Life Rebalanced Live 2024

TINNITUS (RINGING IN THE EARS)

CYNTHIA: Hello, and welcome to the second day of the Vestibular Disorder Association's Fourth Annual Life Rebalance Live Virtual Conference. I'm Cynthia Ryan, executive director of VeDA. And I just want to give a call out to everyone out there who participated in yesterday's event and a special thank you to Dr. Kristen Steenerson for her amazing talk about vestibular migraine, PPPD, and Mal de Sébarquement.

There were so many amazing questions flowing in. We just could not keep up. And I encourage you, if you did not get to watch yesterday's talk, to go back and check it out and also check out all of the Q&As, the questions and answers because there's a lot of really great information in there.

So I want to start today, again, by thanking our sponsors who've made this event possible the James D. and Linda B. Hainlen Discovery Fund and the University of Minnesota's Department of Otolaryngology have generously supported LRL since its inception in 2020. A special shout-out to Jim Hainlen who was a vestibular patient and inspired this event by holding his own vestibular conference in 2018 and 2019 in Minneapolis.

Jim cares so deeply about supporting people on their vestibular journey. And it was important to him to not only educate people about vestibular disorders but provide a platform where people can connect. And that's why we have on the Whova platform, which is what we're using the community boards where you can connect with others and hold meetups. And I saw a lot of that going on. That's great to see.

Another big thanks to Dr. Abbie Ross and Dr. Danielle Tolman from Balancing Act Rehabilitation, who are also generously supporting this year's event. Many of you know Abbie and Danielle as the hosts of the conference. And some of you may know them as hosts of the Talk Dizzy To Me Podcast. But you may not know that Abbie and Danielle also serve on VeDA Board of Directors and have volunteered countless hours to advance vestibular advocacy.

Its dedicated volunteers like Danielle and Abbie that are the lifeblood of VeDA. And I have been honored to work with them and glad to call them my friends. Danielle and Abbie, thank you for everything you do for VeDA and the vestibular community.

Thanks also to the Academy of Doctors of Audiology for sponsoring this year's event. And a personal thank you to Pamela Duncan who attended last year's event and was so inspired that she wanted to make sure this happens again year after year. So she made a donation to support this year's event as well.

So now I'd like to pass it off to our hosts, Drs. Abbie Ross and Danielle Tolman.

DANIELLE TOLMAN: Thank you for the warm and wonderful introduction, Cynthia. It's still hard to believe that this is our fourth annual Life Rebalance Live conference. We are back for day 2 and continuing with all-star lineup of health care providers to discuss various topics pertaining to the management of vestibular dysfunction and inspirational patients who will be sharing their vestibular journeys. We also want to say thank you so much to everyone who's contributed to this conference in some way, including VeDA's donors, staff, and volunteers.

ABBIE ROSS: And with their contributions, we're pleased to be able to put the live version of the conference on at no cost to our attendees. If you do

wish to gain lifetime access to the presentations following the live event, we will have them available for purchase for just $55. And so many of you have already purchased them. So thank you. Your financial support helps VeDA's continued mission to spread vestibular awareness.

Now our topic for today, day 2, is tinnitus. We'll be discussing, well, what exactly is it, how is hearing loss connected to tinnitus, what are the treatment approaches available for tinnitus, are there certain vestibular diagnoses more commonly associated with tinnitus, and plenty more.

DANIELLE TOLMAN: So without further ado, we'd like to introduce you to our speaker Dr. Robert Allen. Dr. Allen is the clinical director, lead clinician, and co-founder of Topple Diagnostics. He earned his communication sciences and disorders undergraduate degree from University of Texas before starting his doctor of audiology program at Auburn University. While in training, Dr. Allen subspecialized in evaluating and managing patients suffering from dizziness and balance dysfunction.

He returned home to Atlanta, Georgia, to begin practicing and help patients in need. Dr. Allen aims to provide quick and easy access to vestibular diagnostic services so patients can be seen faster and begin their next steps towards healing sooner. He also offers complete management so that his patients and their referring medical providers are informed with the recommendations for next steps in care.

Dr. Allen utilizes a comprehensive and patient-centered approach to evaluation and management. This ensures that each patient is fully evaluated while also making sure that there are no unnecessary testing being performed. So welcome, Dr. Allen. We are so excited to have you here today. Thank you for agreeing to talk with us on this really hot topic, tinnitus.

ROBERT ALLEN: Good morning, Abbie, Danielle. I really appreciate the invitation. Thank you so much. VeDA is such a great organization. And I'm

just honored to be in this role here today to help provide a little bit of knowledge that I have as well. So thank you guys so much. And appreciate everything y'all are doing.

ABBIE ROSS: Thank you for being here. We're so excited to talk about this. Because I have to say, so many patients ask me about this. And I am not the expert. So thank you for joining us. We'll get right into the questions first by just saying, what is tinnitus?

ROBERT ALLEN: That's a great question. So tinnitus, usually, people think it's ringing in the ears. However, by definition, we look at it as any noise that a patient hears in their ears, be it ringing, wooshing, crickets, bird chirping, anything like that that isn't there. So it's a sound that they're hearing in their ears that is not actually in the environment.

DANIELLE TOLMAN: So I want to jump into first talking about what creates tinnitus. What is going on anatomically that creates this noise that seems to be bugging everybody?

ROBERT ALLEN: That's a fantastic question. The answer I'll give you is first, we're learning a bunch about it as we continue to do research. Now the thought process is most of tinnitus is caused by hearing loss or related to hearing loss.

Now not all of it is. However, we see a lot of tinnitus is related to hearing loss in some capacity. When we look at the ear and hearing and then the projections into the brain, one of the biggest offenders, if you will, is something we call the dorsal cochlear nucleus.

So that is a small area that's in the brainstem. And it's the first point where the nerve that runs from our ear to the brain to connect the two, that's the first point where our brain is starting to get some information from our inner ear hearing organs. That nucleus there is what we think is the main

contributor for tinnitus. And we think what happens is that basically, it gets overstimulated or is hyperactive in the case of tinnitus.

So with patients, I kind like to think about it like my four-year-old. If we give him a bunch of candy, he's going to run around like crazy for a while. Same thing with tinnitus. In certain situations, either hearing loss or with loud sound exposure, in the case of hearing issues, it can lead to hypersensitivity and overstimulation of that area, which is where we think that the noise is coming from.

With our hearing system, though, we do have projections into other areas in our brain, for example, the amygdala. And that's part of emotional regulation. That's an emotional regulation system. And that's where we start to see some interesting things happen with tinnitus. And that is that we can start to see a lot of emotional changes or responses to the tinnitus. And we see a lot of feedback, almost like a feedback loop can begin to be created in certain situations.

ABBIE ROSS: Now two questions. You mentioned that hearing loss is connected to tinnitus. But you also mentioned in not all cases. So when we get an audiogram, for example, if that's completely normal, but we are having these extra noises, what do you recommend?

ROBERT ALLEN: That's a great question. Like you said, tinnitus doesn't have to be because of hearing loss, most commonly associated with it. But not always. I'll give you a great example is migraine. Patients with migraines often complain of tinnitus.

Now they may have a completely normal audiogram, normal hearing test. In this situation, the thought process is, again, that dorsal cochlear nucleus in the brainstem is what's being overstimulated, overactive. When we look at migraine, we joke, and I feel like I can make this joke because my entire family is migraineurs, they're hypersensitive. Brains like cats in a sense.

So light sensitivity, sound sensitivity, smell sensitivity can be varying because of certain situations with what's happening. During the migraine, we can see that there's overstimulation in certain areas due to changes in blood flow or other things like that. Concussion is another example of when we can see tinnitus begin that's not necessarily related to hearing loss. There are changes in firing patterns in the brain, how the brain's getting energy. And it can lead to this hypersensitivity or overstimulation of certain areas.

DANIELLE TOLMAN: There are so many other directions we can go. And I have so many questions just from that small tidbit of information. So I think where I'd like to go from here in talking about how you can have hypersensitivities and other things that contribute to tinnitus, does that mean that tinnitus in those situations can be resolved with similar approaches to treatment of, say, migraine treatments-- to decrease that hypersensitivity?

ROBERT ALLEN: That's a great question. And the answer is that-- the answer is likely yes. And the reason I'm going to give that a little bit of an asterisk there is because migraines are very interesting. But they don't-- not every person responds to everything the same way. There's different ways you have to approach it. There are different things that are causing the migraine, excuse me, be it hormones. Can be a huge thing for migrainers.

So we have to look at management of it to be able to see if we can reduce the tinnitus, reduce those noises. Now by no stretch am I migraine specialist. So I'm not going to go too far down the rabbit hole / But we do know that when we see a lot of patients that have tinnitus or dizziness related to migraines, for example, properly managing it. Can lead to reduction in those symptoms. In some cases, just outright resolution of symptoms as well.

DANIELLE TOLMAN: So that would maybe indicate that then patients that have this type of cause for tinnitus might see fluctuations in some days where they're tinnitus could be louder, or it could be softer. Would we see

more fluctuations along that reasoning, that some days are more hypersensitive and some days not?

ROBERT ALLEN: Absolutely, we can definitely see that. And you can also see that in patients that have hearing loss as the main cause of their tinnitus, for example. Earlier, the amygdala and emotional connection-- or emotional regulation system, good days emotionally can lead to reduction in tinnitus for a lot of patients in general, be it hearing loss, migraine, whatever it may be that's the root cause.

So there's been some interesting studies. And this has been a little bit since I looked back at this one. But one study suggested that there may be changes actually in brain structure that relates to tinnitus in certain areas that are, again, related to emotional regulation and emotional states.

It can create a little bit of what we call a negative feedback loop. You hear the noise. It makes you upset. Therefore, it gets a little louder. Makes you more upset. You hear the noise at night when you're trying to sleep. You can't go to sleep. So then you're tired. Emotionally, that can be draining for people.

So absolutely, we can have good days and bad days with the tinnitus. And quite frankly, the other thing too is just how much are we hearing it. So what I mean by that is, if we're in a certain situation where it's very quiet, that's the most common issue-- or most common place where patients hear their ringing or their noise the loudest.

I like to use the analogy of think about it like you're sitting in a dark room, and you have a single candle. You're in a quiet room. And the only thing you hear is the ringing. You're in a dark room. The only thing you see is that one lit candle. What you got to do is you got to brighten your environment. Light other candles. Open the door. Open the windows. Turn a light on.

So if folks are in a very quiet environment, if they're sitting there, and they can't hear anything else, you're going to hear the ringing louder. You're going to hear the noises louder typically from what we hear from a lot of patients. But if they're in a situation where there's a bit more noise, be it radio, TV, traffic, noise, a fan, anything like that, well, that may help distract them a bit. And they can have a better day. And they cannot hear it so loudly.

ABBIE ROSS: You touched on something that we speak about in general with symptoms associated with vestibular dysfunction. And that's that negative feedback loop. We refer to something called the dizzy-anxious-dizzy cycle. So fits perfectly with tinnitus as well, it sounds like. Are there any other triggers or aggravating factors you can think of when it comes to these noises?

ROBERT ALLEN: Absolutely. So we've talked about a couple of reasons why we could have tinnitus. Uncontrolled high blood pressure, for example, can cause it. Neck issues can cause it. TMJ actually can be related to it.

So there are a lot of other factors that can be related and can be causes of tinnitus. So when we're looking at it, we have to be able to identify that and then see what we can do from a management perspective to see if we can identify the root cause and then work with that or work around it.

ABBIE ROSS: That actually leads into one of our audience questions as well. Can you touch a little bit deeper on the link between TMJ and tinnitus?

ROBERT ALLEN: Sure. There's a study that came out in 2019 that was looking at TMJ and its relationship with dizziness. And we're actually looking at potentially should this become its own separate category when we are looking at dizziness.

So should people with TMJ and dizziness become its own separate category? We've got the migraine and tinnitus. We got the neck and tinnitus. We got the hearing loss and tinnitus. Should TMJ become one as well?

