

Life Rebalanced Live 2024

CHRONIC IMBALANCE FROM BILATERAL VESTIBULAR HYPOFUNCTION

CYNTHIA RYAN: Hello, and welcome to the fourth day of the Vestibular Disorders Association Fourth Annual Life Rebalanced Live virtual conference. I can't believe we're already more than halfway through. I'm Cynthia Ryan, executive director of VeDA.

Yesterday, we had a great discussion about how vestibular disorders are diagnosed. A big shout-out to Dr. Jeff Sharon, who did an amazing job breaking this huge topic down into digestible pieces. He explained what tests are done, when and why. Something I think is easily forgotten is how important it is to take a thorough medical history and in some cases how that really is what doctors use to make a diagnosis.

Our panelists also had some great words of wisdom. They said what we all to be true. And that is that your body best. So you make sure you find a doctor who will listen to you and don't give up. There is always hope.

I'd like to, again, start by thanking our sponsors who've made this event possible. The James D. and Linda B. Hainlen Discovery Fund and the University of Minnesota Department of Otolaryngology have generously supported LRL since its inception in 2020. A big shout-out to Jim Hainlen who is a vestibular patient. He inspired this event by holding his own vestibular conference in 2018 and 2019. Jim cares deeply about supporting people on their vestibular journey and was important to him to not only educate people about vestibular disorders but provide a platform where people could connect.

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, especially if you've been watching already because they are the hosts of this conference. And some of you may know them as the hosts of the Talk Dizzy to Me podcast.

But you may not know that Abbie and Danielle also serve on VeDA's board of directors and have volunteered countless hours to advance vestibular advocacy. Its dedicated volunteers like Danielle and Abbie who are the lifeblood of VeDA. I've 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 inspired to make a donation to make sure that this event continued. And now I'd like to pass it off to our hosts, Drs. Abbie Ross and Danielle Tolman.

DANIELLE TOLMAN: Thank you for the introduction, Cynthia. Welcome to day 4 of the Fourth Annual Life Rebalanced Live Conference. We are continuing on with our all-star lineup of health care providers to discuss various topics pertaining to the management of vestibular dysfunction as well as inspirational patients who will be sharing their vestibular journeys. We want to say a big thank you so much to all of you who have contributed to this conference in some way, including the VeDA's donors, staff, and volunteers.

ABBIE ROSS: And with their contributions, we're able to put the live version of this conference on at no cost to you, our attendees. If you do wish to gain lifetime access to the presentations following the live event, we, of course, will have them available for purchase for just \$55. And thank you all so much for your support thus far. Your financial support helps VeDA's continued mission to spread vestibular awareness. So thank you.

Our topic for today, day 4 of Life Rebalance Live, is chronic imbalance from bilateral vestibular hypofunction. We're going to be discussing what is bilateral vestibular hypofunction. It's a mouthful, first of all. And what can cause it? What's the difference

between partial loss versus complete loss? And even touch on the exciting new studies being completed with the vestibular implant.

DANIELLE TOLMAN: So without further ado, we'd like to introduce you to both of our speakers today, Dr. Raymond van de Berg and Dr. Amanda Chiao. Dr. Raymond van de Berg is a professor and ENT surgeon at Maastricht University Medical Center with a special interest in vestibular disorders and cochlear implantation. His research initiatives mainly focus on vestibular implant, bilateral vestibulopathy, and vestibular diagnostics.

He obtained his first PhD in medicine, cum laude, which won several scientific prizes. And a second PhD was obtained in biophysics with a maximum score, we might add. He is also the head of the department of audiology, head of the vestibular department, and chair of the Barony Society Educational Committee.

And then we have Dr. Amanda Chiao, who is an assistant professor and the director of the pediatrics and vestibular evaluation laboratory at Texas Tech University Health Sciences Center in El Paso, Department of Surgery. Dr. Chiao is also a pediatric audiologist at El Paso Children's Hospital where her clinical expertise includes audiological and vestibular diagnostic testing in infants and children as well as concussion.

Dr. Chiao was a prior faculty member at the University of Nebraska Lincoln where her research focused on vestibular deficits following sports concussion and funded work on autovestibular toxicity from substance misuse. She recently relocated back to her home town of El Paso, Texas, to be a practicing researcher within her own community. Dr. Chiao's research interests continue with her funded work in studying autovestibular toxicity among people with substance use disorders and understanding the otologic and audiological health disparities among Latinos and underserved patient populations.

Welcome to the both of you guys. We are so excited to have you on.

RAYMOND VAN DE BERG: Thank you.

AMANDA CHIAO: Thank you. Happy to be here.

ABBIE ROSS: Thank you, Dr. Chiao. And thank you, Dr. van de Berg for being here. Thank you audience for joining us. Let's kick this off with, what exactly is bilateral vestibular hypofunction?

DANIELLE TOLMAN: Dr. van de Berg, we'll have you jump in first.

RAYMOND VAN DE BERG: Perfect. Yeah. So yeah, that's already a very good question because with bilateral vestibular hypofunction or bilateral vestibulopathy like many people call it now, at least you have a reduced or absent function of your vestibular system bilaterally. So it can be in your vestibular organs. It can be that your nerves are affected, or even your brain is affected that leads to a bilateral vestibulopathy.

And I think that's important to recognize that it's an heterogeneous disorder. So it means it's like some kind of end stage. A lot of disorders and diseases can result in bilateral vestibulopathy. It's like losing two legs. You can lose a leg because you're diabetic, and it needs to be amputated. But you can also lose your leg because of a trauma. And eventually, you end up with having the absence of two legs, so to say.

So bilateral vestibulopathy is some kind of end-stage disorder that can result from a lot of reasons, so to say. I can talk for longer. But maybe Amanda wants to add something to it.

AMANDA CHIAO: No, I think you did a great job. Thank you. I just add to your point, bilateral vestibular loss can also be a spectrum. So you don't have to have all or nothing. Bilateral vestibular hypofunction can be mild and then progress to a total vestibular hypofunction. It really does depend on the disease process and what Dr. van de Berg said, what caused the initial injury to the vestibular labyrinth on both ears.

DANIELLE TOLMAN: So it can be a wide spectrum, meaning I'm sure patients that experience this type of diagnosis or end-stage diagnosis have different presentations. But let's start with discussing some of the causes of bilateral vestibular hypofunction. Let's start with you again, Dr. van de Berg.

RAYMOND VAN DE BERG: Yeah, so maybe if-- I made a slide. Maybe if it can be-- if you can pull it up the slides because there are so many reasons why you can have it. And on the left side on the slide, you will see the main categories. And this is based on research. And it depends a little bit on the setting.

So if you're in an ENT setting like our center, I think one out of three remains idiopathic, which means we don't know exactly what is the reason. But if you're in a neurological clinic, even one out of two remains idiopathic. But for the people in which we find the diagnosis, you can see on the left the main categories, which might vary from toxicity like gentamicin, streptomycin, antibiotics up to autoimmune disorders like Susac, Cogan.

But also if you have, for instance, colitis ulcerosa or sarcoidosis, you can also have a bilateral vestibulopathy because then you get what we call an autoimmune inner ear disease. So actually the autoimmune disorder also reaches your inner ear. And you get into trouble, which can lead to a bilateral vestibulopathy.

Additionally, you also have neurodegenerative diseases. One very well known is called CANVAS. And then you have a combination between peripheral deficits and also central signs, which means neurological signs which mainly stems from your cerebellum also.

And in some of these disorders, recently, a very nice paper, which was about SCA27B, for instance, is that they said, well, we are not sure if you find a bilateral vestibulopathy whether really your vestibular organs are working not properly or whether it might really the brain that interprets the information from those organs improperly.

So you see, nobody is still perfectly aware of everything that can result to bilateral vestibulopathy and what bilateral vestibulopathy perfectly is. But what we see in the Netherlands, for instance, is a very well-known genetic disorder, which is called DFNA9. And then you have families that have balance issues and at the same time also have hearing loss.

And think I heard that yesterday, there was already a nice talk about diagnostics. And for me, I think that each clinician should incorporate in history taking the family history.

Because if you ask a family history also in patients with bilateral vestibulopathy, you might be surprised how many times it's still a genetic cause, for instance.

I will not go too much into detail about all the other options. But it's just to show you, there are many, many, many reasons that can lead to bilateral vestibulopathy. And this table is not complete. I'm quite sure we are finding more and more disorders that can lead to bilateral vestibulopathy. But you can pull the slide back, if possible. But if you see-- wait, maybe, I'll just wait a little bit before-- I can imagine that Amanda will also want to add something to it.

AMANDA CHIAO: Thank you. So I'm a pediatric vestibular audiologist. So I'm going to be chiming in with some pediatric tidbits if that's useful for anybody on the call and the meeting. So I want to focus a lot a little bit more on causes that are actually going to affect children who then later become adults and perhaps never identified with vestibular loss until they're much older, and now having more concerns for fall risk or other types of imbalance.

A lot of congenital causes of hearing loss in children will also have concomitant vestibular loss, especially bilateral. There was a really great study done by Kristen Janky, excuse me, in 2018 where she identified that one of the main risk factors for vestibular loss in children is actually having a severe to profound hearing loss in that same year.

And the reason for that is that the cochlea, the hearing organ, shares a lot of anatomical and blood supply structures with the vestibular labyrinth, which is in control of our vestibular system in each ear. And so it's no surprise that if there's any mutation or disruption done in utero to the hearing organs, that child will also have concomitant vestibular hypofunction. We just don't see it. Or sometimes we don't pay attention to it because we're really focused on the hearing loss side.

So I would say in children, congenital bilateral vestibular hypofunction is very common. We don't typically notice it until that child is that clumsy kid or delayed gross motor or much older in adulthood. And then it's quite a bit of a surprise.

ABBIE ROSS: Wow. So interesting. And I love that we have both aspects presented today. I want to talk a little bit more about the ototoxicity of some medications. Can you verbalize what some of those medications are? And if we know that they have a potential for ototoxicity, what might be reasons that providers would still prescribe them?

RAYMOND VAN DE BERG: So yeah, I noticed that there is a little bit of difference between countries also. Because in the Netherlands, we are a little bit more careful with those medication, I noticed, and in other countries. I don't know exactly how it's in the USA.

But it's always a challenge also for clinicians because what we say normally for us what kills first. So if you are in a very severe condition and antibiotics like gentamicin or streptomycin are the only antibiotics that you can give in order to save a patient's life, of course, you don't have any choice. But if you have alternatives, you should reconsider them.

