



MIGRAINE WORLD SUMMIT

TRANSCRIPT

INTERVIEWS WITH WORLD-LEADING EXPERTS

FINDING BALANCE IN VESTIBULAR MIGRAINE DIAGNOSIS & TREATMENT

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Introduction (00:05): Best advice I can give is, create your action plan. Find out who your support system can be. Finding a physical therapist, a health psychologist, a physician, or clinician who can help with creating the action plan is also really helpful. But I usually think about your action plan in three categories: your lifestyle, your therapies, and your medications or interventions.

Amy Mowbray (00:31): When we hear migraine, so many of us think of severe head pain, but for some people, there are other symptoms, such as vertigo and dizziness, that are more prominent and disabling during a migraine attack. Vestibular migraine is often overlooked, and so many people are sadly misdiagnosed and passed from doctor to doctor without any meaningful treatment or support. Here at the Migraine World Summit, we want to give this disabling subtype of migraine the attention and gravitas it deserves. Dr. Kristen Steenerson, who is a clinical assistant professor of otolaryngology at Stanford, is here to discuss vestibular migraine and how best to manage it. Dr. Steenerson, welcome to the Migraine World Summit.

Dr. Steenerson (01:12): Thank you so much for having me.

Amy Mowbray (01:14): Please, could you start by giving us an overview of what vestibular migraine is?

Dr. Steenerson (01:19): Yes. First of all, thank you for the introduction. I think that's a perfect way to start off the conversation: Vestibular migraine really is a subtype of migraine, and I like to explain to my patients that migraine is a hypersensitivity disorder. That we think that the brain, for some reason, overinterprets different sensory inputs. So that could be lights are too bright, sounds are too loud, [or] smells are nauseating. And in that similar vein, motion can be hypersensitizing.

Dr. Steenerson (01:46): And what we'll see is that you can have different types of motion-interpretation errors when it comes to vestibular migraine. So that can either be a creation of motion that you know shouldn't be there — rocking, spinning, tilting, swaying, floating, pushing, pulling — or an intolerance of motion that should be tolerable. So simple as moving your head, your eyes, watching visual motion like cars go by, can be enough to cause a noxious feeling or make you feel ill because the brain cannot interpret that motion information correctly, and that is a terrible feeling. And so just like other types of migraine, these motion-dysregulation or motion-interpretation errors can come and go, or sometimes they can chronify and become a chronic symptom that's with you on a daily basis.

Amy Mowbray (02:33): And how common is vestibular migraine?

Dr. Steenerson (02:36): Vestibular migraine is really common. A lovely study out of UCSF [University of California San Francisco] showed that up to 2.7% of the general population meet criteria for vestibular migraine. That doesn't mean 2.7% are diagnosed, but we think that it's so common that up to 3 people out of 100 have vestibular migraine.

Amy Mowbray (02:56): So, you shared some of the really horrible and disabling symptoms to do with movement with vestibular migraine. Is headache also present with patients who have vestibular migraine?

Dr. Steenerson (03:06): It can be, and that's the challenge — it's that headache isn't the most consistent symptom for people with vestibular migraine. So up to 50% of people may have no



headache when it comes to their vertigo or vestibular symptoms, which is one reason we think it can take so long to get a proper diagnosis — it's that many people assume that in order to have migraine, you must have headache that accompanies the symptoms. But we know, based on epidemiology and lots of research, that isn't the case for many vestibular migraine patients.

Amy Mowbray (03:35): And can you experience vertigo and dizziness as a symptom of migraine but not actually have vestibular migraine?

Dr. Steenerson (03:41): That's a really good question and maybe a point up for debate, but we know that dizziness and vertigo is really common in regular migraine — classic migraine, migraine headaches. And those patients, depending on how often they're having vertigo or dizziness, might not meet criteria technically for vestibular migraine yet, but they share so many similar mechanisms. It's really common to have overlap.

Amy Mowbray (04:03): How does vestibular migraine differ from other vestibular disorders such as BPPV [benign paroxysmal positional vertigo], PPPD [persistent postural-perceptual dizziness], Ménière's disease, and MdDS [mal de débarquement syndrome]?

