wow." So trying not to doubt myself is big for me and knowing that 99.9% sure that I'll get back to my baseline. I don't love my baseline, but I can manage it. I've learned how to manage it.

1:52:34.9 Abbie Ross: Yeah. I'm gonna bring in another question from the chat, which I think we've talked about this in so many of our sessions this week, and that's related to your social circle and how having these conditions has affected your social circle and your friends. Because how many people have friends who have multiple chronic health conditions? Kayla, I'll start with you real briefly, especially for you. I bet a lot of your friends revolve around your children and do other mothers understand what you're going through?

1:53:20.6 Kayla McCain: Yeah, it's interesting because this happened to me when I was 27 and I had that group of friends where we were all going out and going to restaurants and stuff all the time. And obviously, as a mom, life changes and it is interesting because I feel like before, the people who were around me kind of saw me going through it and learned about it as it was happening. And now it's like I'm meeting new people, and it's almost where I don't want to be like, "Hi, I'm Kayla, and I have a vestibular disorder." It's kind of a weird thing to discuss because I don't want that to be totally my identity when I'm meeting people for the first time. But it will come up because, for an example, there's this place that my friends and I will go to that is a vestibular nightmare. It's one of those play areas... It's like Chuck E. Cheese, they call it Cheeky Monkeys here in Dallas, and it's bright lights, bright colors, all the children, music playing. And I'm like... But I want to be a good mom and I take my kids. But every time we go, my friends would be like, "Oh, let's sit at this table." I'm like, "Can we go sit in that dark corner over there? How does anyone feel about that?" And it kind of naturally in conversation will come up being like, "Oh, yeah, well, this happened to me," and I tell the whole story. As time goes on, I think some people kind of understand it. I do share actively on my social media about what I'm going through, so I think some friends have kind of understood it that way. I also have some mom friends at the gym. This has kind of been a new thing for me lately because I've been having a little bit more dizziness as of late, but we'll do these classes and everybody will be doing the up-and-downs and I'm like, "I am not doing that. I will just be standing." And then I'm like, "I don't want to have to explain it," but then I'm like, "So this is the reason I didn't do what you were doing," and then I feel like I have to over-explain. It's weird to navigate, but at the same time, I feel like most times these days, because there's enough information out there, by telling your story... A couple months later, someone will be like, "Hey, my best friend's sister's dad had some dizzy episode. I showed them your stuff and it helped them." So you don't want to come out the gate being like, "This is what I have," but ultimately through conversation, it can help other people down the road too and hopefully help them understand what you're going through and maybe why I might be saying no to Cheeky Monkey today. It's nothing personal, I just can't handle that environment.

1:55:44.6 Dani Tolman: Absolutely. I think you have to be honest but decide how much you want to share for sure.

1:55:49.9 Kayla McCain: Right.

1:55:50.6 Dani Tolman: Judi, you've had this for so long. Has your social circle kind of built up around the fact that you have these multiple conditions?

1:56:00.1 Judi Rosenthal: Well, there are people who don't get it and never will. There's a woman that I grew up with and I can't talk about it to her because she'll say, "Well, you don't have cancer. You're not in a wheelchair. You're not in prison." Like, prison? I didn't break the law, so why would I be in prison? "Oh, it's not so bad," and stuff like that. And then I realized that she was having a bad headache at one point and she called me up and she goes, "I think I have a brain tumor." I'm like, "I don't think so. Why would you go down there?" But we moved up here and my best friend lives near us and my in-laws are about 45 minutes away and they get it. My posture is bad now, pretty much going forward, and I don't know if I scare people or crack them up with this, but I have a picture of the X-ray of my upper spine and it's like this and I'm like, "Oh, yeah, you want to see my invisible illness? Boom." And they're like, "Oh, God." So I don't think anyone else is going to go through that, though. Yeah. So I sort of work around what I can do, what I can't do. If I push myself a little and I have to take a rest day the next day, it is what it is.