And I think there is some room for improvement because I think that not all doctors always think about alternatives. And there are a couple of pitfalls when you prescribe or use gentamicin, for instance, as an example is that some people are more susceptible for gentamicin, ototoxicity. And some people even, they test for it if people are more susceptible for it.

But gentamicin can also selectively accumulate in the inner ear. So you can still monitor the blood to see, are the levels of gentamicin OK? But it will not always say something about how it is in your inner ear. So that is already two pitfalls.

But the third pitfall is I think that many clinicians learn that you should monitor gentamicin by testing hearing. And a problem of gentamicin is that it is more toxic for the vestibular system than for the hearing. Actually, gentamicin in a low dose destroys the vestibular system but not yet the hearing. And if clinicians are testing patients with their hearing and looking for high-frequency hearing loss, for instance, and then they

forget about the vestibular system, you are too late for the vestibular system if you try to monitor hearing.

So these are some things that we encounter with patients at least if doctors use gentamicin, that they are not aware of the selective accumulation in the inner ear do not think enough about the alternatives of medication. And also, the last point, I addressed already. So that's, I think, very important to know that you do not check hearing only.

DANIELLE TOLMAN: Very important to know. And, Dr. Chiao, could you maybe take the time to describe what toxicity is and what is going on in the organ itself that's causing this hypofunction when we administer these drugs or somebody has a reaction in that sense?

AMANDA CHIAO: I'm happy for my colleague here to jump in as well for more of the medical aspect. So I'll try my best. But ototoxicity in general can have a lot of mechanisms. It really just depends on what the drug is itself.

From my understanding, it can definitely cause almost like a hypoxia, disruption of blood flow to the certain vestibular hair cells within the vestibular labyrinth. In our world, there's a lot of exciting research being done on reversing and regeneration of hair cells. But once those hair cells are damaged, they're pretty much gone.

And a lot of factors can contribute to ototoxicity that we really can't control for-- the dosage, the person's health comorbidities. So there really is actual structural damage done to the vestibular hair cells within the vestibular labyrinth. And like I said before, it's not always all or nothing.

So we have five what we call rate sensors in each ear. And all of these rate sensors have their individual vestibular hair cells, if you will, in their own types of anatomy. And so the ototoxicity itself could affect one part of the vestibular labyrinth, one of those sensors, part of it. It just really does depend.

And so there is actual structural change, disruption of blood flow. And we need that blood flow for those hair cells to continue to function. And then if we don't have that blood flow, then we have what we call a hypoxia. So we have actual hair cell injury.

ABBIE ROSS: Dr. van de Berg, did you have anything to add? Otherwise, I've got another question coming your way.

RAYMOND VAN DE BERG: No. Perfect, it was perfect answer.

AMANDA CHIAO: He's being very kind. Thank you.

ABBIE ROSS: Now another question, neuritis is a pretty common vestibular diagnosis. And if viral infections can cause a vestibular neuritis, is it more common to have it affect both ears at one time? Or is it one ear and then later on, the second ear is affected?

RAYMOND VAN DE BERG: So yeah, first of all-- but it's also a semantic discussion. Nowadays clinicians prefer to use the term acute unilateral vestibulopathy to stay a little bit away from the fact that it's always some kind of infectious stuff because neuritis, the itis refers to some kind of infectious process.

So yeah, well, if you see that somebody has what you call some kind of neuritis type of problem, first on one side and then on the other side or on both sides at the same time, then we are quite quickly thinking about the autoimmune. We want to rule that out because it's very uncommon that somebody just gets enteritis bilaterally.

It's analogous to the hearing. Because if a patient gets sudden deafness bilaterally, we also have some kind of reflex that we have to think about autoimmune. And we give a lot of steroids. And we try to see if there's an autoimmune background.

So that is just a remark about that. I would not say that the neuritis is one of the most important causes of the bilateral vestibulopathy, by the way. I think there are many more. And sometimes some disorders might look like a neuritis. But if you look careful, it's actually a totally auto disorder that mimics the neuritis, for instance, a genetic disorder in which people can also have a very sudden progression of their loss.

But each time, when you have-- if you have two vestibular organs and just one fails, it's like an attack, you know? And it doesn't recover anymore. And then the other also goes down. So then it seems like you have two separate attacks. But they might be related to another disorder than only the neuritis itself. Is that the answer to the question or not? Let me know.

ABBIE ROSS: No, that was perfect. And now when we talk about partial versus complete loss, how would a patient differ in their presentation?

RAYMOND VAN DE BERG: You want first Amanda or not?

AMANDA CHIAO: Sure, I can take that. So in terms of patients with more of a partial bilateral vestibular loss, a lot of times when we think about losing the vestibular function, we think about it in terms of different frequencies. We call it frequencies in which our hair cells are responsible for interpreting different sensations of motion.

And so a lot of times, these individuals will present with still maybe some oscillopsia. But they might present with actual more symptoms of classic of a unilateral vestibular hypofunction, more vertiginous-like symptoms, more instances of being able to compensate and then decompensate-- you probably heard that term before-- versus individuals with more of a true bilateral total vestibular loss are probably not going to present with those classic vertiginous-like symptoms as much as the oscillopsia with-- so that's this visual blurring with body movement acceleration and then also a lot more disadvantages in overall postural control.

So when we think of it from the audiological perspective, we're always looking to test to see, is there any residual vestibular function? If there's residual vestibular function, then that helps inform, hopefully, our physical therapy colleagues to be able to use that information in the rehab setting and use other types of what we call vestibulo-ocular reflex exercises, habituation perhaps, and gaze stabilization to help stabilize gaze with head movement versus folks in more of the total bilateral vestibular hypofunction camp maybe don't have any sort of residual vestibular function in the inner ears.

The overall balance, gait is really impaired, especially in the beginning of that early on diagnosis. And so the focus there is going to be sure that we work with our physical therapy colleagues to ensure that we minimize the risk of fall significantly in this population and use more substitution like strategies, vision, somatosensory.

And so it looks a little bit more-- sometimes people will say, well, if I a full bilateral vestibular loss, then this person is significantly disadvantaged. And that can be the case. But again, I'm in the pediatric realm. So a lot of times I see babies and kiddos who have complete vestibular hypofunction. And those kids, sure, maybe not be swimming in the Olympics, but they're certainly able to compensate and use plasticity to develop walking and all types of functionality. So it just really depends on also the patient. But that's a general difference.

DANIELLE TOLMAN: Well, it sounds like it's very important for somebody experiencing bilateral loss or bilateral hypofunction to understand what caused that loss, where that loss is occurring from, whether it's more central or peripheral. That includes the end organs. And that's going to help guide them in terms of management for therapies or treatments moving forward.

Since we talked about testing yesterday could, you guys just briefly touch on some of the testing that is going to confirm or guide those treatment decisions for somebody with bilateral loss or hypofunction? Dr. van de Berg, let's start with you. You're muted. Hold on.

RAYMOND VAN DE BERG: If you want, you can even put up this slide again. I selected something. So because, for bilateral vestibulopathy, the Barany Society is a society of people who are really into the vestibular world, so to say, thought, well, let's make some criteria.

So when do we speak about bilateral vestibulopathy? And it's always a combination of symptoms and signs. So the symptoms, on the top, you see it must be a chronic vestibular syndrome with the following symptoms. So unsteadiness when walking or

standing plus at least one of two or three, which means oscillopsia or worsening of unsteadiness in darkness and on even ground.

Then secondly, no symptoms while sitting or lying down on a static conditions. I must admit, that's a little bit a tricky one because they actually meant to say that especially when you're moving, you get into trouble. But to be honest, some people, especially if they have a very severe bilateral vestibulopathy, if they are chewing on their food, they already experience oscillopsia. And then they're sitting down.

So this is a tricky one. But it meant to say, when you move, it increases a lot. That's what it mean. And then you get to the testing. And for bilateral vestibulopathy, you need to have at least in one out of three tests that one of these tests shows a deficit. So you can have the caloric test, the video head impulse test, or the rotatory chair test.

And I'm not sure yesterday you talked about test. So I'll not go too much into detail what all tests mean. But for the video head impulse test, you need to show on both sides that it's really bad. Because, if you are, again, below 0.6-- for the caloric test, it must be the same. You get water in your ears. And then you want to see almost no response. You can still have a little bit of response. Or with the rotatory chair testing, they want to see also a very decreased response.

And what we found actually in our patient population is that if you want to detect a response that is abnormal, the caloric test and the video head impulse test are much more sensitive. So in those tests, you often find a problem before you will find it in the rotatory chair test. There are many ideas and hypotheses why. Maybe because the canals are also most sensitive in the frequencies that are tested by the rotatory chair test. That might be one of the ideas.

But the other test, the video head impulse test and the caloric test, they are much more sensitive. So that's why, to be honest, in our center, we always perform all tests, just because it's easy for us because they had all the tests. They come to me. And then I can give a one-time consultation. So I don't have to send them back for different tests.

So for me, it's very easy. But these are the three tests that have been defined by the Barany Society that must be used to indicate whether it's bilateral vestibulopathy or not. You can remove the slide again. Thank you.

ABBIE ROSS: Now, Dr. Chiao, you touched on something. And then something in what Dr. Van de Berg was just sharing reminded me of it. Can you talk a little bit more on the balance systems that contribute to our balance? So you were talking about somatosensory, vision, vestibular. And then in one of his slides, it says, when you're in darkness, your unsteadiness gets worse. So can you talk about how those systems work together and what you mean when you say substitution, what that might look like from a therapeutic standpoint?

AMANDA CHIAO: Sure. So when we think about balance, sometimes we like to use the word vestibular interchangeably. And they really shouldn't because balance is a multimodality that allows us to use our vision, our sense of touch-- we call that somatosensory-- and our inner ear inputs together oftentimes all at the same time to be integrated and sent to the brainstem and the cell and the cerebellum, which is a very important structure that is regulating these inputs, input/output and regulating them all at the same time to constantly keep a person upright and ready to adapt when something's taken away, which is every day. That's what constitutes dynamic balance.

And so one of the analogies I use is that if you are walking and someone comes behind you and pushes you, how do you automatically adapt to stay upright? Well, that's all of those three senses coming together integrated into your cerebellum to create and execute a very quick reflexive motor plan. And so when we lose our inner ear input, we no longer have a really nicely executed plan. We have to then rely on the other two's cues-- vision and/or somatosensory-- to make up for that to keep that person upright.

And so in our clinics, when we do certain balance tests, that's why we have close your eyes or send out a piece of foam. We are integrating these three senses together. And then we're slowly taking them away to see where does that person fall apart.