Dr. Steenerson (04:12): Probably another one of the challenges of diagnosing vestibular migraine is that we love to call vestibular migraine the chameleon of neurology because it can mimic so many other vestibular disorders. And we also know that vestibular migraine can be easily triggered by other vestibular disorders. So it's really common for patients to have symptoms that sound like other vestibular disorders or to get vestibular migraine in response to another vestibular disorder that they're experiencing independently. For example, BPPV we think of as a positional vertigo syndrome, meaning that when you move your head or change your head position in specific directions, you will trigger a sense of motion that usually lasts just seconds at a time. What's challenging there is that we know you're up to three times more likely to have BPPV if you have migraine and potentially even more likely if you have migraine to have BPPV.

Dr. Steenerson (05:03): So it's this challenging communication between the two systems that can make it really hard to differentiate between the two types of vestibular disorders. So practically speaking, we actually want to consider both because they might have different treatment methods, and we want to make sure that we're covering you for both etiologies.

Dr. Steenerson (05:21): But just [from a] 30,000-foot view, we think of BPPV as being a positional vertigo syndrome that occurs just for seconds. We think of Ménière's disease as being an inner-ear disease that causes hearing loss that's time-locked or that goes exactly in timing with the vertigo symptoms. And then we think of PPPD as a change in the brain's sensitivity to understanding motion and orientation that's there, common, or greater than 50% of the time basis. But because of so much overlap, I always want to consider vestibular migraine whenever someone comes in with one of those other disorders, as well.

Amy Mowbray (06:00): Thank you; that's such a helpful overview and hopefully will help point people in the right direction when they initially go and see their doctor. Speaking of doctors, what type of doctor should someone see if they suspect vestibular migraine but are struggling to get diagnosed or receive appropriate care?

Dr. Steenerson (06:15): Based on your training and your background as a migraine specialist, you may have had a lot of exposure to vestibular migraine, you may have had very little



exposure to vestibular migraine, so it can sometimes be challenging just going off of someone's credentials or background knowing that you'll get appropriate care. But you usually can ask some helpful questions of different doctors: "Do you believe in vestibular migraine? Is this something that you've treated before? Do you feel comfortable treating vestibular migraine?" That can be really helpful, but generally speaking, headache neurologists are going to be an excellent resource. Some neurologists who are ENT [ear, nose, and throat] surgeons who have specialized in skull-based surgeries, some of them are vestibular experts, fantastic physicians, and aids in diagnosing and managing vestibular migraine. So those two specialties are usually your highest yield when it comes to getting help.

Amy Mowbray (07:10): Henry, a member of our community, says: After decades stumbling around with poor balance and a host of debilitating symptoms, vestibular migraine was finally diagnosed and treated in my 50s. Additional diagnoses, including postural orthostatic tachycardia syndrome (POTS) — apparently seen fairly regularly alongside vestibular migraine — hypermobile Ehlers-Danlos syndrome, histamine intolerance, environmental allergies, and small-fiber peripheral neuropathy. What comorbid conditions do you tend to see with vestibular migraine?

Dr. Steenerson (07:43): Yeah, so that list, I agree, is really common, and I'm still trying to wrap my head around exactly why all of them are interconnected. But the numbers definitely support that those commonly agree together. Vestibular migraine I see as a sensitizer to motion, and as a result, we'll see some cascade effects because of that motion sensitivity that is experienced. So first and foremost, of course, the vestibular symptoms. So having a variety of vestibular symptoms is more common than not. So having episodes of spinning or rocking, tilting, floating, but also exquisite motion sensitivity; also imbalance or feeling ataxic when you walk around, having difficulty with orientation, so feeling connected to your body, connected to the world around you. And as a result of all of these disparate symptoms, a lot of cognitive changes, or brain fog, because my theory is that your brain is so distracted by having to manage all of these different symptoms that it's really hard to have the full bandwidth, if you will, of cognitive function to focus on what you need.

Dr. Steenerson (08:48): And as a result, we'll commonly see complaints of feeling fogginess, feeling senses of short-term memory loss, word-finding difficulty, not processing as quickly as you know you're capable of. We'll also see cascade effects of increased tension-type headaches or cervicogenic headaches, and that's because all of us, when we feel dizzy or imbalanced, increase our what are known as postural control strategies. So that means we tighten up our neck or shoulders, or back muscles in order to stabilize our balance with our muscles, but those muscles are meant to be used in short bursts. And when we feel this way on a chronic basis, then we'll overuse those muscles. That creates cervicogenic disease or just tension that can increase the wear and tear on the joints, and the nerves, and the muscles that link up to the head, and that trigeminal system that we know is so triggering for headaches and migraines, as well.