There is a very big relationship with it. And it's one of those things that we have to work in conjunction with other providers-- dentists, oral maxillofacial surgeons in some situations, whatever it may be-- to see if we can manage that TMJ to then help decrease the tinnitus as well.

DANIELLE TOLMAN: So it sounds like there's a lot of different aspects to what could be causing this, meaning that it's likely that these patients are going to go through a multidisciplinary team as well, working with an audiologist and then working with the other type of people who would make up that treatment depending on what's the cause. So what are some of the other clinicians that may be involved in treating or managing tinnitus?

ROBERT ALLEN: That's a great question. In terms of the very close network, if you will, audiology is going to play a huge role. We need to understand what is your hearing. We need to do a tinnitus evaluation, see if we can find a certain pitch of where that noise is. Can we mask it out? So can we do certain things that will help either reduce or resolve the tinnitus in certain situations? And we need a good thorough medical history to understand potentially where that's coming from.

If it's not related to hearing loss, well, we need to be looking at other avenues. So could a migrainer-- for example, if it's a migrainer, well then, we need to potentially look at neurology. If it's unilateral, so just one ear, and there's associated hearing loss, well, we may need to get over to ENT for further evaluation. If it's a neck issue, physical therapy may be beneficial or potentially orthopedics or something like that.

So we have to take each patient case by case and understand the hearing aspects, the full tinnitus evaluation to understand what's going on with the patient from that perspective. And then we need to understand that medical history so we can pinpoint potentially where is it coming from and what are our next steps in management.

Certain cases, we're even getting back to primary care or cardiology if it is related to cardiovascular issues as well. So it's a case by case basis.

ABBIE ROSS: Again, it echoes other symptoms associated with vestibular dysfunction where everyone's individualized. Everyone's a little bit different. So treatment plans look different. But with that being said, I want to get a little bit more into the treatment approach. Can you talk about-- maybe take a few different causes of tinnitus and then describe what the treatment approach would look like for each?

ROBERT ALLEN: Sure. So the first one we'll take is going to be hearing loss because that's the most prevalent. In that situation, we'll do a hearing test. And we'll figure out where the hearing loss is. And then from there, we'll be able to do a tinnitus evaluation.

And again, that's what I was mentioning in terms of, can we identify where that sound is? Can we get a certain frequency behind it if we're capable of it? And then can we what we call mask it out? So are we able to get rid of that sound or really reduce that sound with other sounds in the environment?

For hearing loss in certain cases, actually just fixing the hearing loss alone is enough to help with the tinnitus. So again, brightening that sound environment, if you will, or giving that dorsal cochlear nucleus more information from the hearing system can help with the overstimulation of it. Calm it down. If that doesn't work, we can use what we call tinnitus maskers or different noises that are either in the hearing aid or environmentally to try and mask out that sound so people don't focus on it so much.

So that's really more so the hearing side of things. There are other devices that are out there that have been becoming more popular lately. I know the Lenire is one we've spoken of. There's also something called the Duo sensory wristband, which was brought to my attention, which are working

from one of me-- what I'm able to gather on what we call neuromodulation, which is basically using vibration or electrical stimulation of certain pathways to see if it can better modulate these nerve pathways up through the brain and potentially with tinnitus.

Now let's take something, for example, like a neck issue. If a neck issue one, it's definitely not my specialty, by any stretch. So we'll get that out to the appropriate provider. If we have muscle tension, for example, if that's potentially what the cause is, can physical therapy help? Can dry needling help? Can massage potentially help loosen that up, have better blood flow through the area which can then lead to either reduction or resolution?

If it's related to, again, something like a migraine or a concussion, can neurology help in those situations? And then we do honestly a lot of dizziness. We do have a psychiatric, psychological component. And a lot of these as well that we need to be able to manage.

So there's what we call tinnitus-- there's tinnitus management strategies. For certain folks, it works very well. I always talk to my patients about this, which is just try going to bed with a white noise machine on. See if that's enough to get you some good sleep. You've got something in the environment that is able to provide just a steady signal.

It's not changing that. And patients can hopefully get better sleep. During the day, I think it's fine to use radio or TV in the background music, whatever. I don't really recommend it at night because those signals are constantly changing. And it can potentially disrupt sleep.

If that doesn't work, there are certain approaches like mindfulness therapies, for example, which, again, I don't do personally. But that's where a therapist can absolutely help in those situations to be able to identify potentially certain causes and see if we can change some of those emotional aspects of the tinnitus with it as well.

So it's a bit of, we've got to figure out what's wrong, and then we can address potential therapies from there with it.

DANIELLE TOLMAN: Are there any situations where there isn't necessarily an answer for resolution and the type of patient population has a focus more on management strategies, for example, maybe somebody with long-term noise exposure due to their career, what they were around for decades? The tinnitus that comes from that, is that something that can resolve? Or is that something that more that patients should look into just managing symptoms moving forward?

ROBERT ALLEN: That's a great question. What I will say is that the first thing I always tell my patients with tinnitus is that right now, there's no cure for it. And that's just-- and the reason I use that as a blanket statement is because for a majority of people with tinnitus, that is true.

Now, again, we have special situations, be it a neck, migraine, those kind of things where we can resolve it. But for a majority of patients, there is no cure for the tinnitus. So the things like the pills that you see, Ginkgo biloba, they can potentially be useful. They're not going to cure it.

When you go to CVS, Walgreens, Walmart, you see the stuff on the shelf-- Lipo-Flavonoids and those kind of things-- it's not curing tinnitus. There's no cure out there for it. It is, in my opinion, snake oil. You're wasting your money.

I don't say that to not-- I don't say that to be a downer. I say that because I want people to understand and be realistic and not get their hopes wrapped up in something where they're just giving away money to people. I've seen certain things like if you press your pinkies together and you close your ears for five seconds, it'll get rid of your tinnitus. Maybe it helps some people, but it's not an answer.

So we have to be realistic. And from there, we then need to look at what can we do to help with management of it. Can we get it to be less bothersome for you on a daily basis? Can we help you with sleep if that's an issue for you? And then how do we work to potentially either get rid of it from a management perspective, not a cure? Or can we really greatly reduce it and make it where it's something that you can absolutely deal with on a daily basis?

So that's how we have to approach it. Again, there are some promising technologies and research that's out there. But as of right now, there is not a cure for it for most folks.

ABBIE ROSS: Now from a vestibular standpoint, can you talk about vestibular-specific diagnoses that are most commonly associated with tinnitus? I imagine the ones that are also associated with hearing loss. But I'll let you take the mic.

ROBERT ALLEN: Sure. The big one that we always look for Meniere's disease. It's a bit different. It's low-pitched roaring tinnitus that we have with that. But that is a hallmark symptom that we have to have when we're making a Meniere's diagnosis.

What we call a labyrinthitis or unilateral loss of function from the vestibular system in an ear with associated hearing issues, tinnitus is incredibly common for those patients. A vestibular neuritis, which is similar to a labyrinthitis, but it really only affects the balance side of things, we do have a lot of patients that complain of tinnitus associated with that as well. Now, we don't necessarily see the hit on the hearing side of things. But tinnitus is a common complaint there.

Again, we've talked about it before, migraine, we see a lot of that with a lot of tinnitus with migraine patients also. So typically, if we're looking at more otologic vestibular, true vestibular problems, we tend to see tinnitus more

often in those cases. Not all the time, but those relationships are a lot more common with those vestibular diagnoses.

DANIELLE TOLMAN: What about with superior canal dehiscence? Do we see tinnitus with that diagnosis? And I'd imagine that the treatment for that might be a little bit different in terms of reducing noise because they're a little bit more sensitive or hyperaware to different stimuli in that sense.

ROBERT ALLEN: Yeah, so we absolutely we can. We can see it with superior canal dehiscence. Now it's a different-- it's definitely a different pathology behind it. The ear has that third window, if you will. Or basically, it's more mobile in a sense.

We can get more fluctuations in the hydraulics of the inner ear structure with that. And if sound sensitivity is something that causes the dizziness and we do have difficulty with that sound sensitivity, we do have to try and see if there are other management strategies that are out there because, hey, sound may not be the best option in that situation.

And that's very much a case by case basis. I'll be frank. I don't have a 100% answer on that one because it's a bit more rare. And I think we got to take it patient by patient. But there are potentially certain things we could do in those situations like is reduction in sound in your environment actually better for you? Right so reducing the amount of sound in your environment, is that going to be more beneficial?

ABBIE ROSS: Sure. And while we're on the topic still about hearing and noise, are there certain hearing aids that you recommend over others to help with this?

ROBERT ALLEN: That's a great question. The answer is not necessarily. So hearing aids have come a long way. The technology is great. Quite frankly, I don't do a ton with hearing aids. With my practice, I'm really focused on the dizzy side of things. I'll refer that out for management. That being said, I got

to stay current on it. So I know what it is and when we're talking about it, what's the technology.

So again, the more that we can manage the hearing loss itself, in a lot of cases, that helps with resolution of the tinnitus. And if we need a masking device, for example, I'd say most, if not all, major hearing aids at this point have something for management of it. When we look at severe to profound hearing loss and cochlear implantation, cochlear implants can help with tinnitus in certain situations.

I'm not going to say 100%. But we have seen that it can definitely help patients with tinnitus. But again, it's going to be more of a case by case basis.

DANIELLE TOLMAN: There are so many really great questions in the chat. I'm following along. And I have so many ones I want to address. You brought up cochlear implants. So we'll start there. You're saying that cochlear implants can help with the tinnitus. What about other types of surgeries that cause tinnitus like a removal of an acoustic neuroma or even maybe like extensive dental surgery or skull base surgery? What does that look like in terms of causing tinnitus? And then how can that be addressed following postop?

ROBERT ALLEN: That's a great question. We'll take the example of the acoustic neuroma. In that situation, we'll go the route of what we call resection. Or basically, you have to cut the nerve itself as part of the process of removing the tumor. And tinnitus can happen.

And again, it boils back down to if that dorsal cochlear nucleus is not getting input, it can start to-- it can overstimulate itself. In those situations, we have to see what's the hearing with the good ear. If it was on the right side, the left side, we still got really good hearing, what can we do from a management perspective on that side, potentially to see if we can give the brain what it's looking for in some sense to try and manage it?

When we look at other pathologies-- so Meniere's disease. Again, Meniere's disease is a bit of a different animal in terms of what happens. As the damage to the ear occurs, we can, again, see that the hearing loss is going to happen. But that tinnitus can also become more common and more constant for patients.

So we have to, again, address what can we do with the amount of function that we have left in that ear? From a surgical perspective, different surgical approaches and procedures can cause that. I will say that's not my area of expertise either. I don't want to necessarily speak out of turn on that.

But if we do have changes or damage to certain vascular systems as part of the surgery, could it cause an issue? Sure, it absolutely could. And we've got to just take it. What can we do from a management perspective on that side of things?

Now I do see an interesting question here in the chat as well, which is medications in tinnitus. And I think that does segue well from what we're talking about with surgical intervention because there are certain medications that people will get put on after surgery. Different medications can 100% cause tinnitus.

My dad was an oncologist. And, obviously, with chemotherapies, we can see a lot of changes in the ear itself. Hearing loss can be associated. Tinnitus is incredibly common from that perspective because of the damage that happens from the chemotherapy.

Blood pressure medications, they can sometimes cause tinnitus. Or they can sometimes relieve it, depending on what's going on with it as well. So I look at the medication side of things almost like I do with the dizziness, which is there are so many meds out there that list dizziness as a side effect. I think, at this point, it's over 3,000 medications list dizziness as a side effect. You can probably see the same thing with tinnitus.

And then that also does-- just a quick aside, if you look at those medications, you can find the pills and supplements and all that. Read through. It's interesting if you read through all the different things that are involved in those supplements for tinnitus. Half of them cause tinnitus as a side effect. So why is it helping get rid of it?

ABBIE ROSS: Interesting. Now is there an association between fullness in the ear and tinnitus?