And a lot of times, in one of the hardest conditions, folks are asked to close their eyes maybe stand in a tandem or stand on foam or in a moving force plate. And that's because we're really challenging your inner ear input. And we're not diagnosing the inner ear loss at that point. But we are saying, when we take away your other cues, you're really high risk of fall.

And so in a person with a bilateral vestibular hypofunction, the idea is that there is potentially no vestibular input. And so when we get to that condition where we take away their vision and take away their sense of touch, they're extremely high risk of fall and should not be putting themselves in those situations in every day.

So not walking around at night with the lights off, minimizing loose rugs or cords in their house when they're walking around. So from a therapeutic standpoint, substitution is really that idea of putting in folks in those situations and teaching them, retraining their brain and their cerebellum, if you will, to rely on vision or somatosensory so when this person is in those situations, they can keep upright and not fall. That is really the end goal of substitution.

And I'm speaking with two physical therapists. So I'm sure I did a very gloss over of what that is. But essentially, that's how dynamic balance is described. It's all those cues coming together, the perfect time to create a wonderful reflexive motor plan.

DANIELLE TOLMAN: No, that's a perfect way to describe and summarize that. And on paper in textbook, that sounds amazing. But life happens, especially as we get older. And a lot of those extra systems that we utilize for balance become impaired. Our vision starts to become decreased, whether it's changes in vision or macular degeneration as well as the potential of peripheral neuropathy, which can come from anything from diabetes to low back issues.

So this leads us into something I am very excited to talk more about, which is the potential and the amazing research and forward thinking that we've got going into vestibular implants, helping people who are aging and have deficits in those other somatosensory and visual categories, still maintain some quality of life and some

function by giving their vestibular system new life. So I was wondering, maybe Dr. van de Berg, you can start off discussing what the vestibular implant is and what direction we're moving in with this new technology.

RAYMOND VAN DE BERG: Yes, yes, vestibular implants is one of my hobbies, as you might know. Because in Europe, we're actually-- our team, Geneva, Maastricht, we are one team. We were the first one in the world to implant such an implant in human patients even, which was really nice.

And the vestibular implant is just like a cochlear implant. Maybe people know it. It's an artificial hearing organ. And with the same idea, we want to make an artificial balance organ or vestibular organ, which means that you capture motion. And that motion is then processed by some kind of computer into electrical pulses.

And maybe if you want, you can pull up the slide again. I'll give you a quick overview for people who might not exactly know what I mean. So it looks like a cochlear implant, a hearing aid. But instead of sound, it captures motion. And in our clinic, by the way, for research, we implant a combined hearing and balance organ. So a vestibulocochlear implant.

So it captures motion and sound. And then I'll go into the slide to show you-- the other slides. Because on the other slide, you will see that in the skull, we have implanted an implant by a company which is called MED-EL. And there you see four leads. You see one electrode that goes into the cochlea. There are nine electrodes tips spots on it to stimulate the cochlea. And then you have 1, 2, 3 electrodes that go into the canals of the organ.

So the semicircular canals. And we put those electrodes very close to the nerve. So then the motion information is transferred into electrical pulses. And those electrical pulses are then by these electrodes transferred to the nerve.

So the nerve is stimulated again. Because in bilateral vestibulopathy, the nerve is not stimulated anymore properly because the organ doesn't work. So this implant actually bypasses the organ, the vestibular organ. You can remove the slide again, if you want.

There's a lot of research, also very nice research in the United States from Charlie Della Santina. We know him very well. Really nice person, does a lot of good work. He has a vestibular implant only, which is also very good. Because to be honest, most patients have still good hearing that have bilateral vestibulopathy.

So of course, we also want to implant patients who still have good hearing. But at this point, it's difficult to know whether a hearing will be damaged when you implant the implant itself. Because in that trial, they also found out that hearing loss is quite common. So we are working to improve the surgical technique to make sure that the hearing loss will occur at least less or hopefully not anymore in these patients.

But we are very happy about the results we obtained because what you want is, for instance, to restore the vestibulo-ocular reflex. And in multiple research groups around the world-- so from Geneva and Maastricht and from Charlie Della Santina and Johns Hopkins-- we found exactly the same, that you can restore at least to a certain extent the vestibulo-ocular reflex.

And the nice thing is that if you restore the vestibulo-ocular reflex, you also decrease oscillopsia. And that's what we found in our patients also. So the oscillopsia decreased. Actually, we have now in our trial a patient who can really nicely point out what he feels. He says, if I'm not-- if I'm walking, it feels like the whole horizon is moving. And when I put the implant on, all of a sudden, it becomes way less.

And yesterday, because we were running a placebo-controlled trial, I met him in a room. And he said, I think it's off because there is something wrong. And then I looked at it. He was not aware of the fact that it was off. But I could, of course, see what was happening. And then, indeed, it was just on baseline firing rate. So it was not doing anything.

So you see, it's almost like putting on goggles. If you can't see, you put goggles, and you see more properly. And for some of these patients they can really see the benefit. To be honest, just like with cochlear implants, not everybody has the same benefit.

DANIELLE TOLMAN: Well, I was going to-- that's something I wanted to touch on was that patients who have bilateral vestibular loss that would benefit from this are patients that generally suffered from ototoxicity, correct? The hair cells themselves were affected, but the nerve that leads the information from the vestibular organ to the brain is intact to be able to transmit that information and for the brain to be able to make sense of that. Is that correct?

RAYMOND VAN DE BERG: That is correct because the nerve should be intact because you want to stimulate the nerve.

ABBIE ROSS: I have to say, Dr. van de Berg, this is what we term a vestibuloholics' dream is made of because this is so exciting for our entire population, just the new and upcoming things to look forward to. Can you talk to us a little bit about in terms of trials and research, where are we at? When can we expect this to be a regularly practiced medical practice?

RAYMOND VAN DE BERG: Yeah, that's a very good question. And to be honest, for the USA, I cannot perfectly say. And we are always very open. But when it comes to companies, they don't want to share results of other groups. And I haven't seen Charlie now in a while. Because otherwise, I could have asked him.

But if I'm correct, they at least they are trying to get it to the market in the United States because the FDA is a little bit more relaxed than the European Union when it comes to regulations. That was 10 years ago, totally the opposite. But the European Union became very strict.

So if I understood it correctly, they are working now to get it to the market in the USA. I'm not sure how long that will take. But often that's still a couple of years. I think in Europe, based on the results we have-- because the results, we are very happy with them. But it might still take 5 to 10 years at least.

And it all has to do with regulations. And that's a little bit-- we always find it very pity because you see the patients. Some of them really have a very clear benefit. They

actually say, I want to go home with it, I want to use it for the rest of my life. And unfortunately, in the European Union, we cannot even send them home yet.

Well, fortunately, the people joining the USA trial, they can go home with it. But of course, you want to give the device to many more patients also outside the trial. And therefore, you need to make sure that you do a lot of regulatory stuff. And that's, unfortunately, the case nowadays, which is good to a certain extent. But sometimes, in my opinion, it's a little bit too strict. You're actually depriving patients from a good treatment.

ABBIE ROSS: Very interesting. Now let's shift a little bit from up-and-coming things and instead focus on things we do right now. Are there other alternative treatments that we're advising patients on who are living with symptoms associated with bilateral, either partial or total loss? Dr. Van de Berg, I'll start with you. And then we'll hit the children.

RAYMOND VAN DE BERG: OK, perfect. Well, what I've found really--

DANIELLE TOLMAN: Not literally, I hope.

RAYMOND VAN DE BERG: No, no, no.

ABBIE ROSS: Not literally.

RAYMOND VAN DE BERG: No, no, no.

ABBIE ROSS: Poor choice of words.

RAYMOND VAN DE BERG: So what I find very, very interesting and nice is that patients themselves can really come up with very nice solutions. So we call it just tips and tricks, you know? So recently, we published even a paper which is called Practical tips by peer support in chronic vestibular hypofunction.

And there, we have had more than 200 patients with bilateral vestibulopathy. We just ask them, can you please tell me your tips and tricks? And they really came up with very nice interesting things that maybe at first you would not think about.

But it was really nice because we even made a website with all these tips and tricks. Well, the website is in Dutch, to be honest. But people can really benefit from it. Very simple things.

Always bring a good flashlight with you. Because if you end up in the dark situation, at least you can still see a little bit better. And you're less out of balance. Or if you like biking-- because in the Netherlands, everybody likes to bike because everything is nearby-- maybe use a bike with three wheels instead of two.

Of course, I know it doesn't look sexy because that's a little bit what people don't like. But if you explain why it's better and that you have to use mirrors instead of moving your head all the time-- you can look in a mirror in your bike-- then all of a sudden, they see it starts making sense. And they are much more mobile.

So it starts with tips and tricks. Then of course, the rehabilitation. But I think Abbie and Danielle, you can tell much more and much more in detail about the rehab than I can.

But in addition, what we also do is we have the BalanceBelt. I'm not sure whether anybody of you have heard about it, but it's actually a belt that's around your waist with detectors and sensors. And if you move a little bit too much to the left, there are 12 vibrators.

And the vibrator, they move on the left. And if you move too much to the right, it vibrates on the right. And it actually provides you additional clues about your position relative to gravity. And by that, a lot of people actually find it very nice for them if they have a very severe bilateral vestibulopathy and severe complaints. Especially in that group, it will work. Not in everybody.

The nice thing is it's non-invasive. So you can just try it. And if it works and you're happy, you can buy it. And if it's not, nice. You can just give it back. And you have no obligations.

DANIELLE TOLMAN: Well, yeah. We encourage everybody watching to check out a recent interview that Kathleen Strauss from VeDA did with Dr. Kingma to review the

BalanceBelt. So go on our YouTube or Facebook to check that out. But that is a really good piece of technology that seems to be helping a lot.

RAYMOND VAN DE BERG: OK, nice. I think, finally, what is also important is that if you have a chronic syndrome-- and it doesn't matter whether it's pain or something to do with your abdomen or with your vestibular system. A lot of people eventually get into some kind of-- they become a chronic patient. And it's very normal if you experience anxiety or depression or other kind of feelings. It's very, very normal.

And I think it's also important to emphasize that you are not crazy if you feel anxious or if you feel depressed. You're not a crazy person. It's a normal response for a lot of people if you have a chronic vestibular syndrome. And that is also something you need to address. You need to really address that in parallel.

So if you feel that your mood is not OK or you feel anxious, please also tell your doctor or your specialist or anybody because you need to treat that because your quality of life can even be more affected by the results of your bilateral vestibulopathy than by the bilateral vestibulopathy itself.