Dr. Steenerson (09:43): So we'll see cognitive symptoms, we will see neck and headache symptoms in response. We'll see deconditioning, and so if you add a sensitivity towards autonomic dysfunction, that will unveil that autonomic dysfunction, or you might start to develop autonomic dysfunction because you aren't able to be as active as you once were. So your cardiovascular integrity reduces, and so many people will get a secondary postural tachycardia syndrome because they aren't able to move and be as active as they need to be.



Dr. Steenerson (10:14): And then we'll also see a lot of anxiety and depression. And this isn't a judgment; this is a normal, natural response that anyone would have when you have random attacks of dizziness that make your life really difficult to predict. As well, working against us is we have direct wiring or connections between our stress response system and our vestibular system in the brain. That's supposed to be there so that if you have a sudden dizziness spell or sudden balance problem, you have those lightning-fast reflexes to protect you from harm [or] protect you from a fall. But in this circumstance, where you have these random spells or unpredictable balance, then that wiring gets overemphasized, and so we can have increased responsiveness from our stress system, which of course creates increased anxiety and hypervigilance of the world around us. So we'll see lots of different organ systems involved in response to those initial vestibular symptoms, but then we'll also see other conditions that we're still trying to figure out exactly what the connection is, but there's clearly some increased risk for those.

Amy Mowbray (11:22): That's fascinating. I had no idea about the tension migraine headaches and how, just by tensing up ourselves that would contribute to the pain associated with migraine and not just vestibular symptoms. What role does estrogen play in vestibular migraine?

Dr. Steenerson (11:38): Based on epidemiologic studies, there is a clear association between changes in our estrogen levels and when we become most susceptible to vestibular symptoms. Most common is around perimenopause [when] we see many women in particular transition from their migraine headaches into vestibular migraines. And that, too, might be a reason that it's so challenging to get a diagnosis, because someone may perceive, "Oh, my migraines are finished. My headaches have completed. I no longer have that problem. I don't have migraines anymore." But what we're learning instead is that migraine grows with us as we go through our different life stages and life cycles — presents differently as children, as adolescents, as young adults, and definitely through menopause and perimenopause, there seem to be changes in the quality of migraine. So estrogen withdrawal — and we think the more erratic that estrogen withdrawal is around perimenopause — seems to be a trigger for vestibular symptoms and specifically vestibular migraine.

Amy Mowbray (12:43): Several members of our community have asked about the link between motion sickness and migraine. How common is motion sickness among people with migraine?

Dr. Steenerson (12:51): Motion sickness is very common in migraine. Over 50% of people with migraine experience motion sickness, and in fact, we think motion sickness might be its own form of migraine. The idea being that our sensitivity to motion is an indicator of our overall migraine threshold. So if you have a migraine threshold that's on the lower end for motion, then when you're exposed to a certain amount of motion that pushes past that threshold, then you'll start to get the symptoms of motion sickness — so nausea, clamminess, stomach awareness, knowing that you need to get out of motion as quickly as possible. And we'll even sometimes think of motion sickness as a mini-form of vestibular migraine, too — that it's very situational and dependent on that environment but very similar manifestations in terms of your symptoms.

Amy Mowbray (13:43): I'd like to now move on to discuss some of the different ways you can manage vestibular migraine. So, what acute treatments are available?

Dr. Steenerson (13:50): So, we approach vestibular migraine very similarly to regular migraines or migraine headaches. There are a few studies that have looked into triptans — zolmitriptan,



rizatriptan — and then we typically will combine those with anti-nausea medications. Medications that block dopamine seem to be exquisitely helpful for nausea and dizziness, and so occasionally we can use those as monotherapy or single therapy. But a lot of times you will combine those medications, so you have some anti-nausea and some antimigraine effects working synergistically to try and calm these down as quickly as possible. Just like other migraines, we want to be super mindful of nausea because if you're having too much nausea, it's going to be a challenge to absorb any oral medications. So occasionally we'll look for other routes of administration, too, to see if we can help get the medication into your system as quickly as possible.