ROBERT ALLEN: That's a good question. So for example, let's take a earwax impaction. A lot of people that have an impacted ear will complain of fullness or pressure. And tinnitus is incredibly common. Getting that cleaned out for a lot of folks will actually help with that. When we have what we call middle ear dysfunction-- so if you have an ear infection or something like that and it can restrict hearing, we can, again, see tinnitus related to that.

So feelings of fullness and pressure 100% can be related. We can see tinnitus with it. Another interesting example that I like is when we look at certain cervical issues, certain neck problems. They can cause feelings of fullness or pressure around the ear. And tinnitus could also be related with that.

So we can see that with management of certain things that we can see a reduction in the tinnitus. But just because you have aural fullness doesn't necessarily mean you're going to have tinnitus with it.

DANIELLE TOLMAN: Now we probably should have started a little bit closer to the beginning with this. But is there a difference between steady or persistent tinnitus versus pulsatile or like a pulsing-like tinnitus? What's the difference between the two of those?

ROBERT ALLEN: Yeah, so that is [AUDIO OUT] one. And there is a pretty big difference. A lot of cases, we associate that pulsatile tinnitus with vascular issues. That's a lot of the case. Now something we commonly hear from

patients is, yeah, I hear my heartbeat in my ear. And sometimes it can be as benign as your jugular runs right under your ear canal. And for lack of a better term, patients are just hearing their own plumbing.

It can be a thinning of bone in that area. And it can just be enough where you're just hearing circulation. I'll give you a great example is if you've ever done heavy exercise or been lying down for a while, sit up quickly. Change in blood pressure real quick with that. You can get a feeling of fullness. And then some people, you can hear that thump, thump, thump, thump, thump in your ears.

But pulsatile tinnitus is usually something that we need to investigate. That's definitely a-- let's not put that one aside and wait and see if it changes. Let's get it-- let's get evaluated for sure-- that's a-- I'm not going to say a red flag, but we'll call it an orange flag to see what's going on.

Constant steady state tinnitus, that's way more common. I'm going to say typically, not always. It's not necessarily associated with a-- we'll call it a scary issue, if you will. It's much more common for us to see just steady state tinnitus or noise with patients as it relates to things like, again, hearing loss, migraine, that sort of thing.

ABBIE ROSS: Now when patients report tinnitus and they're describing the noise that they hear, is it more often that the noise is consistent? It's the same tone or same type of noise? Or can it fluctuate?

ROBERT ALLEN: It absolutely can fluctuate. We can absolutely see it fluctuate. It's very much person dependent, person specific. But it is common for it to fluctuate in both volume and the frequency.

All right, now, they're typically not massive fluctuations. So it doesn't go from a super low pitch to a super high pitch commonly. But it's common for it to have a little bit of variability in there. And a lot of people don't necessarily complain of just a pure single tone, just one very single tone.

For a lot of folks, that noise is more almost like white noise, or it's a chirping. It's a wooshing. I've had someone explain it as almost like air coming out of a tire, hissing sound. So that's incredibly common. It's a lot more common that we have almost a combo of noises, if you will, as opposed to just a single pure tone.

DANIELLE TOLMAN: I have a question. After seeing this chat evolve-- and there's other questions about very specific things that might be contributing to their tinnitus. And I'm noticing a relationship between all these things like mast cell activation, increased symptoms following vaccinations, neuritis, migraine. Is there a link between inflammation in the body and tinnitus?

ROBERT ALLEN: That's a good question. And the answer is that if we have inflammation in the body, can it lead to changes with blood flow? And if we're seeing these changes in blood flow, would that then affect the inner ear structure?

So our inner ear is actually only about as big as our pinky nail. And that's both the balance organs and the hearing organs side of things. Smallest organ system. And it's also got the smallest blood supply in the human body.

We know that 15 seconds of interrupted or changed blood flow to the inner ear structure can cause permanent damage to it. So the reason I say that is if we have minor changes in terms of things like inflammation in the body that could lead to a change in blood flow, we absolutely could see the tinnitus related to that as well.

The other thing it's an interesting topic is neuroinflammation. So we do a lot with concussion here as part of what we see. And neuroinflammation is an interesting thing that we're getting more and more into. And we do see that a lot of folks have tinnitus as a complaint.

And if we're able to start potentially managing that neuroinflammation, we see changes in subjective symptoms. Part of that being the tinnitus. Does it

get less severe? Does it resolve? So absolutely, I think there's a relationship with it.

ABBIE ROSS: I want to go back to, if you get your hearing tested, yes. If you have normal hearing, you can still have tinnitus. But what if you have abnormal hearing? Is there a sign on an audiogram that would clue you into the possibility of developing tinnitus? Or is there a link between what an audiogram shows and tinnitus being present, or no?

ROBERT ALLEN: That's a great question. I would say that no, that there are not-- there's not a specific thing that I see if you've got hearing loss at 6,000 hertz, I know you're going to have tinnitus. But it's just that link between hearing loss and tinnitus is so strong that likely, most folks will have a complaint of some kind of tinnitus. Now if it's bothering them is a different question with their hearing loss. But we see it-- we see it very commonly.

DANIELLE TOLMAN: We have a question that is actually piquing my interest too. "Is it a problem to use noise masking for tinnitus all the time?" Like being exposed to this much noise on a constant basis, is there any downside to that?

ROBERT ALLEN: The only real downside, in my opinion, is if it's too loud. We don't want to cause further hearing loss with a noise mask. Or now you can supplement a little bit. So if you've got hearing loss or if you are-- one thing I haven't mentioned, which I feel I should, is that you don't have to have hearing loss to use a tinnitus masking hearing aid. There are plenty of folks out there that use a hearing device, a hearing aid with masking technology for their tinnitus that don't have hearing loss associated with it.

So, sorry, back to the original question, one of the big things that we look at is you can use your hearing aids. We always want you to use them if you've got hearing loss all day. You can use the masker with it. But when you get

home, just like you want to take your contacts out, people like to take their hearing aids out. You're not going to wear them to bed necessarily.

But you can mix and match. You can have your hearing aids on all day. You can have the masker in the background. Then you go to bed at night. And you have a white noise machine on. Or hey, you don't have hearing loss. You're not using a masking device and a hearing aid if you have the radio or TV on in the background. You go to bed at night. You got a masking white noise.

I have tinnitus personally. I've got normal hearing. I just don't sit in quiet environments. In my office here, I've got a little something on in the background. When we go to bed at night, we've got a white noise machine. My two beautiful kids are great masking devices in the background as well. So that's why we're so concerned about the volume as opposed to using the sound all the time.

ABBIE ROSS: Now is there an association-- or can this happen where you have-- I believe they're speaking about ear pain, specifically. But can you have pain that is associated with tinnitus, or the two exist together? And do you treat that differently since pain is part of the equation?

ROBERT ALLEN: Yeah, 100% yes. We need to figure out what's wrong. Are we looking at something like a cholesteatoma, for example? Are we looking at a glomus jugulare tumor, severe earwax impaction? Is there a foreign body in the ear?

So that's much more of an emergent condition, in my opinion. We need to be looking at what is going on, why are we having the pain, and what do we need to do about it because that's not normal. That's not a normal thing that we would see.

DANIELLE TOLMAN: There is a question that I think more relates to Meniere's disease asking about if decreasing your salt intake can have an

impact on your tinnitus. And I'm linking the two of them because I know a very common treatment for many years is to restrict salt intake. But is there a connection between the two of those?

ROBERT ALLEN: So in the context of Meniere's disease, if we can reduce sodium intake, we can look to either prevent or lessen the number of episodes that we have or the frequency of those episodes. Now generally, if we reduce sodium intake without Meniere's disease, is it going to help tinnitus? It can.

It can but not necessarily. It's not necessarily if I just cut out sodium 100% from my diet, my tinnitus is going to get-- it's going to go away. That's not necessarily what's going to happen. But again, in the context of Meniere's disease, whatever we can do to lessen the severity and frequency of episodes, it's going to help for all aspects.

ABBIE ROSS: Is that then the same thought process we'd have for someone with vestibular migraine specifically and dietary implications? If there are certain diet triggers that they experience and we reduce those could we also see a change in the tinnitus if they have tinnitus associated with vestibular migraine? And then I have a second part to that question from the chat. "Are we speaking about just vestibular migraine that can have tinnitus associated with it? Or is it migraine in general?

ROBERT ALLEN: OK, I'll answer the second part first. Migraine in general. So vestibular migraine is a subset of migraine as a whole. And there are a lot of different types of migraines, and symptoms can happen. We can get a variety of different symptoms from it.

Back to the first part, yes. If we have dietary things that are potentially triggers, be it certain additives; be it, again, sodium, chocolate, caffeine, alcohol, nicotine-- I like to joke, anything fun in life for our migraine patients. If those are the triggers for it, if we can either lessen our exposure to those

triggers or get rid of them completely and it leads to less of our vestibular migraine or our general migraine, then if the tinnitus is related to that, yes, we absolutely should see a reduction in the tinnitus with it.

DANIELLE TOLMAN: So going over everything that we've covered so far, it sounds like tinnitus can come from multiple structures within the body, whether it's from the peripheral system and potentially its vascular influences or the brainstem or the amygdala, migraine activity within the brain, neck muscles. It sounds like there's multiple areas that can be affected that contribute to this.

What are some of the alternative or holistic management of tinnitus that patients have had some success with or that we see the evidence supports that we can use in combination with these other types of treatment methods that we've been discussing?

ROBERT ALLEN: I am a huge fan of mindfulness. I know I said earlier, I don't do it necessarily. But I think mental health in general is something that we need to be better about as health care providers. But mindfulness therapy for tinnitus is a great way to really help patients. I've seen a lot of success with it.

Now, again, it's not for everybody. And it's not necessarily going to get rid of it. But I do think that it's very beneficial in helping reframe some of these things for folks, to give them, if nothing else, a better relationship with it and try and wrestle back some control to not let it define them necessarily, to not let it take everything away from them because we can see that tinnitus can absolutely be-- it can be debilitating.

Very unfortunately, suicide happens because of tinnitus for patients. And if there are ways that we can approach it where we can potentially help people manage that better, if there are ways that we can reduce the stress, the

anxiety, potentially the depression that's associated with it, can we help patients just generally?

If we have an emotional response to our tinnitus via the amygdala or whatever it may be, if there's that emotional component and it's a negative feedback loop with it, it can be overwhelming. It can control us. If there's ways that we can learn to re-evaluate that and change our mindset and if that can help-- not maybe not fully, but if it can help patients get some control back, then that's going to be wildly beneficial for them.

Obviously, if there is someone struggling that either here today or that you know with tinnitus and depression, talk to somebody. Absolutely, there's nothing wrong with speaking with a mental health professional. Again, in fact, I think it's probably good for everybody. be it if you think you have anxiety in your daily life or stress in your daily life or not, probably be good for us all to have a therapist in some capacity. And I mean that truly from the bottom of my heart.

But anybody that either you know or if you personally are dealing with this, there are ways to help. I'm not saying it's going to be fixed. I don't want to set that expectation for anyone. But you can get help. There are therapists out there that we can work with. There's mindfulness therapy. There are professionals that are working for you and with you to try and help manage this and give you a better quality of life.

DANIELLE TOLMAN: We've been so fortunate in this realm to hear from so many of these different trained clinicians, practitioners, coaches that either work in different realms like cognitive behavioral therapy, psychology, psychiatry, but also an actual formal training in mindfulness and bringing awareness to symptoms and working on that feedback loop.

But one thing that I've heard about, and I don't personally know a lot about, is tinnitus retraining therapy. Can you talk a little bit about what that looks like and what type of a person would administer that type of therapy?

ROBERT ALLEN: Yeah, so tinnitus retraining therapy, we can look at that through a lens of a hearing device. And we can use it to see if that we can retrain the brain with neuroplasticity. OK, so the concept that the brain can still learn and change even as adults.