Today, I'm actually in a hotel room because we're at a psychosomatic course for specialists. And they're also-- again, they emphasize that all the sequelae of your disorder are sometimes worse than the disorder itself. So if you feel, have feelings of anxiety or depression, please tell it to your specialist. They need to treat it also.

So we look at all these aspects, not only at the vestibular organ. You need to look at the whole patient, some kind of holistic approach, we would say.

ABBIE ROSS: I love that you're hitting on this because we echo this, I think, in every talk that we do. So thank you. Now we're not going to hit on the children. We're going to move over to talking about the children. Does treatment approach differ at all, Dr. Chiao?

AMANDA CHIAO: Yes, thank you. So our knowledge about the effects of vestibular loss in children is really emerging. I would say probably in the last 10, 15 years, we are starting to catch up, if you will, in understanding the effects in children.

And so one of probably more consistent findings that we're seeing is that we do still want to have intervention for children, particularly to promote good gross motor development. And so a lot of work done at the University of Alabama Birmingham with Dr. Jennifer Christy and her group have really looked at the benefits of more traditional vestibular rehabilitation for children with bilateral vestibular loss.

Of course, working with kids, that rehab looks a little different, a little more fun than maybe traditional vestibular rehab measures to keep their attention. One of the things that her group and a lot of what the research is working on is really improving the VOR as traditional vestibular rehab does but doing it for other purposes-- promoting good reading skills.

So reading involves an eye tracking. But it's possible that it could involve a little bit of VOR if the child's moving. And so a lot of those rehab strategies are really fun things like sitting on a balance ball to work on core strength while reading a book.

And so really trying to still work on traditional measures as an adult would but really trying to do a different intervention. So we're trying to promote gross motor development. We're trying to promote good literacy by focusing on giving them good access to visual cues with and without head motion in the classroom.

So that rehab is being supported for children. And we're trying to identify more children with vestibular loss early on. So that way, we prevent gross motor delays and we get them into vestibular rehab quickly. Access to vestibular rehab is not universal. It depends on where you live and who you have a good access to a good physical therapist who understands the vestibular system.

So if you have a good PT, hold on to them because they're not common, but even more so is a pediatric vestibular physical therapist. And so what we're trying to work on in the peds world is to educate our physical therapists and educate our audiologists to identify

vestibular loss quickly in children because there are benefits by having them go to vestibular rehabilitation.

Another facet that is still emerging-- so we don't know a ton a lot about it yet-- is the effects of vestibular loss in children on spatial cognition, executive function. So higher order cognitive facets. This is a whole new world that we're still learning a lot in adults. But with children's, a little bit different because we don't have as much of other health comorbidity that also affects cognition.

So there's some preliminary work being done. That'll be really exciting that I think will also change more of a cognitive rehab for children with vestibular loss. But as of right now, vestibular rehab is still one of the key interventions for children.

DANIELLE TOLMAN: We had a specific question in the Q&A about a child, an infant who is exposed to gentamicin when they had a bad infection at a very, very young age. His hearing is being monitored every few months. But their question is, if they had vestibular deficits, would they have already noticed that over time? Or is this something that can present later on after having exposure to these ototoxic medications?

AMANDA CHIAO: Yeah, that's a really good question. So some of the ototoxicity research being done in more of the vestibular realm is showing that some of these adults, for example, who have hearing loss or were presented with ototoxic medications, that they might have some damage done to the vestibular organs like maybe just the otolith, for example.

And so maybe they may not present with maybe the most gross symptoms that we classically think of-- vertigo, dizziness, that kind of thing. But there's something a little bit off. And so that's some of the research is showing in the adults.

Collecting and having research to inform on vascular toxicity in children is tough because not every study uses the exact same test measures. It's hard to get a large number of kids to do all the test measures.

So I would say right now, in terms of a clinical recommendation, we're not trying to just recommend universally that all children need vestibular testing. It's not a good use of resources. It's really about looking at their gross motor delay.

So I would say for a patient like this, if your infant son is delayed on being able to independently sit, stand, or walk, then that would be a reason to suggest that there may be vestibular testing is warranted. At this time right now, we don't have-- and without having hearing loss, for example. Now if he presents with hearing loss at some point, I would also recommend vestibular testing because, again, we know that those two tend to come together in terms of having insult and injury.

And looking at the overall ototoxicity protocols, Boston Children's has a really great protocol that we also follow in our hospital. And we typically will test the vestibular system and the hearing system every year for five years once they're in their survivorship clinic. So once that child is already out of remission five years, we typically stop testing unless there's a reason to.

So I would say for this particular case, in terms of clinical recommendations, we just don't know enough to universally test all children. But at this point, if there's a delay in gross motor, sit, stand, or walk, there's presentation of hearing loss, those two really suggest that vestibular testing is warranted.

ABBIE ROSS: Now continuing on in our Q&A, we've got a bunch of questions here. And we're going to go back to you Dr. van de Berg for this one. We talked about the pros and the positives coming from the vestibular implant. But are there any risks associated?

RAYMOND VAN DE BERG: Yeah, I think the main risk of the vestibular implant is that you have to open the inner ear to put the electrodes inside the canals. And when you open the inner ear, fluid leaks out. And that's really a risk to your hearing.

So the main risk of vestibular implantation is actually the hearing loss. So that's why, actually, we have almost, I think, two PhDs now working on trying to get the surgical techniques improved to make sure that people can get it without losing the hearing.

And in the past, we also developed an approach where you don't need to open the canals. You put the electrodes directly onto the nerves. That was done by our colleagues in Geneva. But the drawback is that-- and the lateral canal and the superior canal, the two canals are very close to each other.

So if you want to stimulate the nerve that when it comes out of the canals, actually, the nerves of both canals already merge together. So you cannot selectively stimulate those two canals anymore. So that's a drawback of that. That's why we still go for canal implantation and try to improve the surgical technique. So that's the main risk of a stable implantation.

And in addition to that, most risks that you have normally with surgery. But actually, to be honest, it's quite a routine surgery, eventually, which is similar to cochlear implantation.

DANIELLE TOLMAN: Now, if somebody already has a cochlear implant, would they potentially be eligible for the cochlear vestibular implant that you guys have been working on in your university medical center?

RAYMOND VAN DE BERG: Yes, could be. Well not now yet because it's research. And we are only allowed to admit at this moment Dutch patients because of some interviews we have to do with them. And it needs to be in the Dutch language. But for the next round, we are also probably open to people from abroad because we want to extend the criteria a little bit. So it might be the case.

But each patient, we need to look, is it really a severe bilateral vestibulopathy? Because you see that in the normal bilateral vestibulopathy criteria, you might still have some function left. And from an ethical point of view, we don't want to damage people further in a research trial.

Maybe if you make the analogy with hearing implants, previously, you only implanted patients when they were really deaf. Now, when all the techniques are better, we also implant patients with residual hearing. And I think that might also be the future for the vestibular implant.

But at this point, we must make for sure-- we first have to make sure that there's really a severe deficit that even if the implant would not work because you cannot predict it yet in all patients, that we don't damage them further by destroying the vestibular system by the implant. So those are a little bit the things we have to think about in the trial.

ABBIE ROSS: Thank you Back to you, Dr. Chiao. There's a question in the chat that asks, "Is there any correlation between vestibular loss and ADHD or maybe any other diagnoses that we see present in children?"

AMANDA CHIAO: I saw that question. And I thought that was really interesting. From a research standpoint, no. There isn't a really established correlation between these two. Anecdotally, probably. I see a lot of children who do have just overall sensory loss, whether it's hearing loss, whether it's vestibular loss.

And ADHD, whether it's diagnosed or not, let's just call it more difficulty with attention. I see that a lot clinically with young children. And it has a lot more to do maybe not so much with a diagnosis of ADHD, a true diagnosis, but more of a overall sensory processing dysregulation.

A lot of our kiddos with hearing loss and then also vestibular loss can sometimes be vestibular seeking. So they love to move. They love to be busy. Or maybe they're the opposite. And they're quite apprehensive to move, in which case I wouldn't necessarily say that the vestibular loss caused that, or vice versa. We don't have the research to support that.

But it makes a lot of sense that when you do have a loss of a sensory cue, whether it's hearing or vestibular, that the overall sensory processing, how a child processes different senses altogether to figure out where they are in space can sometimes be dysregulated. And so if you have concerns about a child who can't sit still or is constantly-- or very apprehensive, sometimes reaching out to our occupational therapy colleagues can be really helpful to provide some functional strategies in the classroom or at home to help regulate those sensory processing cues.

That's my clinical hypothesis as to why I see some of that in children. But from a more scientific standpoint, there is not that established relationship at this time.

DANIELLE TOLMAN: We have another question from the chat that's actually piquing my interest too. But it asks us about the presentation differences between those who have bilateral vestibular loss to bilateral otolithic function loss. Maybe Dr. van de Berg, you can start with that. What does that look like for somebody with otolithic loss versus bilateral vestibular loss in total?

RAYMOND VAN DE BERG: Yes, very good question because nobody knows the answer perfectly. Because if you look at what is otolithic dysfunction and how does it present, nobody knows. A lot of people have some ideas, or they claim to know the answer. But actually nobody knows perfectly.

And it has to do with multiple things. First of all, how do you reliably test otoliths? Because VEMPs can be abnormal. But the normative ranges of VEMPs are so wide that you cannot really-- eventually, you have to interpret VEMPs more as an on or off mechanism in most of the cases. You have them or not. But does a present VEMP response mean that it's still intact? Because there can be maybe a deficit in otoliths that you just don't detect with your VEMPs response.

So there are many drawbacks in order to make this conclusion. So at this moment, there is not yet a perfect otolithic idea. This is otolith dysfunction. There are people writing papers about it. But there are so many criticisms about it that I think we still need to find some consensus and also know how to even more reliably measure otoliths in order to say this is really associated to otolith, and this is more to canal.

Furthermore, I think it should also be emphasized that if you look at symptoms and quality of life related to testing, there's also not a perfect relationship. So presentations and test findings are not always exactly the same. And that also makes it that if you want to diagnose bilateral vestibulopathy, that's very difficult.

I think bilateral vestibulopathy, I'm quite convinced, it's much more common than you would find in literature, to be honest. But there are often missed from the patients

where it was found. It's been more than 30 months to get to the right diagnosis on average.

So that already says how difficult it is. And it has to do with the different clinical presentations. So for instance, as you maybe remember from the beginning, that bilateral vestibulopathy can be caused by a lot of disorders. So it means that patients can have vertigo or might have had vertigo and get bilateral vestibulopathy. But there are also patients who never had vertigo but still have bilateral vestibulopathy.