Dr. Steenerson (14:47): So medication is always a good start, but sometimes we want to look at behavioral changes, too, that you could employ. So interestingly, mindfulness, especially that focuses on grounding techniques, can be helpful. So it can help ground that fight-or-flight response, but also actually literally can ground you to help you feel more oriented if you can find a meditation or mindfulness technique that helps with your orientation sense. And then some other aspects of behavioral changes — cool compresses, sometimes essential oils — all of those can be complementary, depending on how significant and how long your symptoms are.

Amy Mowbray (15:28): What preventative treatments are there for vestibular migraine?

Dr. Steenerson (15:32): So similar story, there have been a lot of small studies looking at different migraine headache medications in the context of vestibular migraine, and it seems like most migraine headache medications can help. But we'll typically use antidepressant medications, blood pressure medications, anti-seizure medications, and we've also started to use a lot of the anti-CGRP medications now that those are much more widely available.

Amy Mowbray (16:00): Great, and which neuromodulation devices might be helpful for those with vestibular migraine?

Dr. Steenerson (16:06): The three neuromodulation devices that we use the most are looking at trigeminal nerve stimulation, at vagus nerve stimulation, and at the remote electrical neuromodulation. And the studies are still developing, but there is some helpful information coming out that the vagus nerve stimulator might be helpful. The trigeminal nerve stimulator might be helpful as well, especially if you have comorbid headaches. So there might be some differences based on people who have a large headache burden versus people who don't have a large headache burden in terms of which neuromodulation devices are going to be helpful, but they're so safe, I will try any of them, and occasionally people will find them helpful.

Amy Mowbray (16:48): It sounds like, with research and the development of specific treatments for vestibular migraine, we still have a long way to go. Are there any new treatments that are just becoming available or that are on the horizon for those with vestibular migraine?

Dr. Steenerson (17:04): I'm really optimistic about the CGRP medications. There's an ongoing randomized control trial evaluating specifically vestibular migraine response to CGRP medications — one of the injectables. And so far, too soon to tell, but at least anecdotally, based on my clinical experience, those have been really well tolerated and really helpful and not just for vestibular symptoms. There may also be other otologic or hearing changes that might respond to those, too. Again, too soon to tell, but I'm really optimistic based on the basic science that is available and the trends that we're seeing so far.



Amy Mowbray (17:46): What advice would you give to someone struggling with severe nausea and vestibular migraine when usual anti-nausea meds just are not working?

Dr. Steenerson (17:54): I would really recommend looking into preventative treatments for migraine. So, some schools of thought believe that nausea really is a better marker of overall migraine activity instead of your headache burden or even your dizziness burden because nausea might be an indicator to us of your overall brain sensitivity. So if the nausea is there to a significant extent, that to me sends the message that migraine is still quite active and we need to have a long-term plan to help reduce that. So for those who aren't responding to anti-nausea medications, are having a hard time with keeping up with it, they're needing a lot of anti-nausea medications — it can be a good time to look into preventative medications that you take every day for migraine that aren't technically nausea medications but are helping to reduce your overall migraine burden. That might actually help your challenging-to-treat nausea.

Amy Mowbray (18:46): Yeah, a great reminder that when we actually treat migraine itself, we also, in turn, treat the nausea symptoms. So, you touched on some behavioral techniques that can help with managing vestibular migraine. What other lifestyle modifications can people make to help?

Dr. Steenerson (19:03): So, this might be an area that is pretty different from migraine headache management: where we partner significantly with vestibular physical therapists. And vestibular physical therapists are just fantastic aids in treatment plans because our vestibular system is our motion system, and we really have to train that motion system to desensitize and to habituate so that we can tolerate motion and push that threshold up as high as possible, as well as make sure we're not sacrificing our other important motion activities like aerobic exercise, strength training exercise, that we know is protective for all types of migraine. The vestibular therapists are excellent helps and aids in figuring out what that exercise plan is going to be — what are the motion- and motion-desensitization and habituation exercises that are going to benefit you the most, and how can we build this plan so that it's tolerable?