Can we retrain the brain, basically, around the tinnitus, be that through use of a hearing device and through a masking device? That's where I'm most familiar with tinnitus retraining therapy. Can we work with specific sounds and noises that in a sense fill that void? if? There is hearing loss or where that tinnitus is, can we fill that void with something to take the brain's focus off of the ringing or the noise in the brain and focus it more so on that actual objective thing that's there for them to listen to?

ABBIE ROSS: OK, now is there any predictive factor of developing tinnitus? So for example, people will say the old saying like, oh, someone's talking about you if you hear ringing in your ears. But it's a quick-- it comes, and it goes. If you have that over the course of your life, are you at greater risk of developing tinnitus later on? Is there anything that talks about that in the research?

ROBERT ALLEN: That's what we call normal tinnitus. So the description I like to use is that basically someone turns the radio off for a second. Your hearing drops out for a second. You hear eee. Then it comes back maybe 15, 30 seconds or so. That's not necessarily indicative of anything. We call it normal tinnitus. It happens to everyone. It doesn't necessarily mean you're going to have it down the road.

The biggest risk factors, quite frankly, are hearing loss and noise exposure. Go to a concert, have a great time, wake up the next morning, and you hear

that ringing. And it's your constant friend. So making sure that you are safe in loud noise environments, use of earplugs or earphones to try and manage that, that's incredibly important. That's not just a concert.

That's if people are around cars; if they're shooting-- the active duty military, veterans, police officers. Anybody that is in a loud noise environment absolutely needs to be using any kind of hearing protection that they can, that they can also do their job, of course, safely with just to really try and reduce those risk factors as much as we can and preserve that hearing.

ABBIE ROSS: Are there support groups that exist for just tinnitus alone? Of course, we have our vestibular support groups. But do you know of anything specific to tinnitus?

ROBERT ALLEN: Absolutely. There is the American Tinnitus Association, which is one of the biggest things out there in terms of management-- I'm sorry, not management, but support for people that are suffering from tinnitus. Highly recommend it.

And then there are, I believe, more local support groups, similar to VeDA. We've got the larger groups. And we have state by state, city by city. I would highly recommend the American Tinnitus Association is a great resource for folks that have tinnitus-- learn more about it, find providers in the area, and be able to start managing that, for sure.

DANIELLE TOLMAN: We did have a question in the chat, which I think which is interesting. But, "Is there a link between tinnitus and persistent postural perceptual dizziness?" Can that be-- can they be concurrent with each other? Or does one cause the other? What's the link between those if there is one-- if one exists?

ROBERT ALLEN: That's a good question. Tinnitus is not going to cause triple PD. It's not going to cause it. But it absolutely can be associated with it. So we know that when we have something like triple PD, the other things that

can be associated from that perspective, tinnitus is one of them. But it's not necessarily going to cause it to occur. But it falls under that same general umbrella. And with management of it, we would hopefully see reduction in the tinnitus as well if we can.

ABBIE ROSS: Can you speak a little bit more-- we talked about sleep in the past in this conversation. But can you speak a little bit more on whether sleep can impact if you're going to have tinnitus or worsening tinnitus the next day? Like in the vestibular world, if you have poor sleep hygiene, you are likely to experience more vestibular symptoms. Is it the same with tinnitus, or no association?

ROBERT ALLEN: Yeah, it is, for sure. They all fall under the same general umbrella. You have a bad night of sleep. You are not in a great headspace for the rest of the day. And we're back into that feedback loop with emotional regulation and its relationship with tinnitus.

One of the biggest things that we always talk about and discuss with it is, what is your sleep hygiene? That's such an important part of it. Lack of sleep leads to-- it can lead to anxiety, can lead to depression, other changes. And tinnitus is 100% associated with that. It's definitely associated with those issues. We've got a bad night's sleep. Probably going to have louder ringing in your ears the next day.

DANIELLE TOLMAN: Can you speak at all to anything exciting coming up in the future? Where do you see the realm of treatment for tinnitus and how it's being addressed coming up in the future? Is there anything new and exciting for us to keep an eye out for?

ROBERT ALLEN: That's a great question. What I'm really excited about-- and I think it's still a little bit away. But there's been so much research that's been done on what is our ability to potentially regrow hair cells in the ear or fix damage to certain parts of the interior structure, the brain.

I am incredibly excited about that. I think it allows for us to have a way more targeted approach in terms of how we're managing patients. Now I think it is-- it's definitely in the future for us right now. But I think it's coming a lot faster than we realize and people realize. But I think it's going to be a game changer once we have those technologies.

Hopefully, we should see a cure for tinnitus at that point. And I'm incredibly excited for that day because the next time that I don't see a tinnitus patient means that things are getting better. I know it seems kind of silly. But the less tinnitus patients we see, the better things are getting for folks.

ABBIE ROSS: Absolutely. Now can you tell me a little bit about your day? If you have a patient that comes into your office, and tinnitus is one of the things they just describe to you, what direction are you going in terms of questions you're asking them back? What should a patient be prepared to answer to help you guide your treatment approach?

ROBERT ALLEN: Yeah, that's a really good question. I frame it through the same lens I frame my dizzy evaluations, which is, first of all, what is the symptom? What is it? Is it low pitch? Is it high pitch? Is it there all the time, one ear or both ears? Does it come and go? How long has it been there?

Again, has it been there for a couple of days, couple months, years? When did it start? What else changed around it? Did you change a medication, new medication, stop a medication? Was there any injury to the ear, head, neck? Is there a hearing loss associated with it? Is there dizziness associated with it, other things like headaches potentially associated with it, neck pain?

And then we're-- obviously, we want to get a good full medical history and understanding of what medications that a patient is taking so that we can see the lay of the land and then decide where do we need to potentially go next. But I would absolutely say, we've got to understand, first of all, just generally what is it that we're dealing with here.

Tinnitus, it encapsulates a lot just like dizziness does. So we need to figure out what specifically are we dealing with. And then from there, we can start to make decisions in terms of where do we need to go. Is it constant? Does it come and go? What are our associated symptoms with it? And then what do we need to do to work on getting this better?

DANIELLE TOLMAN: And if people who are experiencing tinnitus for the first time and they're wondering who should they go talk to first, where should they start? Where should they start in their journey of figuring out how to help themselves? Who should they see?

ROBERT ALLEN: I would always say an audiologist is going to be your best bet initially. But personal plug here. No, I do think that an audiologist is a great starting point because of our training, our ability to be able to evaluate the hearing, and then either rule that in or out and then make the decisions as to where do we go next.

The last thing that I want to see is someone bounce around and around between different providers trying to get to the source of it. So I think that audiologist, ENT is a great starting point for a lot of patients so that we can get to the point and then make our decisions as to where do we need to go next.

DANIELLE TOLMAN: Are most audiologists working out of ENT offices? Or can they also have their own standalone practices?

ROBERT ALLEN: Yeah, so it's a smattering. So you will see audiology and some ENTs. But there are plenty of private practice audiologists out there that have their own clinics as well.

ABBIE ROSS: Are there any hallmarks in a provider that a patient should look for to understand that they will be a good provider? So for example, in the vestibular world, you can go to a neurologist. But they might not have any

clue how to treat something like vestibular migraine. Is it the same in audiology?

ROBERT ALLEN: Tinnitus is absolutely a specialty. It is very much a specialty. Now most audiologists will be able to evaluate for it. However, outside of-- when we get-- let's say we get past the hearing aid side of things in terms of if we're not seeing resolution of symptoms with a hearing device, then that's where the specialists can really jump in and be able to really help out.

Now I will tell you that a lot of audiologists, if they're not fixing the tinnitus with a hearing aid, they are looking to try and refer that patient to someone who can manage it. There are providers out there. Again, the American Tinnitus Association is a great resource to try and find providers in your area.

But an audiologist that-- I would look for what is their ability. When we look at their practice, are they tinnitus focused? Because there are tinnitus focused practices out there. Or do they just list it? Same thing with dizziness. Some people say, yeah, we do dizzy. Whereas other people, no, no we actually do dizzy. And I would look for the same thing because we need to be able to have someone that fully understands all the complexities involved in what it is to be able to manage it from there.

DANIELLE TOLMAN: I want to throw in here and have you also make this distinguishing factor too. But not everybody who gives hearing aids is an audiologist. Is that correct? So if you go to the place that says hearing aids outside the front of a building, are they all audiologists? Or are there differences in people who deal with that side of things?

ROBERT ALLEN: Yeah, that's a great question, a great distinction. The answer is that, no, not all hearing aid dispensers are audiologists. I would say that you need to do your due diligence. If you have hearing loss, sure, you can go there. But an audiologist is going to be trained in the anatomy and

physiology and the pathologies that are involved from both hearing and balance disorders. Tinnitus being one of those things that we look at.

A hearing aid dispenser can help people with hearing loss. But an audiologist is going to be able to understand what's wrong and then be able to manage that and understand the complexities behind that. So I would do the due diligence, look for either doctor of audiology is the current degree. There still are some masters that trained a while ago. But the doctor of audiology, AuD, is the current professional degree. So I'd absolutely look for that as part of your provider.

ABBIE ROSS: And can this be done virtually? Meaning in your practice, do you help people manage this via telehealth at all, maybe after an initial evaluation? Or is this something you really need to be seen in office for?

ROBERT ALLEN: That's a really good question. I would say that telehealth can be beneficial. I think that telehealth can be useful for checkups and follow-ups. If it's been a few months, just a general checkup, I think absolutely that that's viable.

But if we're having problems, I like to see-- I think it's beneficial to see patients in clinic, be able to lay hands and actually work with the person, make changes, and do any potential testing that we need to right then and there. So telehealth is a very useful tool from certain aspects. But I think it's up to the provider. And hopefully, the provider saying if we've got a problem, let's bring it back in.

DANIELLE TOLMAN: This has been absolutely amazing. And I cannot believe how much we've put to the test and your knowledge in the last hour. You have definitely expanded my understanding of tinnitus a lot more as well as provided our audience with so much great information, resources, and tips. And, Dr. Allen, thank you so much for being here today. We really appreciate your expertise and everything you had to offer.

ROBERT ALLEN: I really appreciate the opportunity. Thank you all so much. Thank you for everything that you do, to Cynthia as well, and to VeDA as an organization. I think it's an incredible resource for patients. And I just really appreciate that there are individuals like you all out there that are willing to spend so much time and effort to make sure that patients are getting these resources. So thank you both as well.

ABBIE ROSS: Thank you so much, Dr. Allen. We are going to switch gears now and head over to our patient panel, which is hosted by Heather Davies and Patrick Parkinson. Hi, guys.

HEATHER DAVIES: Hello.

PATRICK PARKINSON: Hi.

HEATHER DAVIES: Wow.

ABBIE ROSS: I want to know. You both may or may not have experienced with tinnitus. Heather, can you share your experience first?

HEATHER DAVIES: Yes, yes. Oh, gosh. So much of what he said, I resonated with. I will tell you, I've been always-- I was always told that with my hearing loss, it was associated with the tone of "tinaytus" or "tinnitus" that I hear. So that was interesting to hear how all that works, yes. And my tinnitus is decreased and does come on with stress. So it's a warning sign.

ABBIE ROSS: By the way, before we went live, we had a whole conversation on, can you pronounce it "tinaytus"? Or can you pronounce it "tinnitus"? And he said either way is fine. So your tongue wants to say "tinaytus," it's OK. What about you, Patrick? Do you have tinnitus?

PATRICK PARKINSON: Yes, I do. So yeah, I've had Meniere's for 18 years now. And I had tinnitus the whole time. And yeah, mine modulates or changes with the inner ear pressure that I have. And yeah, like Heather said, it's another one of those signs that I may need to be doing something to take

better care of myself and at any given moment. That's how I'm trying to reframe it. But yeah, certainly recognize the challenges of dealing with that.