So the clinical picture is so different so much between patients that it's really a difficult diagnosis to make. So if already bilateral vestibulopathy is difficult to make based on the clinical presentation, let alone that we talk about otolithic bilateral vestibulopathy.

But this is something, in our opinion, that needs to be investigated further. We recently published a paper about detecting VEMPs in multifrequency testing so that you test VEMPs at nodal frequencies. And then we found out that the otoliths are actually quite still giving a response at least in patients with bilateral vestibulopathy.

So what does it say? Yeah, we don't know yet. But it's at least a very interesting thing to find out for the future.

ABBIE ROSS: Now, I have a question for both of you. In terms of patients who have some sort of bilateral loss, whether it's partial or complete, what words of encouragement are you providing to people, whether it's moms and dads of children or adults to, I guess, give them hope and guidance in living as, quote unquote, "normal of life as possible"? Dr. Chiao, we'll start with you.

AMANDA CHIAO: Yes, I'll speak from the pediatric side. We don't typically-- because a lot of our children that we see have other comorbidities like a new diagnosis of hearing loss, we take a different approach. We really want to emphasize the importance of hearing for language and speech and language development.

From a vestibular standpoint, the children have an added benefit usually. This is going to be them relying a lot on neuroplasticity and their other cues-- so vision and

somatosensory-- to help them be functional and, what I would tell parents, to be an everyday kid, whatever that looks like for them

And so when we talk about counseling with parents about this, I usually talk about how there is a disruption to the vestibular organs. But we have the benefit of a really young smart brain. And the only way to keep that young and smart brain going is to give it input. Don't stop moving. So we really try to give parents the hope that we want their kids to run and play and be very active because that's the best medicine that we can do for the vestibular system in a child.

We also talk about the benefits of vestibular rehabilitation. And we spin it of saying, this is a really fun time with the physical therapist. They're going to be running and jumping and hopping. And a lot of times, that's very uplifting for parents, especially coming off of a hearing loss diagnosis because sometimes the vestibular loss diagnosis is invisible.

And we don't usually get that sometimes with hearing loss. And so they're actually quite-- I've had really good parents say this is positive. We know something's wrong. And we can help fix it. And I said, yep. And the best medicine for a kid is to be a kid. Get them out there. And we want to just do it safely.

ABBIE ROSS: I love that. Dr. van de Berg, what about you?

RAYMOND VAN DE BERG: So yeah. I think we always start with, you're not making this up because many patients took a very long time. And all of a sudden, they really start thinking, am I crazy or not? Because I have problem with my eyes, and my eye doctor says there's nothing wrong with my eyes.

No, of course not, because the eye doctor tested your eyes when you were sitting still. So your vision is normal. I went to the neurologist. He tested everything. They said there's nothing wrong with my balance.

So I think those patients, when they come to us, they have already tried to find a diagnosis even for such a long time that they really are doubting themselves, am I just making this up? No, you're not making it up. So we really tell them and explain them

that your eyes are linked to your vestibular organ, and your balance is also affected by it.

And most of the time, they're already so happy that they finally get a diagnosis that they understand what's going on that the counseling is really important. That's why I just want to say. And it's really underestimated.

So we have for each patient one hour of which half an hour is for history taking and physical exam. And then they already had the vestibular testing. And then almost half an hour, we spend only on counseling, just to make sure that the patient understands what's going on.

And, well, based on the feedback, they're very happy with it. And they finally understand what's wrong with them. And then they go to what is possible. And that's, of course, not a very nice conversation to say. There's nothing too much possible. But most patients are really very happy that they finally get the diagnosis. And at least also their environment will more understand them. They can show what there is. They show brochures. They can tell them what is the problem. And then they feel more hurt by their environment also.

DANIELLE TOLMAN: Patient validation and education is just so big and a common theme that we've heard all throughout this week. By day 4, I shouldn't be surprised on how fast these hours just fly by. But I just want to say that we're so grateful to have both of you here today to share your expertise and knowledge. It has been a wonderful hour of just pure learning. And we're so excited that you are here with us. Thank you so much for your time today.

RAYMOND VAN DE BERG: Thank you for the invitation.

AMANDA CHIAO: Yes, thank you so much.

ABBIE ROSS: Such wonderful contributors to not only our conference but just the vestibular world in general. And now, as every day, we're going to hand it off to our patient panel led by Heather Davies and Patrick Parkinson. And I think Dr. van de Berg

gave us a great segue into this segment in him talking about, did you ever feel invalidated by any of the providers perhaps that you initially saw? Patrick, let's start with you.

PATRICK PARKINSON: Yeah, I'd say absolutely. And I talked about some of that yesterday. I lived with Meniere's disease. A lot of the talk on vestibular hypofunction is relatively new to me. But for my physician, the regular diagnosis for Meniere's disease comes with a handful of treatments.

And when those treatments didn't work for me or didn't really get me where I needed to go, I felt like the rest of my experience was somewhat invalidated, which was a lot of dealing with the crazy cycle of stress and symptoms. And once I was able to break free of that immediate diagnosis and find new tools to help manage stress and help just be overall more healthy in general, was able to dramatically improve my symptoms, so.

DANIELLE TOLMAN: Can make a big difference with your journey in recovery and finding that sense of understanding what's going on and finding that path forward. Heather, what about you? Have you ever had a similar experience?

HEATHER DAVIES: I have. It's unfortunate. But yes, I have. I have found that-- well, through the doctors talking, I think that we need to lean a lot on therapy more than it's actually encouraged. And I like to use it loosely, the abuse that I received from some of the doctors and the less empathetic approach would have been better off for me if I was encouraged to see a therapist to deal with my anxiety and things with those new diagnoses than to be talked down to and treated less than.

So that's tough. I hear that a lot in the vestibular community. It's very sad. But it is part of it, unfortunately, until you find that right match, so.

ABBIE ROSS: Absolutely. Finding the right care team can make a world of a difference. I hope you both have a great session. Thank you, audience for--

HEATHER DAVIES: Thank you.

ABBIE ROSS: --sticking with us.

PATRICK PARKINSON: Thanks so much.

HEATHER DAVIES: Thank you. Hello. Well, 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 disease and vestibular migraine in 2016 and 2017. And I am super excited to be here on day 4.

PATRICK PARKINSON: Great. Thanks, Heather. Yeah, and my name is Patrick Parkinson. Live with Meniere's disease for just under 20 years now. Originally diagnosed when I was 15. I'm also a VeDA ambassador and also the owner of My Meniere's Coach, which provides resources and support to those living with Meniere's and other vestibular conditions.

And you're more than welcome to learn more about that or reach me directly on my website at mymenierescoach.com. And as always, doing my best to keep track of all the awesome questions that you all have been asking throughout the week. And I'm excited to chat with our panelists here today.

HEATHER DAVIES: Yay. Well, let's head on over. Today our panelists are Kalyn and Lynn. And I will introduce Kalyn. Kalyn Asher lives in Texas with her husband Greg and two dogs, Macy and Milo. Kalyn owns two advertising agencies that support businesses with - excuse me, with media buying and planning.

In 2009, she started having issues with her vision and balance. Her stress level was high. And after several months of bumping into walls, having difficulty riding and driving, walking while turning her head, she started seeing doctors.

For four years, Kalyn met with three neurologists, one ENT, two eye doctors, and finally a neurotologist specialist. There were multiple MRIs, a lumbar puncture, and many other tests. The neurotologist finally diagnosed Kalyn with, I'm sorry, bilateral vestibulopathy. It is believed that Kalyn was given gentamicin during her C-section in 2004. And this may have caused damage to her inner ear.

PATRICK PARKINSON: And Lynn Johnson's life became unbalanced, Thanksgiving of 2015. She had been feeling off and out of the blue, woke up with imbalance and loud tinnitus in her right ear. As days passed, her symptoms continued to get worse. Five months and four doctors later, she was diagnosed with autoimmune ear disease and bilateral vestibular hypofunction.

Her symptoms include bilateral hearing loss, oscillopsia-- I'm not sure if I said that right-- or jumping vision and imbalance. Lynn says that if she had been given the correct diagnosis in the beginning, they might have been able to save her hearing.

Lynn is a VeDA ambassador because she is passionate about spreading awareness, educating, and advocating on behalf of patients like herself so that misdiagnosis like these can be prevented. She currently helps facilitate the Autoimmune Inner Ear Disease Facebook group.

HEATHER DAVIES: Welcome, ladies. Hi.

KALYN ASHER: Hi.

LYNN JOHNSON: Hello.

PATRICK PARKINSON: Hi, Kalyn. So good--

KALYN ASHER: Hi.

PATRICK PARKINSON: --to see you.

HEATHER DAVIES: Yes, nice. Well, let's just jump right in. Kalyn, really briefly, can you tell us about your vestibular journey? And how did you find out that you had a bilateral vestibular hypofunction?

KALYN ASHER: Yeah, it was a really long journey and very stressful for four years. So for some reason, it didn't start until 2009. And my daughter Reagan at that time was five. And so for five years after that C-section, somehow I was OK, didn't notice anything. And then out of nowhere, I was just-- I couldn't walk straight. Bumped into walls. People thought I was really drunk or something. And it was crazy.

So I went on the journey with all the doctors trying to figure it out. And it got exhausting, just trying certain doctors and then going to test. And they're just throwing their arms up. And what ended up ultimately happening after four years of all of these doctors and tests was, oddly enough, going back to the very first doctor I saw, which was an ENT, who put me through around of tests and just said, I really can't put my finger on it, I don't know what it is. He believed me, which was good.

He handed me a card of a specialist at UT Southwestern who said-- he goes, I really don't think you have this. I mean, I just can't imagine. Only 10% of people have this. I really don't think. But he's got the spinning machine. And he's the only one in the area who can really test for this. But again, I don't think it-- so then I spent that four years going down all these other paths.

And that's all I had left. I had nothing else to go try. And so it took months to get in to see this doctor. And I did. And yeah, he knew immediately what it was. And he did all the tests. But before that, he saw me walk up and down the hallway. And I explained the story over and over and over again. And he's like-- yeah, it was great.

So then it just, I knew-- at least I knew I had an answer. Then it was doing the exercises and going to therapy and getting stronger and understanding that sleep is by far the most important thing to let my brain rest. If my brain doesn't rest, then my eyes and my feet just continue to work over time, trying to keep me upright.

So without having both sides of the inner ear-- the hairs on the inner ear are gone. So I just have a hard time staying straight up.

HEATHER DAVIES: Oh, I can't wait to hear more about your story. Lynn, what about you? How did you find out that you had bilateral vestibular hypofunction?