Dr. Steenerson (19:57): Some of the old adages said: "Don't prescribe vestibular therapy for people with migraine because it's too much to handle. It's going to make [them] sick. It's going to make [them] worse. Don't do that." But we've come a long way in terms of vestibular therapy practices, and we found that by having very gradual, gentle exercises that you build up and build up through, you can actually tolerate a lot of vestibular therapy, and that can be the most helpful step for getting functional again and getting back to being able to tolerate the world around you and be able to do everything you need to do at home, and work, and with family so that you aren't feeling afraid or at risk of injury.

Amy Mowbray (20:39): Is it similar to — with regular migraine or classic migraine — where we try and exercise below our threshold? Is that a similar thing with vestibular migraine?

Dr. Steenerson (20:49): Exactly. So, think of it as this pacing concept and figuring out where your threshold is so that you can push that threshold a little bit, but not so far that you're having a breakthrough spell or having to recover for a significant amount of time after the fact.

Amy Mowbray (21:05): What advice would you give to someone who's watching this who thinks any movement or exercise will trigger them — they are struggling just to get around their house and do any basic activity. What would you suggest?



Dr. Steenerson (21:19): So, first is a little bit of cognitive therapy. So, helping to teach your brain — why is it giving you those signals? So because of that threat response and that increased connectivity in the brain between our fight-or-flight system and our vestibular system, we get a really significant negative feedback loop telling us, "Don't move. Don't move your head, your eyes. Don't look at movement. This is going to make you feel really ill, and that's potentially dangerous." But if we can try and start having a conversation, if you will, with our own brain, changing the narrative, saying, "All right, this is my brain just being hypersensitive. It's trying to protect me, but it's actually working against me if I avoid everything and I isolate myself too much. So first, I need to try and figure out how to make me feel comfortable and confident that this is just a warning sign, and that's something that I can listen to, but I don't have to obey, if you will, or I don't have to only listen to that narrative and can start to change that thought process and understanding why those warning signals are happening."

Dr. Steenerson (22:19): When that starts to ingrain, then you start to notice: "Oh, I actually can tolerate a little bit more, and I can start to push myself a little bit more, and then can start to actually reduce that negative feedback loop so it's not as strong as signaling, so then you can start to make bigger gains gradually over time." And that's a tall order for someone who's dealing with a lot of symptoms, which is why I think having a partner with physical therapy, sometimes even a partner with a health psychologist, that can help with some of those narratives and can be really, really big aids in getting over that initial threshold, which can feel just insurmountable at first.

Amy Mowbray (23:03): That leads us really nicely onto my next question: What role do neuroplasticity and brain training have in the management of vestibular migraine?

Dr. Steenerson (23:13): Yes, I think so much of this is neuroplasticity. I'd love to have a cure for migraine in general, and definitely for vestibular migraine, but really, when we step back and take a look, we're trying to help mitigate the migraine activity. We're not curing it or taking it away entirely. So much of this is helping to reduce that migraine sensitivity, and that migraine sensitivity we know is rooted in a few different aspects of how our brain functions. And so, if the brain gets really used to functioning in a specific way and is on that high-alert, hypervigilant state of trying to protect you from any harm or any type of uncomfortable sensation, then that's really hard to break through. But neuroplasticity training — this idea that you can retrain the brain, you can make new connections to help overcome some of those ingrained pathways or ingrained behaviors — can be the most important intervention for a lot of people.

Amy Mowbray (24:10): Do you have any advice for people who are looking to explore this, specifically for vestibular migraine?

Dr. Steenerson (24:17): There [are] a lot of really nice online resources and a few books that have been written that explain neuroplasticity to a larger extent, help to contextualize it for the vestibular system in particular — how that incorporates our balance and motion detection and perception — and then helps to give some tools or some techniques on how to start that process of engaging neuroplasticity to change how your brain approaches these different circumstances.

Amy Mowbray (24:45): Are there any books you'd recommend in particular?

Dr. Steenerson (24:48): Yeah, there [are] some really good books. So, *Victory Over Vestibular Migraine* by [Dr.] Shin Beh is excellent. Joey Remenyi in Australia has written a nice book called



Seeking Balance. There [are] a lot of online free resources that can be helpful, too; you don't have to spend a lot of money. That there's just open-access techniques and tools that can also be helpful.

Amy Mowbray (25:10): Thank you for sharing those with us. Are there any specific supplements that you'd recommend for vestibular migraine?