ABBIE ROSS: It's like--

DANIELLE TOLMAN: Oh, I was going to say I was amazed by how much I learned in terms of where tinnitus can be generated from, where it can be stemming from, all the different approaches on treatment and management of that. And you guys have two amazing panelists who are going to talk with you guys about that. And I don't want to take up any of their time because I know that they've got a lot to share. So we'll pass the torch off to you guys. And Abbie and I will see you tomorrow for day 3.

HEATHER DAVIES: Yes, thank you.

PATRICK PARKINSON: All right. Thank you so much.

HEATHER DAVIES: Hey, guys. For those of you that don't know me, I am Heather Davies, host of the Meniere's Muse Podcast, where vestibular warriors, regardless of their diagnosis, share their journeys. I was diagnosed with Meniere's and vestibular migraine in 2016 and 2017. And I am so excited to be here moderating alongside Patrick.

PATRICK PARKINSON: Yeah, thank you so much Heather. Yeah, and for those of you who don't know me, my name is Patrick Parkinson. And I've lived with Meniere's disease, as I said before, for just under 20 years now. I'm a VeDA ambassador and also the owner of My Meniere's Coach, which provides resources and support for those living with Meniere's and other vestibular conditions.

And throughout the conversation, I'll be doing my best to keep track of your questions and relaying them on to the panelists. But I think we are good to go ahead and introduce our panelists, Heather.

HEATHER DAVIES: Awesome. Well, let me share a little bit about Steve. Steve Schwier was diagnosed with Meniere's disease in 2013. At that time, Steve was able to do very little, except stay on his couch and manage his symptoms.

Then in September 2020, Steve rode an e-bike 1,400 miles from Denver, Colorado, to Columbus, Ohio, to raise awareness to Meniere's disease. His difficult and grueling ride is chronicled in his memoir, On the VertiGO. Despite the horrendous nature of his disease, Steve tells his story with humor, grace, and heartfelt reflection. His ride raised more than $10,000, all of which went to Meniere's disease awareness and research.

PATRICK PARKINSON: Thanks, Heather. And yeah, for the other panelist is Glenn Schweitzer, who you may have heard of, is an entrepreneur, health coach blogger, and the author of two best-selling books-- Mind Over Meniere's and Rewiring Tinnitus. He is passionate about helping others who suffer from tinnitus and vestibular disorders and has worked with nearly a thousand people one-on-one from all over the world over the last eight years, helping people habituate to their tinnitus and find lasting release. And Glenn is also a columnist for healthyhearing.com and is a VeDA ambassador.

HEATHER DAVIES: Hi, guys. Welcome.

GLENN SCHWEITZER: Hey everybody. Good to be here with you.

PATRICK PARKINSON: Good to see you.

HEATHER DAVIES: Well, we are excited to get started. I guess we'll start. Steve, really briefly, can you tell us about your vestibular journey and when you first started to experience tinnitus?

STEVE SCHWIER: Yeah, the tinnitus is, that's an interesting symptom when you have it. But when you put it with Meniere's disease, I separate my tinnitus from my other symptoms because tinnitus is easy to explain, for one.

It's just like I explained it by-- it's like having someone blow into your ear constantly like blowing right into your ear hole. And it just makes that [SWOOSH].

So my first symptom was tinnitus. And that showed up in 2012. So I had tinnitus for an entire year before I had any other symptoms that finally got diagnosed as Meniere's disease. I had to deal with the tinnitus for a year with just the tinnitus. And that was really bad enough. Then when the Meniere's hit, it got a lot worse.

But my tinnitus has always been the same. Like Patrick just said, it's been constant for 13 years now, my tinnitus. And it fluctuates, good days and bad days. It's just one of those symptoms where it's a constant reminder that I'm sick.

And that's what I hate about having tinnitus the most. The tinnitus itself is annoying. But it's just a constant reminder. Every morning I wake up, there's the ring or the wooshing. Every night I go to sleep, that's the last thing I say bye to at night. So it's a constant reminder that I am not at my full health.

So my journey, to get to your question, it all involves accepting that, grieving that process, that this is the way my life is going to be now. I can manage certain symptoms. But tinnitus is one of the ones where I just really feel like I have very little control over it.

Because I try to be as active as possible. So I do drive. I do go on trips. And I fly on planes. And I do a lot of things that probably a lot of people with Meniere's can't do, which I feel so bad for them. Yet I pay a price for that. And tinnitus is one of the things that I can pay a price for being a little too active sometimes.

HEATHER DAVIES: Yes, I know. We watched you. But before we dive into more of your story, Glenn, could you answer the same question? And when did you first experience tinnitus and a little bit about your vestibular journey?

GLENN SCHWEITZER: Yeah, absolutely. So I've actually had some degree of tinnitus for as long as I can remember. I presume I was born with it. A lot of people in my family live with tinnitus. But when I was young, it was just this very quiet, high-pitched tone. And I would hear it when it was silent, and it never bothered me. And for a long time, I just thought it was normal. I thought everyone could hear a sound when it was silent.

But as I grew older, like in my teens and I started going to parties and concerts, anytime I was in a loud environment-- I think I have pretty sensitive hearing and always have-- my tinnitus would get very loud. A lot of people experience this after loud events. But I was very sensitive to these sort of changes.

And there'd be sleepless nights. And it'd be somewhat stressful. But I have no memory of it being any sort of a real problem for the most of my life.

But that all changed in 2011 when I was diagnosed with Meniere's disease. And it was suddenly much, much, much louder. Just that high-pitched tone increased significantly and is pretty much-- that increase has remained.

And there was-- especially early on, there was other tones and noises I would hear as well, though I've-- at the time, it was very difficult and challenging. But the other symptoms of Meniere's that I was experiencing like the vertigo attacks and all the constant dizziness and disequilibrium and brain fog and ear pressure, it was at the top of my list of things I was worried and panicked about.

And it really-- even though the tinnitus was probably the most intense it had ever been at that point. And it really wasn't until I was able to start managing my symptoms a bit better and get a handle on those other symptoms but not able to get a handle on the tinnitus-- as everything else was slowly improving, the tinnitus wasn't. And that's where my attention shifted. And I

went through a period of struggle, though today, eventually, I was able to habituate.

And though my tinnitus is there and it's still loud and it like Steve, if I push and do too much or I'm in loud environments or I don't sleep as well, it will increase, but it doesn't bother me anymore. And I can manage it extremely well. And I've had not really had any sort of issue with the tinnitus impacting quality of life for probably like 10 to 12 years now.

HEATHER DAVIES: Glenn, can I ask you something? You said the word habituate. I know we hear that a lot in the community. And I know that until I spoke with you recently, I really didn't understand what that meant. Can you just go into that just a little bit?

GLENN SCHWEITZER: Sure thing. Yeah, so this is what-- I was listening to Dr. Allen speak in the fireside chat. He was talking more about the tinnitus management side of things. He touched a little bit on tinnitus retraining therapy, which is one strategy for tinnitus habituation.

So the idea is that we have these filtering mechanisms in our brain that allow us to become distracted from sensory perceptions that don't matter. And it's this unconscious process running in the background of our brain at all times. So at any given moment, there's lots of different things that you could pay attention to, but you're not paying attention to the feeling of your clothing, the feeling of sitting, other sounds and lights in the room.

People can work in very noisy offices and not be distracted by that noise. You can go to a noisy restaurant with family and friends and still focus on the person talking. And it's almost like your brain can turn the volume down of that background noise so that you can focus.

And we're fully capable of doing this with the sound of our tinnitus as well. The challenge is that when tinnitus becomes bothersome and problematic and there isn't a clear underlying cause that can be treated and where the

tinnitus can be resolved. There's some pretty big psychological and emotional obstacles and this vicious cycle of fight or flight and nervous system activation that occurs where it becomes impossible to ignore the tinnitus.

But you can through neuroplasticity-- or thanks to neuroplasticity, you can fundamentally change the way your nervous system and brain-- the relationship it has with tinnitus where you can become distracted from the sound all the way up until the point where distraction just becomes the default state. And then noticing the tinnitus in that context in absence of it bothering you at all is sort of like hearing your air conditioner or your heater turn on. When you're watching TV, you'll notice it for a second.

But your attention can bounce off. And so what I always tell people is the promise of habituation is that you can restore your quality of life to pre-tinnitus levels, even if the tinnitus doesn't actually go away. It doesn't need to go away for you to get your life back. And I think that's important to understand, especially if you have a type of tinnitus that isn't responding to some medical treatment, or there isn't a treatment, or you can't identify what caused your tinnitus in the first place.

PATRICK PARKINSON: I've got one question in the chat here, Glenn, that's on this topic. And I know that one thing that Dr. Allen talked about and you referenced a little bit as well as this idea of masking the tinnitus. And the question here is around whether you still can feel fatigued and brain drained and brain fog even when you do that masking. Glenn, you can go ahead and take that first if you want. And then it'd be good to have Steve on as well.

GLENN SCHWEITZER: Yeah, sure. I think it depends on what's causing the fatigue and the brain fog. Like in the case of Meniere's disease, if I'm masking my tinnitus and-- and masking is just putting on background noise to cover some of the volume of your tinnitus and reduce the perceived volume, help you to become distracted, you some relief.

If it's just the tinnitus that's causing the brain fog and the emotional distress, then masking absolutely can help on that front. It can make it much easier to just get back into the swing of your life, focus at work, focus on your reading and watching TV. So on the one hand, yes. But if the brain fog is being caused by a vestibular diagnosis like Meniere's, then probably not, though I imagine that taking one symptom off of your to-do list in that moment certainly isn't going to hurt. It'll help, but I don't think it'll solve the brain fog.

PATRICK PARKINSON: Sure, sure. Yeah, Steve, curious to get your take on this as well, especially since I'm curious to hear more about your relationship with music as well and how that has morphed with tinnitus. But on the masking front, if you're still listening to music, I'm curious if that helps, or if you still do feel some of that--

HEATHER DAVIES: Or playing.

PATRICK PARKINSON: --fog and depletion.

STEVE SCHWIER: Yeah. I literally quit listening to any kind of music for at least five or six years because I just couldn't-- like Glenn said, you can mask it. But sometimes masking it can do more harm than good if you don't do it the correct way. So it took me a while to figure out what masking things I use. And music is definitely a huge one.

But like Dr. Allen was speaking earlier, you couple the tinnitus with the hearing loss in my left ear. And it makes me single-sided deaf. So that's a whole other thing that you get with Meniere's, that the tinnitus is in my left ear. My right ear still hears decent. But that's a hyperacusis situation on that side.

So I have the ringing in one ear. And then the hyperacusis in the other. So for me, it was learning how to mask. And I've tried every white, brown, orange noise there is. I wear a hearing aid where I can listen to waves. And it just makes-- all those make me feel worse.

So a lot-- I always have a TV on in the background or music going on in the background. And then once I figured out how to listen and enjoy music again, when you hear it in mono instead of stereo, it's a different experience. And it's not nearly as fun or not nearly as good. But once I figured out how to at least enjoy it on a mono level, then I actually started playing music again live and performing again, which has been what I've done for about the last year. Been experimenting back into that.

But I just really wanted to say hi, Glenn. I've never talked to you before. And you've inspired me greatly through your stuff, so. Sorry, we've just never met face to face, so.

GLENN SCHWEITZER: Nice to meet you too, Steve. And I'll just add one thing to what Steve was saying like about trying to find the right masking sound. That'll probably be helpful for people.

So the type of sound Steve was talking about is called broadband sound. So this is like white noise, brown noise, pink noise. It's like constructed sound algorithmically generated sound. But there's nothing particularly special about any one type of brown noise or white noise that's just magical for tinnitus.

I always tell my clients, it's finding whatever works best for you. And so most people seem to find better relief with nature sounds when broadband sounds aren't working. And there's a million apps for Android and iPhone that are excellent for nature sounds. The higher the quality the nature sounds, the better, in my opinion. But it really can be any type of sound where it's sort of like a constant wash of noise that can cover a steady-- constant wash of noise that can cover some of your tinnitus volume.