1:57:40.8 Abbie Ross: I love that your sense of humor is intact. Well, I want to ask, this is going to be our final question today, unfortunately, but what would you say or want to share with someone that was experiencing something and starting to realize that they might have more than one vestibular health condition? Judi, do you want to share with us briefly what you would share with them?

1:58:04.3 Judi Rosenthal: Yeah. Keep looking for a provider that will tie things in together. Even just the vestibular situation, I went to a vestibular therapist who diagnosed me with bilateral vestibular hypofunction. The doctors weren't going there because they saw the Meniere's and the status post left-sided perilymph fistula and they just stayed with that. It's like, there's more. I thought it was just the left ear. How can it be both? I do try to keep my sense of humor. Like if a doctor says to me, "Wow, you have a lot of diagnoses," I'm like, "Oh, yeah, total train wreck. Hello." Because that's how I deal with it. It's a coping mechanism. And I am funny.

1:59:02.7 Dani Tolman: Absolutely. I love it. I love it. We have to laugh at ourselves sometimes. Sometimes that's the only thing that gets us through without crying. And what about you, Kayla? What is something you would share with a vestibular warrior that's just finding out that they might have another vestibular health condition or another health condition?

1:59:21.1 Kayla McCain: Yeah. I think to not be afraid to try different treatments that maybe you didn't think worked for you previously. I think I was so stuck on, "I'm not doing these medications. This isn't for me." And by finally just not giving up on myself with my second diagnosis, I found a treatment plan that's worked. Yeah, I think you can kind of go back to the drawing board of what worked the first time to help you feel your best, but there's always going to be new options and you should stay open-minded and work with your healthcare provider on finding a way that's going to help improve your second diagnosis.

2:00:02.0 Abbie Ross: Perfect. Thank you so much, both of you, for sharing your experience with not just one, but more than one vestibular disorder. Awesome. Yes. Oh, yes. If you want to follow Kayla, there's her blog. And Judi, I believe you participate in the Long-Term Warriors support group, don't you?

2:00:29.0 Judi Rosenthal: In the VEDA retired...

2:00:33.2 Abbie Ross: Right.

2:00:33.4 Judi Rosenthal: And the people there are so amazing. And it's not... I always thought a support group would be like, "Eh," and they're fun and they're smart and they're interesting and I love them so much.

2:00:49.4 Abbie Ross: Well, you can find them in the discussion board as well as on VEDA's website. Thanks again, Kayla and Judi. It was great talking with you today.

2:00:57.9 Judi Rosenthal: Thank you.

2:00:58.6 Dani Tolman: Thank you. Such a great conversation.

2:01:02.9 Abbie Ross: Yes.

2:01:03.4 Dani Tolman: Thank you again, Judi and Kayla, for sharing your personal experiences and so much about your life. It was very heartwarming. I didn't think I'd laugh that much during this session, but Judi's funny.

2:01:16.5 Abbie Ross: Humor is medicine. I want to thank again the James D. And Linda B. Hainlin Discovery Fund and the University of Minnesota Department of Otolaryngology for sponsoring this conference and making it available for free for all of you.

2:01:32.9 Dani Tolman: Yes. And as a reminder, you can purchase lifetime access to the recordings and the transcripts of this entire conference @vestibular.org/lrl-recordings. And you can help make sure that this valuable information that is presented at this annual event remains free to everyone by making a donation @vestibular.org/lrldonate. Now, those links are also listed in the description box below.

2:01:59.8 Abbie Ross: Thanks, everyone, for another great event. And don't forget to participate in our post-event survey to let us know what you thought about this year's conference and give us ideas for topics and speakers we can bring in to next year's conference.

2:02:13.2 Dani Tolman: Absolutely.

2:02:14.0 Abbie Ross: Bye everyone.

2:02:15.5 Dani Tolman: Bye.