LYNN JOHNSON: Boy, I would have to say that the initial diagnosing period was the scariest. And it's the hardest part of this journey for all of us because so many practitioners don't know about vestibular disorders.

But it began in 2015, where, literally, I woke up. And my hearing was gone. I had loud tinnitus, but my balance was off. And it felt so spontaneous. It wasn't emergency. But I immediately contacted my PCP who referred me to go see the ENT that day. And when I went to ENT, measured the hearing loss and put me on a low dose of prednisone. But something was off with my walk. I couldn't walk. But that wasn't addressed. The hearing loss was the emergency.

But anyway, make a long story short, I had to go back and forth to the ENT. And finally, the PCP suggested I see a neurologist because I was having problems balance walking. Couldn't stabilize my vision. The neurologist-- as many have said, my journey, I know, is echoed by many-- said there's nothing wrong there. But she did suggest vestibular rehab.

And I went there and got-- I went to a new ENT. I happened to mention my symptoms and my frustration. You talk about being invalidated by your doctors. But as an African-American woman, I'm used to being invalidated and dismissed, especially in the medical times where I have to advocate and search for myself.

So I began to search and look for information. Also being a biologist and having some medical background, I began to search my symptoms myself. And that's how I found VeDA by coincidence. But I began to then say, oh. I began to see this was on the vestibular realm. But at the same time, the ENT that I saw literally said to me. I just don't know what this is. You need a second opinion.

And I happened to also at the same time mention it to one of my dear sisters at church. And she has Meniere's disease. And my symptoms mimicked hers. And she said, I want you to see my ENT. As soon as I walked into his office, he knew. He said, I know exactly what you have. And he sent me for vestibular testing.

So at the-- so all these things were merging together-- the rehab, the testing, the new ENT. And I also got a rheumatologist. And what happened was when the testing came back, my rheumatologist communicated with my new ENT. And they put it together. AIED BVH.

But it was a long journey. And I think what's important is the reaching out. Not only did I reach out as far as researching for myself to validate what I had. But I also expressed it and spoken to not only my medical care providers but to my friends, my community because it was her that gave me the referral. So it is very important that even though we're feeling silenced and muted, that we express ourselves and we gather the information for ourselves.

HEATHER DAVIES: Can I ask you, Lynn? I know a lot of people struggle with that. They do struggle with verbalizing to friends and family, especially when it first starts out because they don't really know what's going on with their bodies. How did you communicate that with your friend, that you were having issues? Or did you know about her Meniere's diagnosis?

LYNN JOHNSON: I did not know about her Meniere's diagnosis at all. It just so happened. Oh, she has dizziness and vertigo too. That was communicated. But to be honest with you, being a biology teacher in nature, I don't have a problem expressing to others what I'm feeling. And I don't feel all the time that it's necessary.

I believe people actually see what I'm going through, the difficulty in walking, because they always go, are you OK? You're looking a little drunk and tense. So as a matter of fact, with-- I love baby T-shirt that said, I'm not dizzy-- I'm not drunk; I'm dizzy. That was what I want all the time because people just noticed that my gait is off.

But my expression is-- the best thing I can say is I'm a bobblehead. The bobblehead, how it moves back and forth, that was what I would say. I feel like it's a bobblehead. But people don't have a problem with grasping the real depth and issues, an intenseness that we get because that minimizes really what we're feeling.

So it's hard to really communicate that part of the disorder to people. But I don't find it necessary, to be honest with you, to communicate. If I share with them, I'll just describe my symptoms as best as I can.

HEATHER DAVIES: OK, and Kalyn how about you when it comes to communicating your limitations and their symptoms?

KALYN ASHER: Probably didn't really say much about it in the beginning other to my husband-- had a really off day, don't understand, I feel this way. Just trying to express it to the point where then you start going to doctors. But you didn't know what it was. You really just couldn't-- you really couldn't describe it. Because when you tried to describe it, you're basically telling someone you're drunk. And so then, yeah, it worked. They're like, hey, you can't be drinking at the office. But it looked like I was drinking at the office like going down the hall. Let's see. We lost her.

So anyway, it didn't really talk about it. And then over time, though, after trying to figure out what it is and you hear other people having some issues-- a lot of it was my eyes. And so you really-- so really, I think I'm having conversation. It's just that my vision's been so impacted. And my eyes are having trouble focusing or having trouble seeing.

And clearly in-- so I really went down the eye doctor route for such a long time because it was impacting that. I don't have great vision to begin with. And so talking with other people, just saying, hey, I have these eyes-- my issues with my eyes.

So that just led-- and eventually, over time, you just-- it was what it was. And so being able to explain it to my kids, to my husband, how I really can't walk down these stairs without holding your hand, I need lights on, I can't-- it was scary because I really-- for a very, very long time, I really-- I didn't understand it. But I couldn't function in a normal setting of going up and down stairs and darkness and uneven grass to pavement to floor to carpet, all of that. And it just didn't make sense.

So it's hard to explain that to people. But when you do, a lot of times, the conversations come up with other friends who they have migraines all the time. Or they experience some dizziness. And so that opens the door to, yeah, I have these off-balance moments as well.

But it has been helpful because there was a friend who then led me to one doctor who was a neuro eye doctor for some reason. And it didn't pan out anything other than a spinal tap for me, which was not fun. But at least it led me to yet another source to try to find the solution that led me to the next one and led me to the next one.

HEATHER DAVIES: Did you mentioned that you-- do you have BVD? Maybe I heard that in the first conversation.

KALYN ASHER: It's bilateral vestibulopathy. It's where the hairs on both inner ears are gone. They're just gone. And they won't come back. And that's something you can't see unless someone's in there really digging around or whatever, I guess. And it's the little hairs are what keep you upright. So that's why I was told my eyes-- my feet were tired every day. My eyes were tired every day. And it was my eyes and my feet keeping me upright.

HEATHER DAVIES: I'm sorry, Pat, were you going to say something?

PATRICK PARKINSON: No, no, no, I was just going to-- I mean, there's so much I'm thinking about blown away by both of your stories. And I mean, the first thing is if VeDA is in need of some T-shirt ideas, I think the not drunk is may be a top contender. I've been told that as well, actually, at my high school was the first time it happened. And the police officer at school thought that I was drinking at school, which was not a good situation. But anyways. But I just want to--

[INTERPOSING VOICES]

PATRICK PARKINSON: --both of your stories. I mean, just dealing with something incredibly scary when you first get these symptoms, and you have no idea what's going on with your body. And then you go to your physician. And they look back at you like, I don't know what's going on with your body.

And amidst all of that fear, being able to find it within yourself to advocate for yourself and continue pushing to find those answers in the face of all that adversity, just want to call that out. I'm just blown away by that for both of you. But I want to address some of the questions that are coming out from the users-- or from the listeners.

So one person is asking about any cognitive challenges that you have living with the condition. And what do you do to help mitigate some of that and let your brain get

some rest amidst all the symptoms? Lynn, do you maybe want to start with that? And then we'll--

LYNN JOHNSON: Well, that is a very good question. And yes, I felt like in the beginning of this, is this affecting my memory? I felt like-- but there's so many facets to my condition because of the autoimmune. Like, that is what caused my BVH.

So I'm now on medication. And it's the medication that could also be causing some of the cognitive issues. But yes, I felt like my memory was being affected. So what I did was kept challenging my brain and made sure that I do puzzles and things like that. But not really recently have I felt like I was losing some ability.

But the question did come up in the beginning, like I said, where I was like, oh, I'm getting forgetful. But once I began treatment, it got better. But it is a good question. I think there is a cognitive component to this, the decline. And--

PATRICK PARKINSON: Absolutely. Thank you. Kalyn, do you have any thoughts on that?

KALYN ASHER: Sleep was definitely the most important. If didn't get a good seven-, eight-hour sleep, it was worse the next day. And then if it continued-- I could maybe go a day or two where my nights were kind of restless. And I had two young kids at the time and dogs. And we were up. And I'm running a business.

And so yeah, it was hard for me to really get a good solid night's sleep. And I definitely felt it. So there were times where I had to figure out how to really power down. And so I would go to bed super early. And so like, I'm sorry, honey, take care of the kids and dinner, I got to go to bed. I did notice that getting those solid hours of sleep is what kind of brings me back into somewhat normal.

Another coping thing was one of the first neurologists, still not knowing what was going on, really recommended electrolytes in the morning to start my day. So an electrolyte water, a Gatorade, something. He said it really just-- it will spark your brain and really get it going. So to this day, I still have electrolyte water. I don't drink it all day long. But I

start my day off with it. And it just really-- anything I can do to just get the brain going and making sure it's just firing on all cylinders and I'm able to function.

I think other elements we've used in our home have been-- we installed lighting for the floors. So I'm getting up to use the restroom in the middle of the night. There's a switch. And I don't have to-- all the bright lights will hurt when it comes on all of a sudden. So having at least a light that I can then follow paths and not feel like I'm going to fall is really--

PATRICK PARKINSON: Definitely. Definitely.

LYNN JOHNSON: Can I just add? I think that cognitive issues that came up, especially for me in the beginning, was really tied to the overwhelming challenges it was putting on the brain to deal with the deficit but mostly the stress, the stress of dealing with the chronic condition too. So once you alleviate that, it gets better. You know what I'm saying? So.

PATRICK PARKINSON: Yeah, I 100% agree. People talk about brain fog. And that's something that I get. But I've found that it's definitely tied to my stress and anxiety. And for a while, I thought that it was Meniere's. I was just doomed to have the brain fog. I thought it was just another symptom. But as I started to unwind that stress piece, then things started to clear up.

Kalyn, one follow-up question I want to ask about the sleep because I know that this is something that a lot of people ask about. And one thing that I challenge with, that I find myself being challenged with, and I know a lot of others do as well, is sometimes when you say, OK, I have to get sleep tonight to be able to perform tomorrow, you put that added pressure on yourself. And it makes it harder to sleep. I go through it almost every night. So I'm wondering if you have any specific tips on things that you do to make sure that you get that seven to eight hours of sleep.

KALYN ASHER: A lot of it is definitely whatever people need. Like, I definitely need the quiet space. I need the dark room, you know? I don't need my dog jumping up and down on my bed, I don't need the kids coming in.

So it is sort of like, hey, keep the dogs out, keep the kids out. give me this night so I can make it for the next couple of-- the next couple of days. Because sleep is also super important, knowing that I'm a snorer-- I snore. And I'm like, OK, that's keeping me awake at night. So what do I do about that?