And one other thing there. If people are trying to find the right masking sound and they're having that experience that Steve was talking about, where it's like, I keep trying things and everything seems to make it worse

and they just-- don't just give up. In my experience, if you look hard enough and through enough apps and try enough sounds, usually, you can eventually find some kind of-- one or two options that work somewhat well, even in the case of severe hearing loss and hyperacusis and varying degrees of hearing loss. There's probably something to be found, even if you haven't found it yet.

PATRICK PARKINSON: Yeah, word of the day.

STEVE SCHWIER: The one I landed on-- the one I landed on finally to be able to sleep at night as I listened to thunderstorms on YouTube.

GLENN SCHWEITZER: Exactly, yeah.

STEVE SCHWIER: I tried all the noises. And nothing worked. But nature, just listening to a soft thunderstorm-- you can hear the rain pattering. And every once in a while, a thunder rolls through. That seems to calm me down. And that's my go-to now. I didn't mention that.

HEATHER DAVIES: I'm curious. I'm curious. Patrick and Steve, you guys both live on the East Coast with the mountains and everything. Do you guys find a fluctuation or problem with elevation or barometric pressure with your tinnitus? Is there any association? Pat, do you have that or notice that?

PATRICK PARKINSON: For me, I'd say in general, elevation does impact my Meniere's symptoms overall. I'll get a little bit more inner ear pressure. And I think with that naturally comes the tinnitus. And so I live in Denver. And we'll do a lot of weekend trips up.

And in the past, we would do that trip. And I would always know the following week, especially early in the week was going to be a little bit rough from doing that change. I'd say over time, I think it's similar to the habituation process that Glenn's talking about.

Just by not focusing on it as much and understanding that the sensitivity of my overall system impacts these swings in my symptoms, just the ability to expose myself to more trips to the mountains while remaining calm and not focusing on it as much certainly has helped with that. And I can now do those trips without having as much of an impact. But it takes time, so.

HEATHER DAVIES: What about you, Steve? Glenn and I are in Florida. So we have our own issues with barometric pressure.

STEVE SCHWIER: No, Patrick's in Denver. I'm about an hour and a half west of him up in the Rocky Mountains. And so I live at a little over 9,000. So that's almost 2 miles up instead of 1 mile in Denver. I can't really say that my tinnitus gets worse if I'm going down or, like he said, taking a trip to Denver, which I do quite often because I'm distracted. And I'm driving or looking for a place or meeting up with people.

I don't just go to Denver and then go to a hotel room and just sit in the silence for hours to see if my tinnitus is worse. Because I'm just constantly being distracted by the trip itself. So I can't really say that that's worse.

Yet the one thing that does impact it, though, is the 24 hours before a snowstorm up here or a rainstorm. That's when I'm at my worst. That 24 hours where the barometric pressure is pushing up against the mountains and it gets held there. And I just feel like I'm being squeezed down. I feel like I weigh 300 pounds. And then my tinnitus will go crazy along with all my other symptoms.

So it's instead of having a leg or a hip to gauge the weather, I can use my head pretty much to tell when there's a storm coming.

GLENN SCHWEITZER: I'll throw a quick tip out there for everybody. If you're bothered by barometric pressure, if it activates any of your vestibular symptoms or migraine or tinnitus or anything really, there's a type of

earplugs you can get called aviation earplugs that are very helpful. Like if you're flying, you can pop them in on takeoff and landing.

But specifically for just general life, there's a company called WeatherX. It's the same company that made EarPlanes, which is the one that you can find in every drugstore and even at the airports, this type of earplugs. And WeatherX has a free app that will track your weather and your location.

And if a storm front or a pressure system is rolling through, it'll send a notification like alert to your phone like, put the plugs in now. And then you can pop them in. And it will tell you when to take them out. And that can sometimes stabilize the experience a little bit through a storm front.

HEATHER DAVIES: Yeah, thank you so much for mentioning that. They do work. What are we saying, Pat? I'm sorry.

PATRICK PARKINSON: No, I was just going to say, while we're on the topic of triggers, there's a couple questions in the chat here, inquiring about what are some other triggers that you two encounter for your tinnitus. One specifically asking about food. Another one asking about hydration, even movements, how you move your face, and different things like that or moving your jaw. Is that something be able to comment on? Maybe we'll start with Glenn and then have Steve weigh in.

GLENN SCHWEITZER: Sure, yeah. So for me, personally, stress, loud sounds-- so for most people with tinnitus, the three big ones that affect pretty much everybody are going to be like stress and anxiety, sleep deprivation, and loud sound exposure. Generally across the board that's, what I see.

Beyond that, it varies a lot person to person. And if your tinnitus is caused by a vestibular disorder, oftentimes, the food that trigger you specifically in your symptoms will probably make the tinnitus worse as well. For a long

time, sodium was a big trigger for me. Caffeine was a big trigger for me, although much less so now.

So as far as the facial movements and jaw movements-- so Dr. Allen was talking a little bit about TMJ as a cause of tinnitus. So TMJ disorder like having a problem with your TMJ joint, there's a whole wide variety of dysfunction you can have in that joint. And if you have somatic tinnitus where there's sort of like an overactivation of these somatosensory nerves that cause an overactivation in the dorsal cochlear nucleus that Dr. Allen was talking about as well can lead to these increases in tinnitus.

So TMJ can cause tinnitus. But it doesn't necessarily need to be just TMJ. I clench my jaw. So bruxism, it's called, clenching. And it's like an unconscious stress response that absolutely makes my tinnitus worse. And it's just adds to how much stress triggers my tinnitus.

And so jaw relaxation and massage exercises can be good. And also if you have TMJ disorder and-- well, actually, you can know if you have somatic tinnitus if any sort of neck or facial movements or physical movements cause any temporary fluctuations in your tinnitus.

So if I flex this muscle here like any of my-- really, any of my facial muscles but especially my jaw muscles or my neck muscles, my tinnitus will go up 50x with a completely different pitch, extremely loud, until I release the tension. And it all just drops back away. And when you have somatic tinnitus, it's definitely worth getting assessed for TMJ disorder, even though it's expensive and not often covered by insurance. I've seen a lot of people have really great treatment results for their tinnitus by treating TMJ.

And often TMJ can cause Meniere's symptoms as well. I've known many cases where what a person actually had was-- it was a misdiagnosis of Meniere's. And what they actually had was very severe TMJ where a lot of

the symptoms started to clear up as a result of treating it with orthotic splints.

But that's been-- it varies so much person to person. And I've really found that on a case by case basis, something that makes my tinnitus better might make another person's tinnitus worse or vice versa. There's so much variance. And if you want to find your own triggers, the best way to do that is to just keep track with a journal where you can track your diet, macronutrients like sodium and sugar and carbs, and environment and sleep and lifestyle.

And also keep track of your tinnitus and try to find some of those patterns. It's not an exact science. But if anyone's interested, I have a rewiringtinnitus.com/journal. I have a free just one-page PDF, trigger tracking journal that you can grab, if anyone's interested.

PATRICK PARKINSON: Sure. Great. Great. Thanks. What about you, Steve? I know you mentioned barometric pressure. Any other biggies turn on the ringing for you?

STEVE SCHWIER: A lot like-- almost everything Glenn said word for word, I could have said. I'm a clincher. I don't grind my teeth, but I clench. So when I sleep at night, literally, my teeth are just clenched as tight as they can go while I sleep every time, every night.

So when I wake up, my tinnitus is worse. And I know that's a trigger. But I can't do anything because I'm sleeping. And so there's no really way to relax your jaw when you're doing that. But like Glenn said, during the day, stress, number one; anxiety.

When I go into a fight or flight mode, my tinnitus will grow because my brain's deciding-- it's just working-- my brain's working overtime to decide what it needs to do to moderate my body for the day. And so I can get really, really irritable super easy. And that's what I call fight. And then flight is I just

want to shut down and pretty much not talk to people. I don't want to go out into public. I don't want to be around anything. I just want to distract myself by myself. And that's my flight.

So I gauge my days and go through fight or flight. And every day, it's a journey on these roller coasters. We say we have good days and bad days. But that doesn't really-- that's a nutshell explanation. It's bigger than that. And our experience is like Glenn said. What works for me probably won't work for a lot of other people, but it may.

So I don't claim to be a doctor whatsoever, a medical professional whatsoever. But I do have experience as all four of us do. So that experience alone is more valuable than I think knowing all the medical stuff about myself at this point. I wanted to know what was causing all this. Now it's just, I just want to learn how to live with it and have a productive life.

PATRICK PARKINSON: Absolutely. It's like we have so many things as Meniere's patients, as vestibular patients that we have to deal with in addition to the regular day-to-day tasks. And it just puts our system always-- it's always acting at a higher level of alert. We always have our guard up.

And you mentioned the clenching of the jaw. I have the same thing. I had to get a mouth guard. I was grinding my teeth, especially up in this area. Everything is just a little bit stiffer down through my neck and shoulders. It's just our body protecting ourselves from all these unseen risks, so.

HEATHER DAVIES: Patrick, did you find that the night guard-- because I also wore a night guard because of TMJ years ago. Did you find that that gave you relief from your tinnitus? Or did you not notice?

PATRICK PARKINSON: I didn't notice any change with the tinnitus.

HEATHER DAVIES: Just the clenching?

PATRICK PARKINSON: Just the clenching. Yeah, I mean, it was my dentist that recommended it. I think it was more of a protective to make sure I wasn't grinding the teeth as much. But I didn't notice too much specifically on if it was loosening up my jaw or decreasing the tinnitus for me personally. Other people may have had a different experience there.

STEVE SCHWIER: I sleep with the night guard also. But I just [demonstrates tightening jaw] as hard as I would if it wasn't there. It was just to keep me from busting my teeth out, I think, more than rest any other--

GLENN SCHWEITZER: I couldn't do it.

STEVE SCHWIER: I got tested for TMJ and didn't have it. Yeah, some people, the night guard just doesn't work. It's just uncomfortable. Takes a while.

GLENN SCHWEITZER: It makes me gag too. I just get so uncomfortable. I tried so hard to make it work. And I just couldn't do it, so.

PATRICK PARKINSON: I have nights like that too. Actually, when my Meniere's is really bad, when the press is really bad, and I can't sleep sometimes, I'm like, I just need to get back to my natural state. Let's get rid of this plastic in my mouth and just relax, so.

HEATHER DAVIES: I'm glad you mentioned that, Patrick. Do you guys do anything? Are there any go-to strategies that you have like meditation or bringing yourself to center? Or are there any techniques that work for you as individuals as far as your tinnitus? I know there's a lot of things out there, questionable. But everybody's so different.

GLENN SCHWEITZER: I'll take it-- I'll go first. So for me, the big one was meditation. If any of you has followed any of my work for a while, you'll know that's a huge component of my work. So I was a-- I had been a meditator for several years, like pretty disciplined meditator prior to Meniere's.

And when Meniere's hit, I couldn't do it anymore. I would sit down in a quiet room and try to relax. And my ears were just screaming. And I couldn't relax. And it was awful because I felt like I was losing this thing that was so valuable to me at a time that I needed it most.

And one night, I didn't give up completely. But I came close. I just kept trying. And I wasn't relaxing anymore. I didn't find it useful or helpful. But I didn't want to just stop because it had benefited me so much. And finally one night, I just thought to myself, I'm fighting so hard to ignore the tinnitus and focus on my breath. What if I just focused on the tinnitus instead? And it was this crazy idea that just came into my head. And I figured I had nothing to lose. And so I tried it.

And a few crazy things happened right away. Like, the first thing that happened was when my mind wandered-- and everybody's mind wanders in meditation-- I noticed that it wandered away from the sound. I was suddenly thinking about something else. And I caught the distraction. I came back.

But I remember thinking, like, whoa, that was kind of weird. I focused on it. And my brain went away from it. That hadn't happened before. And then when it was over, I had finally started to relax a little bit again for the first time. I finally stopped fighting it. And I started to relax.