Dr. Steenerson (25:16): Supplements are a great option for people who are very sensitive to medications or who are just apprehensive about trying medications. And there's probably some need for all of us for some increased nutrition in our lives because, unfortunately, at least in the United States, we don't necessarily have the most nutrient-dense diet that's available to us on a regular basis. So there might be some relative nutritional deficiencies out there, which might be one reason that vitamins can be helpful for some people and not for others. The one caveat here in the United States is that we don't have great regulation over our vitamin industry. It's considered a food and not a drug or a medication. That being said, we adopt a lot of the same supplements that migraine headache providers recommend. So, magnesium, vitamin B2 (also known as riboflavin), coenzyme Q10; sometimes feverfew can be helpful for some people.

Amy Mowbray (26:16): Great. And lastly, what advice do you have for those who are living with chronic vestibular migraine and are struggling to cope?

Dr. Steenerson (26:25): I think the best advice I can give is, create your action plan. Find out who your support system can be. Finding a physical therapist, a health psychologist, a physician, or clinician who can help with creating the action plan is also really helpful. But I usually think about your action plan in three categories: your lifestyle, your therapies, and your medications or interventions. Lifestyle: We always want to think about our general brain health practices. So, are you getting enough sleep? Are you eating healthfully and eating often enough? Are you getting enough exercise — both cardio and strength training? Are you hydrating enough, and what are you hydrating with? Is it water with some electrolytes every once in a while, or is it a lot of caffeine or alcohol, which can be really irritating to migraine? So it's worth cutting those out or reducing [them].

Dr. Steenerson (27:17): And then, how is your stress? Stress is everywhere. I wish we could get rid of stress, but generally, there's a lot of stress we can't really change but we can change how we respond to that stress. Then therapies: We've already touched on this, but finding a vestibular physical therapist and/or a health psychologist or some type of psychological practice, behavioral practice, that resonates with you. And then medications or therapies — are there rescue medications that are helpful for you? Preventative medications or vitamins that can be helpful for you? And any neuromodulation devices or any other health issues that need to be taken care of? Are you going through perimenopause and menopause, and you need some support there? Was there a major health change that has stressed your overall system and needs to be addressed to help improve your migraine threshold? Do you have any iron deficiency or vitamin deficiencies that need to be addressed? Those can all be helpful parts of the action plan to reduce your overall burden of migraine symptoms.

Amy Mowbray (28:22): It's really helpful you identified this three-pronged approach because I'm sure there'll be many people listening who might feel like they've really ticked off one or two of these, but hopefully there's a third one or even a second one which can have some more attention and really bring people some tangible results. Where can we learn more about what you're doing or follow your work?



Dr. Steenerson (28:45): Oh, thank you for asking. I have a website at the Stanford Otolaryngology (Head and Neck Surgery) Department website, so you can search for me there. And we have our lab listed with some of our ongoing studies as well as some more information about vestibular disorders. So you're free to check that out.

Amy Mowbray (29:06): Thank you. And you've already recommended a few books, but are there any other resources you'd like to recommend or offer to our audience?

Dr. Steenerson (29:14): I have a lot of them listed on my website if you want to look into the more granular details, but I just can't overemphasize the need for that psychological support. This is a really challenging thing to go through. It's an invisible illness, much like other migraines, and so many people can unfortunately look at people externally and say, "You look great! Everything looks normal." And that's really challenging psychologically to have to constantly advocate for yourself, and defend yourself, and try and help other people understand in an invisible circumstance. So, getting that support system that can help validate you, that can help understand you empirically so that you're not having to take on that burden entirely by yourself is just incredibly helpful. And there's the science part of this, where your anxiety and depression are automatically irritated, or activated, or created because of vestibular disorder. So, this is by no means a judgment or fault on yourself personally, but those are just common, common, common things that have to be addressed, or else it's going to be really challenging to work on any of these treatment plans to get better.

Amy Mowbray (30:29): That's such a great reminder that if you are struggling with your mental health because of migraine, or vestibular migraine, it's really not your fault. Dr. Steenerson, it has been an absolute pleasure to speak with you. On behalf of the vestibular migraine community, thank you very much for sharing your expertise and your time with us today at the Migraine World Summit. Thank you.

Dr. Steenerson (30:49): Thank you.