So a couple of years ago, I went to a sleep apnea place. And originally, the first thing, he tested me for that. And they're like, nope, you're fine, you're fine. And I'm like, OK. So now I did score pretty high on sleep apnea.

So just biologically, I am just waking up throughout the night and don't even know it sometimes. So now I have mouth guards that I put in for sleep apnea to help me, again, try to get through that full night and getting the full solid sleep that I need. So if it means that I have to come home early, missed out on something at night, then that's just what I end up doing.

Sometimes now it makes me wake up pretty early in the morning. And I function. And I'm learning that new super earlyness and maybe go to bed earlier. But it really is making sure you understand your patterns of, I need darkness, I need quiet, I need non-interruption. Or it could be soft music for you, whatever it is.

PATRICK PARKINSON: Excellent. Thank you. Yeah, that's great advice.

HEATHER DAVIES: Yeah. I have to say, Kalyn, when you were talking about the nighttime, one of my most difficult times with balance is at night, whether that's out in the community. And my daughter who's 10 also knows this. So if I'm walking by myself, she even just having her loop her arm in mine is enough stability to allow me to continue walking.

And then at home, we have very-- it's almost like the old alarm clocks with the red lights, that if I can wake up in the middle of the night and everything's dark and focus on one thing in that room, I can walk. Even if my eyes don't move, I just focus on that one thing, I can walk to where I need to go. And those are little tips that I have found walking in the dark because I'm very unstable. That's where I am-- where my balance is the worst, so.

KALYN ASHER: It is when your family knows. And again, it's hidden. No one really remembers a lot of time. And so it really took several years and repeating situations where we walk out of a volleyball gym one night. It's dark now. We've been there all day. And all of a sudden, you walk out, and it's pitch, black dark. And like, I don't have my phone on me to try to turn a light on. But even then, that's not really a lot of light to try to-- and you're walking on grass.

So I just remember the time when my daughter did immediately-- just, it became intuitive then to turn and give me your hand because she knew automatically I wasn't going to be able to see very well, walk very well. And so it's going to be those close family members to really explain what you're going through, really talk through how you feel and what's happening and why.

And we can't even understand it. But it's just knowing that, yeah, I'm not going to be able to walk very well at dark on grass. So thank you for remembering to put out your hands. Appreciate that, you know?

PATRICK PARKINSON: Yeah, yeah. And this makes me think of another question. Just, what other coping strategies do you two use when you are out in public spaces to help manage things and--

LYNN JOHNSON: Oh.

PATRICK PARKINSON: You can share if you want.

HEATHER DAVIES: Go ahead, Lynn.

PATRICK PARKINSON: Yeah, sorry. I didn't mean to confuse you there.

LYNN JOHNSON: Did you ask me?

HEATHER DAVIES: Yeah, go ahead.

PATRICK PARKINSON: Yeah, go ahead. No, you're good. You're good.

LYNN JOHNSON: Oh, I'm sorry.

PATRICK PARKINSON: No problem.

LYNN JOHNSON: Well, I use it all. Meaning, in the beginning, I had to use a walker. I have a walker. I moved to a cane. Now I have-- my family and my friends know I cannot walk long distances. No matter how much I do, long distance walking is just not in me.

So when we go on vacation, I have a transport chair. I refuse to change my quality of life, so I actively seek accommodations. I have to get closed captioning if I can, hearing assistive devices. I use my husband's trusted arms when necessary, like you guys were talking about. My twin sister, I use her to be my voice, her arm, my cane my, whatever.

But I would just say, I actively accommodate what I need. I also find it important to help with my balance. Some days is bad, some days is good. On the bad days, when I know I'm slipping back, I do grab my activator polls because they help more with almost giving me a rehab again with my positioning. So I do not hesitate. And I'm talking to everyone out there, do not hesitate, even if it's visible like a walker that visualizes your disability, just get it to make your life more easier and livable.

The other things that I-- other tools that I use is that it is good for you to have a support group to verbalize and to just join in community about what's happening with you. But those are the tools that I have found that help me have to express what's going on with me to others. So that's something that has helped me in my day to day living.

PATRICK PARKINSON: Yeah.

HEATHER DAVIES: Lynn, can I ask you something about those support groups? I know a lot of people attend them, but there's a larger group that don't. Because I think some people are apprehensive that they're going to get in there and not want to say anything. Can you elaborate on how-- say, if someone was to show up at the group, how were they welcomed or what is expected of anything?

LYNN JOHNSON: Well, I been with my group for several years now. But the first thing that happens, you really don't have to say anything. I belong to the Monday Night

support group led by David Morel, who is the volunteer coordinator for VeDA. But we meet every second Monday of the month at 7:00 PM.

And it's really for any diagnosis, but the first thing that they will do is you introduce yourself and you state where you're from and what your diagnosis is. And whatever question you have on your mind, we all talk and give our opinions and share our journey. But it's such a welcoming community. And we share information, tidbits, tips, tools. But it's some place where you can regularly go to make forged friendships and get advice and it's very welcoming. So--

HEATHER DAVIES: Absolutely.

LYNN JOHNSON: --it's like a family. As a matter of fact, I've made several friends not only with David, but with participants such as Deborah Lansing. And now I have become very close just through meeting in that group once a month. And I've been very faithful and been attending that group for over five or six years now.

HEATHER DAVIES: Oh, awesome.

LYNN JOHNSON: So--

HEATHER DAVIES: That's great. And there are--

LYNN JOHNSON: --they see me at my worst. And even where I am today, because I've been diagnosed eight-- I'm thinking, it's going to be nine years in November living with this. And it feels like yesterday at some time, but it's been nine years. And that group has really helped me cope to make me know that I'm not alone.

There are others that are going through this. And it's very valuable. So to all of you who are out there feeling alone, you're feeling discouraged, join a support group either in-person or virtually. Because as I said earlier, reaching out-- God has a way of using people to help you. So it's very important to be a part of a community.

HEATHER DAVIES: Yes. And VeDA's got a load of support groups. I mean, there's all different times of days and hours. And I know there are reminding us that we do have

an exhibitor section in Whova that does have the support group. So be sure check on it. It's great, and it's just a bigger part of our vestibular family and community. And they get it. They understand what we're going through, and we need that on this journey. I mean, our friends and family don't necessarily always understand, and it's good to have those people to lean on. So--

PATRICK PARKINSON: Absolutely. Yeah. And Kalyn, I'm giving you a chance to chime in here if you have any input on coping strategies that you use in public.

KALYN ASHER: I think I definitely have Flashlight always with me just in case. And then I end up looking like the old person who is-- I shouldn't be having to hold on to every rail. But when I'm going up and down stairs, I'm doing the-- and I definitely have to go down more slowly. And I'm sure people are looking at me kind of crazy. I'm like, whatever, I got to have the rail. I'm not going to try to brave it and go down without a rail.

For me, I know it's not-- if I'm going to fall, it's when I'm going to fall. And the older I get, I think I get more concerned on my body and the toll it's going to take. I have fallen. I have broken my wrist. So I am making sure that I am wearing the right shoes when I'm out that are going to help me and I'm not going to trip. So I do look for those things just to make that life easier.

And again, watch out for those times when my brain is tired at the end of the day. And when I think-- I haven't figured out yet how to walk on a sidewalk next to somebody. I don't know how to cope-- I don't know what strategy to use. And it can be a wide sidewalk. But for whatever reason, it's a narrow lane for me, and I'm just going to bump into them or the bush or whatever. So I have to walk behind somebody, and it's just a weird-- it's a weird feeling of-- and it's hard because you're trying to explain-- you're having a conversation.

You could just be on a walking path with a friend and you're just talking and you're just walking, and it doesn't-- for me, I don't even have to turn my head. It's just the straightness of it. But having that person or something right next to me makes me want to go the other way. So I haven't figured out a coping strategy for that one yet.

Or the driving where you feel like the cars are really coming into your lane. And they're really not. I mean, they're not. I mean, yes, sometimes people do that. Sure. But you feel like it all the time that any minute, this car is switching lanes over into me. And so I think I drive definitely a little bit more tense and I'm just more alert on it.

My eye doctor just recently prescribed me a pair of glasses-- I wear contacts, but it's a pair of glasses to put on at night or after work. So my eyes are tired during the day. I've got a 45 minute drive home from work, a lot of back roads, windy, twisty, dark, two-lane roads.

And I noticed that by the time I make it home, the drive itself wasn't bad and it's actually pleasant. The intensity of which I'm holding my steering wheel to make sure a deer is not popping out or I'm not-- oncoming cars and bright lights, all of it is all affecting me. So I'm just exhausted by the time I get there.

So he gave me a prescription glasses that I put on to help open up the light a little bit more where I can see on the road. It really gives it a little bit more clarity of signs that are coming up that I could read faster. So I'll probably more likely to catch an animal across the road or something like that sooner.

So it just gives me a little bit more comfort. So I've been testing those out so far, working pretty well. So just whatever you can think of that would it make your life easier to have, just asking doctors or asking people, what do you do? So someone has that sidewalk answer, I'm all for it.

PATRICK PARKINSON: Yeah. What I'm hearing is this continued theme of continuing to advocate for your needs no matter what it feels like, no matter what it looks like.

KALYN ASHER: Yeah.

PATRICK PARKINSON: But I also want to call out that there is some apprehension around that too. There's feelings of being self-conscious. And I've heard this from other Vestibular warriors, and myself included. With many years ordering at a restaurant, I still

to this day feel self-conscious when I say, hey, can I get no added salt? and all these things. But at the end of the day, you got to advocate for your needs and--

HEATHER DAVIES: Absolutely.

PATRICK PARKINSON: There are some other questions here about just how the condition impacts your ability to do everyday tasks, including work, but then also just other chores like cooking and doing laundry. Is that something you two could weigh in on? And Lynn, maybe we'll pass it over to you.

LYNN JOHNSON: Yeah. It has affected everything, every aspect of my life. Well, I can't work anymore, so I had to retire, which very early in the beginning. She was like, stress it's got to be one of your biggest triggers. So she said, we have to eliminate the stress. Being an inner city high school biology teacher was very stressful.

But so even adjusting mentally and emotionally from not having a job-- I thought-- and I'm saying that because I'm clarifying this because in the beginning, I thought BVH took away my purpose. So that's not the case though. What I found out through going through this journey is that your gifts-- I thought BVH stole my gifts. Like, what am I going to do now? I can't teach. I can't drive. What's my purpose?

But your gifts are never-- they don't leave you. You are still who you are in spite of this disease. So I'll get back to that later maybe on another question because that's deep. But I can't do a lot of things. I had to-- I remember very early in this journey-- because I do want to tell everybody.