And I didn't know what was happening. I didn't know the word habituation at that time. I just knew I found something that seemed to be helping. And so for a while, I just started meditating to my tinnitus instead. And now looking back with hindsight, knowing everything I know now, I know that this is what helped me to habituate.

And this is sort of like what I now teach to people in my work. I teach a meditation-based protocol to help people habituate. And what I just described there is very challenging if you just go in a silent room and try to

do this. But you don't have to go in a silent room. There's all kinds of ways to make this easier.

You can turn on some background noise. So you're just hearing it a tiny little bit. There's types of background noise that are very relaxing. Or you can do other things to relax first. And there's other meditative practices and techniques.

But just being able to incorporate the tinnitus into your meditation practice, that's what changed everything for me and led to me completely getting my life back. And that's been the thing that I've seen help countless, hundreds of people in my one-on-one coaching practice. So meditation is the biggest one for me hands down.

HEATHER DAVIES: Wonderful. What about you, Steve? Do you find anything?

STEVE SCHWIER: Oh, I used to be a regular meditator. And then once I got Meniere's, I had to stop doing it. And I just got out of the habit. And as you know, that's a hard habit to stick, give up, and go back and forth to you. I mean, you got to make it a part of your daily routine. And I just don't have the energy right now to make that a priority.

But the one thing I did find that does help my tinnitus is when I get my neck worked on. And I've never done vestibular therapy. But my doctor, my specialist down in Denver, who is a total godsend, he wrote me a prescription for just neck physical therapy, just normal physical therapy for my neck muscles because holding my head up all day with a dizzy head, my brain is telling my neck, hold your head still because you're dizzy. Hold your head still.

So my neck muscles are always fighting, especially the ones on my right side. So a month or two ago, I started with a therapist up in my town. And she specializes in vestibular issues and therapy. But she just worked on me with physical therapy for my neck muscles.

And that's been helping a lot even with my tinnitus. Because my neck muscles, when I can get those relaxed in a little bit more in shape, my brain doesn't have to worry so much at that level. So then all my symptoms dropped. And I noticed my tinnitus dropped a little bit.

Of course, it spikes here and there. And it's always there. It's there right now, driving me crazy. But I do notice that when I've got the work-- started working on my neck muscles, it really helped everything with my brain the way it was deciphering my disease. And I did try dry needling my neck. And I'm never doing that again. Nothing--

HEATHER DAVIES: Dry needling?

STEVE SCHWIER: Yeah, dry needling. They stick the [AUDIO OUT].

HEATHER DAVIES: Oh.

GLENN SCHWEITZER: Oh.

STEVE SCHWIER: And they put them into--

HEATHER DAVIES: That's deeper.

STEVE SCHWIER: Yeah, that was weird. They put that into your-- they put these needles in to your muscles. And then they hook them up to electric pulses that pulse inside your muscle. And it was horrible. I couldn't do it. I did it. But it was not comfortable. And for the next three days, my neck hurt like hell. So I--

HEATHER DAVIES: The things we go through to have some relief.

STEVE SCHWIER: I'll try anything. But if I don't like it and it doesn't work, I'm-- my tinnitus spiked for three days after the dry needling. So I was like, OK, that's out, you know? But like Glenn said, you try a million things. And you'll find something out there that does help with whatever your symptoms are, including tinnitus.

GLENN SCHWEITZER: Yeah, definitely. And I'll just add too, like, when I'm talking to people about coping, there's so many different coping techniques and relaxation techniques and things that can help. But the simplest way to summarize it is just anything that helps you to be more relaxed mentally or physically, more sound enrichment and masking in your environment and anything that helps you to feel distracted, all are going to be beneficial in terms of coping and calming down and dealing with tinnitus in the moment. And also combinations of tools as well.

Like, one thing I always tell people is the more senses that you can activate in a distraction at once, the better the likelihood that it will pull your attention away from the tinnitus. So don't just take a hot bath. Take a hot bath, put on your favorite music or some nature sounds, and light a scented candle, and do deep breathing and muscle relaxation all at the same time. Just the more sensory activation you can give yourself, the better the chance that you actually will lose the awareness and become distracted from the tinnitus.

HEATHER DAVIES: Steve, I have a quick question. Is dry needling like acupuncture?

STEVE SCHWIER: Kind of. I never tried straight up acupuncture. But it's more medical than it is Eastern. They take these little metal rods. And they just stick them into your muscles. And--

HEATHER DAVIES: Oh, kind of like a TENS unit, it sounds like.

GLENN SCHWEITZER: Like acupuncture combined with TENS, maybe.

STEVE SCHWIER: Exactly that. It's a combination of that. But you have to be licensed. You can't just-- not everybody can just do it. Obviously, you have to do it right. And I had to sign a waiver that said if they punctured my lung, I wouldn't sue. And I'm like, how deep do these things go? And she's like, a lot deeper than you think. And I'm like, you're going to puncture my lung through my neck? That's--

[INTERPOSING VOICES]

GLENN SCHWEITZER: That's crazy.

STEVE SCHWIER: Exactly. But I don't know where the needles went. I knew they went on the back of my neck. But that was about it. But yeah. And then it just made me pause for-- they leave it in for two minutes and just pulse the-- use something electrical they attached to the stem of the needle. And it just throws an electric pulse into your muscles. It's supposed to relax them. But not mine, boy.

GLENN SCHWEITZER: Wow.

STEVE SCHWIER: But it may work for Glenn. I don't know. So try it, Glenn. Tell me what you think.

CYNTHIA RYAN: Right.

GLENN SCHWEITZER: I found acupuncture to be really helpful early on in my Meniere's diagnosis. I had sort of a wild experience the first time I went, where they-- I remember he put the last needle into my forehead. And I literally felt this physical sensation of electricity or energy or something surging through my body. It only happened that first time. I have no idea what that was. But I found it to be extremely relaxing every time.

I don't know if it-- I was doing so much to try to improve. I was trying a million things at once. So I was not testing in a way where I could really clearly differentiate what was helping more than anything else, but I definitely found it to be very relaxing. And with tinnitus specifically, anything that helps to relax the nervous system and relax you is going to be helpful overall. So I never tried dry needling, but I'm definitely a fan of acupuncture.

STEVE SCHWIER: Yeah.

PATRICK PARKINSON: I want to quickly pick up on two things I heard earlier there that I think were shared between both of your stories. One is experimentation, right? Experimenting and kind of playing with different things to figure out what works for you. And you both mentioned a change from fighting it to more towards acceptance, right?

And I think sometimes, like for me personally with my Meniere's, all my Meniere's, symptoms, tinnitus included, is that sometimes you-- part of fighting it, which is our natural instinct when we're faced with something like this and is absolutely nothing to be ashamed of, right, is that we start locking on to all these different ideas, and we go after one after another, and we're going about it in a very effortful way and we're really trying. We're trying really hard to get rid of it.

And I'd say a big shift for me was moving towards more of that acceptance. And I'm still going to try these things. I'm going to experiment. I'm going to play around. But I'm not going to take it too seriously. I'm going to give it kind of that C-minus type effort. And I'd say meditation helped with that as well.

CYNTHIA RYAN: Yeah.

GLENN SCHWEITZER: That brings up some thoughts, a couple of things. One, you know, I want to-- I think it's important to-- when we talk about acceptance, to say that acceptance isn't tolerance. Acceptance doesn't mean you have to like the fact that you're experiencing--

PATRICK PARKINSON: Absolutely.

GLENN SCHWEITZER: --these symptoms or that you have to-- that you have this sound that you'd prefer not to have. For me, acceptance, I always try to think of it and talk about it in the stoic philosophy sense. We're here now. This happened. We have Méniere's disease. We have tinnitus. If we could get in a time machine and go back and change that somehow, we would all do it. But we can't, right?

So we're here now. There's no cure. Some things are not within our control, but many things still are. And so it's about learning to differentiate between what you can and can't control, and focus your efforts on what you can control. And at least in the case of tinnitus, even if it never goes away, even if it's very loud, even if it's fluctuating a lot and changing a lot, you can still reach this point of habituation where you can really boost your quality of life and eliminate it as a problem in your life.

And the fighting it part that you were saying, Patrick, every type of problem gets worse when we ignore it or try to push it away, right? And we think it'll be different with tinnitus because it's a sound, and we can easily ignore other sounds. But it's an emotional problem. It's a psychological problem. It's a physiological problem. And all those types of problems get worse when we ignore it, right?

And I'm not saying you need to just wrap your arms around it and just sit with it all day. But I think confronting it head-on needs to be at least a part of the journey and is an important step in acceptance and can lead to some helpful improvements.

STEVE SCHWIER: Absolutely. And also, it was definitely worse the first five years than it was these past five or six. You get to a point, like Glenn said, where this is my life. So what can I still do? What can I not do? What should I not do? What should I do? You find through your journey by experimenting those things.

Like for me, coffee is an absolute no-no. And I used to drink a pot a day. And all of a sudden, it's just like I couldn't take a sip or my tinnitus would go crazy, along with my other symptoms. So it was easier to quit because every time I kept testing the waters because I didn't want to have to give it up. And each time I was just like, OK, this is making me feel so bad each time that I just got to stop. And so that was the way I experimented.

But I don't have the energy that Glenn has, obviously, because I can't juggle eight things at once to try to distract myself. So I would just pick one thing and cut it out of my diet and see if it helped. And then I'd pick another thing. Then I'd try to run around the block. I just tried every single thing there was possible. And I found out the best thing for me to do is to lay on my butt and just rest my head.

I mean, to be totally honest, it seems like I'm out there doing all these crazy things, and 90% of my time is resting my head because that's when I feel at my best. And my tinnitus lowers a little bit, and my dizziness lowers a little bit, my nausea lowers a little bit. So right now I'm resting my head because this is how my brain likes me to be. And then it says, OK, I'll make you feel good because you're doing this.

So I call Meniere's disease, along with my tinnitus, I call it The Monster because it's like you're haunted by this thing that you can't put your finger on. And you never know what's going to feel good or bad or what's going to work or not. And it's, like Glenn said, I can fight the monster or I can just give it a hug and say, OK, I'm going to get through this day. And make me feel like crap if you want, but it's not going to knock me down, you know?

HEATHER DAVIES: Yeah. And everybody's--

GLENN SCHWEITZER: I'll add another dimension to-- oh, sorry. Go ahead, Heather.

HEATHER DAVIES: I'm so sorry. Go ahead, Glenn. You can go ahead.

GLENN SCHWEITZER: OK. So I was just going to say, I'll add just sort of another dimension to it. To me, putting aside any treatable causes of tinnitus, like when you're stuck with tinnitus and it's really destroying your quality of life, and it really does become really quite severe, I don't think that gets talked about enough.

To me, the condition that severe and bothersome tinnitus most closely resembles is PTSD. A lot of the people I'm working with, I mean, this is an all-encompassing, life-destroying-- or quality-of-life destroying, I should say-- kind of a problem. And to me, with all the stress and the anxiety and emotional issues and psychological disruptions that it causes, at the bottom of all of it is this central feeling of powerlessness.

And I think that it's there with Meniere's too. But with tinnitus, it's this crystallized thing in my mind where it can all be sort of traced down to this idea that there's this sound present that we don't like. And we're trying to push it away. And we're failing to do that and feeling powerless to do that, but just recognizing that you're never actually powerless like you think you are.

But the problem is that-- you know, Dr. Allen was saying how tinnitus is a specialty. It's very difficult to find good help from the medical establishment, oftentimes. Almost everyone I've ever worked with has a story of a doctor or a medical professional that said something along the lines of like, oh, yeah, I'm sorry you have tinnitus. There's really nothing we can do to help you. You're just going to have to live with that.

And what would make you feel more powerless than that? But just recognizing that you're never powerless like you feel like you are, despite what your doctor might have said. There's so many different things you can do to find relief and improve tinnitus. And I would argue Méniere's Disease as well.

HEATHER DAVIES: Absolutely. What I was going to mention when you guys were talking about acceptance, I recently met someone named Callie. And she's had tinnitus for a long time, and it has fluctuated over the years. And she has-- it's ongoing. And she has come to know it as just peaceful to her now because her tinnitus is like-- um, I'm sorry-- cicadas. So she has come to know and just embrace that.

And it's easier said than done. It does take time, of course. But it doesn't bother her so much. And it doesn't send her on that flight or fright thing anymore. It's more of, OK, this is happening. I'm just going to get out in nature and enjoy the cicadas. I know that a lot of people are more severe than that. But just knowing that, with work that you can get there--

GLENN SCHWEITZER: 100%.

HEATHER DAVIES: Yeah.

PATRICK PARKINSON: And really that's the most compassionate acceptance, like Glenn was saying. It sounds like giving up, right? But it really is, ultimately, the most compassionate and courageous thing you can do to say wherever I'm at on my journey, wherever my body's at, wherever my inner ear is at, it's good enough as is. I'm good enough in this moment however my body's showing up, however my thoughts are showing up, however I may be trying to fight it. Wherever I'm at is enough.

GLENN SCHWEITZER: Also, Heather, what you were saying, I always want to-- like you were saying her tinnitus might not be as severe as other people's. It's worth mentioning here that volume isn't the only variable that determines severity. Now, if you have very loud tinnitus, there's a high correlation there. The louder it is, the more you're going to hear it in most environments. Certainly pitch-- if it's a very high frequency sound, like above 8 kilohertz, you're going to tend to hear that over most environments because most environments are usually within the 0 to 8k range.

But I have found now that, really, it doesn't matter what it sounds like. And it could sound like anything. I mean, I've worked with people with every type of sound you can possibly imagine and some people probably couldn't imagine. And I'm sure if we asked everyone on Earth, like, rank these hundred sounds in order of least to most annoying, we'd get some kind of consensus.

But just because it's one sound or another, or it's loud or it's quiet, I've met people who have extremely loud tinnitus and aren't bothered in the slightest and people with very quiet tinnitus and it has completely destroyed them. And everything in between is also possible. And so I don't want anyone to feel minimized here.

HEATHER DAVIES: No, no.

GLENN SCHWEITZER: Whatever your tinnitus sounds like, if it's a problem, it's something you can deal with.

HEATHER DAVIES: Absolutely. Well, we're coming to a close. Did you want to say something, Steve?

STEVE SCHWIER: Nope, I'm good.

HEATHER DAVIES: Nope. Well, I wanted to circle back and ask you guys, if you were to meet someone that's fresh and new just experiencing this tinnitus on their vestibular journey, what would you say to them?

STEVE SCHWIER: I'll take this one right off the bat because, for me, it's surround yourself with good people who love you for all your flaws. And tinnitus is a flaw. Now, we've learned to accept it. We've learned to cope with it. Yet in conversations, it affects my conversations with people. It affects when I'm out in public, when I'm in a restaurant.

And so to have really grounded friends, a circle of friends and family that support you 100%, then that would be where I would say start. Because my second one would be find the best doctor you can get, which is probably your first thought. But even with my doctors, it took me getting the people around me to understand how I lived.

And even right now, my brother Dave, who doesn't have tinnitus or Meniere's, he's watching this right now from Ohio because he cares about

how I'm doing and how it's affecting me. And so he's collected a lot of information on my behalf. And that's a huge help for me.

My wife is totally supportive, my son totally supportive, and my dear friends up here in Colorado. And that has just been the game changer for me. Because when I say I can't do that, I don't get the, well, why not and blah, blah, and la-di-da. They get it. So that takes some of the stress off of me, being able to be sick, knowing that I'm accepted for it.

GLENN SCHWEITZER: I really love that. I think having a good support network is super important. For me, what I would tell someone just early on in their journey, you're in such a vulnerable place in those early days. It's such a fragile place where it's a new problem. You're not really sure of what it is. Or it usually it takes time. Sometimes it's panic-inducing right away, but more often than not, it builds.

And then along the way, you suddenly are confronted with the fact that it's hard to find a doctor who understands or can offer treatments. And then you go online and you read all these scary things. And pretty quickly, you're in this very vulnerable place and things start to fall apart.

So for me, when I encounter someone who's early on their journey, regardless of how their tinnitus came, a couple things. One is that you always want to find a good doctor to just rule out any treatable underlying medical causes because it's possible that you can treat whatever's causing this and see some improvement.

But regardless of whether or not your tinnitus can be treated, and regardless of what you might have heard or read online, there absolutely is hope. No matter how bad it is right now, you can get your quality of life back and get to this point where it's not bothering you anymore and you feel more in control of your life again, whether it goes away or not, thanks to this process of habituation.

So wherever anyone's at in their journey, definitely don't lose hope. There is a way forward. Even if there's no treatment, even if there's no cure, you can completely restore quality of life to pre-tinnitus levels, regardless of whether it goes away.

STEVE SCHWIER: Yeah.

HEATHER DAVIES: Yes. Patrick, did you have anything you wanted to say?

PATRICK PARKINSON: Sure, sure, yeah, I could chime in. And I totally agree with everything that's been said so far. And I'll see if I can offer up something new, although it will probably end up being kind of a repeat of what I've been teaching here because I think it's so important.

But I would just say, early on in my journey, I was in that fix-it mode, which is completely natural. But I said this is a problem, and I got to fix it. But underneath that was kind of this belief that if I'm not successful, then there's something wrong with me. And there was that self-blame and kind of fundamentally this idea that I needed to be in a different place than where I was at right now.

And I think that that kind of thinking and saying I need to get from point A to point B, and if I'm not there I'm constantly pushing the limits and trying new things, and that just keeps our system at a much higher level. And so again, just the idea that wherever you're at throughout your healing journey is completely fine.

And that realization was one of the most significant pieces of my healing journey. We can continue to try new things, but whatever comes of them is absolutely fine.

HEATHER DAVIES: Absolutely. Absolutely. I know we're coming to the end, but I have one quick question to ask you guys. With my tinnitus, it is a warning sign for me. If I don't stop what I'm doing or de-stress, then my

Meniere's symptoms amp up, and vertigo, everything follows suit. Do you guys have that also, as we're all fellow Menierians?

GLENN SCHWEITZER: Yeah, definitely. I definitely do. There's always a progression of symptoms as I'm kind of going down the wrong path or pushing too hard and going past my boundaries and limits. And increased tinnitus is always one of those warning signs for me. Although I can get increased tinnitus for a whole variety of reasons, even at times where I'm not experiencing any other Meniere's symptoms.

So while, yes, it is a warning sign, it's not only a warning sign.

HEATHER DAVIES: Right.

GLENN SCHWEITZER: It often is an indicator that something is off, like I haven't been sleeping well, I'm sick or I'm getting sick. I'm under too much stress, I'm not taking care of myself. It's a pretty good indicator of something is off, and sort of a signal that I need to take better care of myself in that moment.

HEATHER DAVIES: What about you, Steve?

STEVE SCHWIER: I agree with that completely. It's my tinnitus is definitely a warning, but it can warn me of many different things. And it took me a while to figure out which ones were which. Oh, maybe I'm just overstressed, or I'm leaving tomorrow on a trip and I'm just kind of anxious. Or it can trigger different things.

But I think one of the most important things with all this is that it's not just the physical hearing and the severity of that, which is super severe. There's the emotional, the guilt, the shame, all the stuff that comes with not-- like Patrick was saying, all the things that aren't getting me from A to B,

I can just keep beating myself up over these things, and it just makes everything worse. And then the emotional feeling of letting down my family,

or letting down my friends, or not living up to who I think I should be, that's the toughest battle, I think, with tinnitus, is the emotional stuff and the psychological stuff and the tricks it can play on your mind.

HEATHER DAVIES: For sure.

GLENN SCHWEITZER: Definitely.

HEATHER DAVIES: For sure.

GLENN SCHWEITZER: For sure.

HEATHER DAVIES: Well, we could just talk forever with you guys.

PATRICK PARKINSON: Yeah. And Heather, what do you think? We could try to pick another question here or--

HEATHER DAVIES: Yeah, go for it. We have a couple minutes if you want to grab another question.

PATRICK PARKINSON: If we can really quickly talk on-- one thing we haven't talked about is therapy for tinnitus. Is that something either of you have experience on? And maybe we'll keep it brief, maybe like a 30-second answer each, if someone wants to chime in on that.

GLENN SCHWEITZER: I was seeing a therapist the whole time in my early journey, to varying degrees, more when I'm struggling, less when I'm not. It was hugely valuable to me and important to me. And it can be very helpful for dealing with a lot of the stress and mental health battle of tinnitus. So I'm definitely a big believer of that, especially if you have anxiety disorders or OCD or things like that. It can be extremely useful when you're trying to find relief from tinnitus.

STEVE SCHWIER: No, I think it's almost mandatory to do some sort of therapy because, like Glenn mentioned earlier, a lot of people-- and my early

therapist was like, you know, you have these things that are like PTSD, like soldiers that come back from war and their lives--

GLENN SCHWEITZER: Yeah, totally.

STEVE SCHWIER: --are just upside down. And I never really thought of it that way until she said there's a lot of symptoms that you have that go along with PTSD, people I deal with. And just getting that knowledge was huge, just so I wouldn't be, oh my god, I am crazy. I could just put that on the shelf and be like, it's just a PTSD type of thing. And I just got to wiggle my way through it and deal with it, with what's on my plate.

GLENN SCHWEITZER: Absolutely.

STEVE SCHWIER: So yeah, I think everybody, whether you have tinnitus or not, needs therapy, on this planet, if you ask me.

HEATHER DAVIES: Absolutely.

PATRICK PARKINSON: Yeah, yeah. We tend to downplay the severity of something. Like, how bad could just a little ringing in your ear be, right?

STEVE SCHWIER: It's huge.

PATRICK PARKINSON: And then we beat ourselves up for how it impacts our lives. But having that experience seen and normalized by someone can go such a long way.

GLENN SCHWEITZER: Definitely.

PATRICK PARKINSON: So yeah, love that.

HEATHER DAVIES: Absolutely.

GLENN SCHWEITZER: But before we wrap up, I hope it's OK to mention, if anyone wants to connect, I have a virtual exhibitor booth at the conference, for rewiring tinnitus. Please feel free to come by and say hi. And yeah, I just

wanted to throw that out there if anyone's interested in connecting with me or working with me.

HEATHER DAVIES: Perfect.

PATRICK PARKINSON: Definitely.

HEATHER DAVIES: Yay. Well, thank you guys so much. This has been just an informative-- and it's so nice to see both of your faces. So I hope everybody has a great day.

STEVE SCHWIER: Well, thanks, Cynthia and s

HEATHER DAVIES: Thank you. Wow. Patrick, that was awesome.

PATRICK PARKINSON: Yeah, yeah, I wanted to say bye to them there. I didn't know they were signing off so soon.

HEATHER DAVIES: I know. Thank you. Thank you to our panelists, Steve and Glenn, for sharing so much of their journey. Cynthia, Elizabeth, Kyler, and everyone behind the scenes, thank you so much.

As a reminder, you can purchase lifetime access to the recordings and transcripts of this entire conference at vestibular.org/lrl-recordings. And you can make sure the valuable information that is presented at this event remains free to everyone by making a donation at vestibular.org/lrl-donate. Those links are also listed in the description below.

PATRICK PARKINSON: Yep. And I just wanted to quickly send another thanks out to the James D. And Linda B. Hainlen Discovery Fund and the University of Minnesota Department of Otolaryngology, and Abbie and Danielle, who spoke earlier with their physical therapy practice, Balancing Act Rehabilitation, and the Academy of Doctors of Audiology for sponsoring this conference.

HEATHER DAVIES: Yes. All right, well, thank you guys for joining us, and we hope to see you tomorrow. Bye, Patrick.

PATRICK PARKINSON: Yeah. Thank you all so much. Thanks, Heather. Bye.