In the beginning, my rheumatologist said to me, this has got to be the worst of it. Even though it's not going to leave you, you're never going to go back to where you are now. So that was something that I held on to. But in the beginning, I couldn't even cook. I couldn't do laundry. I couldn't, couldn't, couldn't.

But eventually, what I did was I made up my mind that I was still going to have a life. So I made room maybe 5, 2 minutes. I would cook by sitting on the stool chopping up

onions. And believe me, those meals took forever. A meal that was prepping for 20, 30 minutes turning to a meal that was prepping for an hour, two hours. [LAUGHS]

But I was determined to still do it. I still wanted to show up as a wife. I still wanted to show up as a mother. I still wanted to show up as a productive member of society. So even though I can't drive-- Uber has become my best friend. Now as I said before, I now am chauffeured as the queen I am.

[LAUGHTER]

But laundry, I couldn't do for a while, and I couldn't do it. But as you challenged the system and you keep moving, eventually, those daily routines can come back. But not to the normal way that you used to do it. It's a new way of performing those things. Even driving. Even though I feel like I can drive today, I choose not to. But it hasn't even affected me spiritually. Those are the physical things.

But emotionally and spiritually, as I mentioned about purpose, spiritually, it has been more of a positive effect because it has made me more of a thankful person, a more gracious person. But every aspect, it affects us. And we do have to make up our mind and our discipline as to whether or not we're going to keep our quality of life or not. And we have to push forward so that we can still complete and show up like we're supposed to.

HEATHER DAVIES: So true.

PATRICK PARKINSON: Yeah.

HEATHER DAVIES: So true.

PATRICK PARKINSON: So much in that. And--

HEATHER DAVIES: I know.

PATRICK PARKINSON: Yeah, on the identity front, I totally hear you there. But I agree. I left work in January of 2022 after a career. And yes, had that same kind of identity crisis and feel like I'm coming out of it now. But agree on the spirituality side and saying, my

life before when I look back on it, it was defined by my ability to please my bosses and do this work. And now, I'm exploring like a whole other different level of--

LYNN JOHNSON: Yes.

PATRICK PARKINSON: --who I am and who I want to be as a person. And I see that ability to take on these challenges and find the lightness and find those gems in these dark times and situations in both of you. So yeah. But Kalyn, can you weigh in on that too, just how it has affect maybe your work and everyday tasks?

KALYN ASHER: Yes. I would say, obviously, near to the disability level that Lynn's been going through. So for me, it was, can I run the company, the company that was running at the time? Can I keep our clients, our staff? Are they going to lose faith in me as a leader because I am having these issues?

There was a lot of travel back then. Not that the travel-- although being tired and dehydrated from travel, walking off of a plane and going down the whatever, when you leave the plane and-- the jetway, again, I found myself bumping into the walls. It was like it was too narrow. But I'm like, I'm trying to stay up to pace with everybody else and just blend in and act normal. But I know I'm going slower and probably keeping you from you being able to get to whatever appointment you're getting to.

So for me, it was more of, am I going to be able to do the things with my kids, go to the theme parks? Yeah, I can go. A little over stimulation by the end of the night. And can I ride some of the rides that I used to ride? No. I think it was, what am I going to give up more in the things that I loved? I'm a huge-- love to snow ski. I'm terrified of doing it now thinking of the falling.

And I think for me, those were the goals of getting back to, can I do that again? Can I actually go snow skiing? And did, and it was great. But it's scary. It's scary to think that the things that I used to be able to do, now I just would shy away from them. So now I just try-- again, I try to get as much sleep as possible so that I can take on each one of those challenges and try to get back to that normal life that I felt was a very active life as well.

HEATHER DAVIES: Have you had a serious fall, Kalyn?

KALYN ASHER: I had had a fall. I was gardening and happened to pick up an old light in a ground that had a bunch of bees, yellow Jackets or something, a nest underneath, and I didn't know. So as they come after you for interrupting their home, I'm wearing flip-flops. And I'm outside, and I'm trying to run backwards, which then I'm on grass. And I'm now in my driveway. I just fall backwards.

So that wasn't a fall because of the vestibular issue. However, could I have been a little bit more aware of the shoes I was wearing, the fact that I was like near grass versus concrete. So when I did fall backwards and put my hand down, I did break the clavicle in my hand. And it took a month to figure that out too.

So that then just-- every time I try to-- I do try to fall, I try to think of which hand am I reaching out, with my left hand my right hand? Or to prevent falls, I try not to have things in my hands. And now we're right now trying to sell the house, we have had for the last 13 years, and it's got stairs.

Every time I tried to go up and down those stairs, I would grab things for the kids and take them up. Going up wasn't as bad. But going down, I couldn't hold on to everything and go down stairs. And so I'm hands on a wall, hands on a rail. Now we've moved into a house with zero stairs, no stairs.

And the poor builder, when we said, I want you to pour the sidewalk up from the driveway to the front door, no stairs. Like, just straight. And he looked at me like crazy. I go, I'm telling you right now, I know later on it will be worse. So just eliminate any stairs in my life as much as possible. So we try to do things like that. Just crazy.

HEATHER DAVIES: I understand that so much. We lived in a stilt house when all my symptoms came on. And I remember having to sit on the stairs and scooch down each step in order to just-- yeah. And I had many falls too. [LAUGHS]

LYNN JOHNSON: Can I just share with you where--

HEATHER DAVIES: Please do.

LYNN JOHNSON: My fall was a big turning point for me. It was about maybe 10 months after I got my diagnosis. And I fell-- I had a very bad fall in the shower. And when I fell, I was-- there's a lot of symbolism in what I'm telling, you I was naked. And I couldn't-- I hit myself so bad I couldn't get up. And you know that TV commercial, I've fallen and I can't get up? That was my cry. I had to-- I cried out for my soul. I can't help.

But I was at a point in this journey where I was so discouraged. I felt so alone. I felt so helpless. Nothing was helping. Nothing was working. I was still dizzy. I was vertigo, spinning. And I cried out, help, I fell. And no one can heal me even though my daughter was home. And my daughter heard me finally, and she came. And she lifted me up. I was so embarrassed because I was naked. I felt I couldn't even help myself.

And stood there crying. I prayed out to the Lord, help me. What's going on? And I looked out the window. And when I looked out the window, I saw the leaves from the tree fall off and hit the ground. And the spirit told me, Lynn you fell, but the leaves fall too. And the trees come back full and beautiful. So that spoke to me about my--

HEATHER DAVIES: Oh, you're giving me chills.

LYNN JOHNSON: --condition.

HEATHER DAVIES: [LAUGHS]

LYNN JOHNSON: It spoke to me about my condition. There was nothing really wrong with the inner core of Lynn. This is just something that was happening to me. But that the inner core-- I was going to come out better and more beautiful. And I held on to that. And that was the turning point in the beginning of my recovery because I began to accept the condition. And we all have to get to that place. So for me, the fall was very pivotal. It was a spiritual awakening that I had to accept what was happening to me.

And it was a part of God's plan. So I just also wanted to add, you said, the tools to help me. One of the tools that is very important is that I heard my therapist tell me, keep moving. There was just-- you could only take therapy up to a point. At some point,

there's nothing else that can do for you. And I was at that point. And my therapist said, but keep moving.

So one of the things that I have done is I have remained active by doing exercises. And it might be hard for us to do, but I found the virtual community of fitness challenge with Fit To Dance, which you can access online. And I started doing it in my chair, and now I'm actually dancing and balancing--

PATRICK PARKINSON: Love it.

LYNN JOHNSON: With that-- [AUDIO OUT] about my fall.

HEATHER DAVIES: That is fantastic. Thank you so much for sharing that story. I think that as we're coming to a close, I think that is the perfect quote-- one of the perfect closing statements we could have. And your encouragement and inspiring story, Lynn, just makes me want to hear more about your journey. Kalyn, what is something that you would like to tell somebody starting out in their journey towards recovery?

KALYN ASHER: Don't be afraid of it. Don't be afraid to talk about it. This is just who I am and what I live with. Interestingly, we obviously shared with beyond family members and friends. And my brother-in-law out of nowhere ended up having some symptoms and some issues, and he just recalled the conversations that we'd had over dinners. And he's like, who did you go see? How did you get this diagnosed?

So if people don't know about this at all, it's not like you start off every conversation with it. But just basically sharing that part of you that makes you a little different. And yeah, it's not quite visible sometimes, but they just remember. A lot of people-- because it's not maybe happening to them right now, but they do. And then they hear somebody else having this and they immediately call and go, hey, what was that doctor's name that you used? What did you do?

So I like helping people in that way, connecting them, networking them, making sure they know about VeDA. That has been a big one as well. Trying to just even-- once I finally knew what I had, just trying to go online and go, well, there's got to be something

out there that supports this. I don't know what it is. And mine was such a hard one because it's not many years, and it's not a specific. And so I'm really trying to-- I had to read all through back.

And 2013, back then is this really the right place for me. Do they really-- do I have what they really support? And that's really what it's been. So people have come to me and asked questions. I've sent them-- like, here's the site. You need to just go check it out. Or I definitely share the Facebook post with friends who talk about ongoing migraines and issues that they have. And say, you might find some help in here. So to me, those have been the best resources.

HEATHER DAVIES: Wonderful.

LYNN JOHNSON: I'm sorry, I just--

HEATHER DAVIES: Please do, Lynn.

PATRICK PARKINSON: Go for it, Lynn.

HEATHER DAVIES: I can listen to you for another hour. Go ahead.

PATRICK PARKINSON: Let it rip.

LYNN JOHNSON: I just want to say to the people who are going through this to help them is one, celebrate all those wins, small and large. And also, have a thankful and gracious heart and love those people around you. But I want you to be joyful and hope. There is always some goodness around you. And be patient in this. Be patient in this journey. Expect God to show up. Expect good things. Expect a miracle.

And be faithful in prayer and meditation. That has helped me. Meditate, pray on the good things. Don't emphasize the bad. Look at what you can do. Don't look back at what you can't do and what you was, but look forward and expect something good to happen in spite of our dizziness. In spite of the spins, just enjoy the moment, be present, and just be thankful for what you have.

HEATHER DAVIES: Wow, thank you, Lynn. Thank you for that closing. Yes, thank you Kalyn also for sharing so much of you.

KALYN ASHER: Yeah.

HEATHER DAVIES: We appreciate you guys being here so much. And sharing so much of yourselves. Thank you.

KALYN ASHER: Yeah. Thanks for having us. Yeah, appreciate it.

HEATHER DAVIES: Wow, I could listen to Lynn all day. [LAUGHS]

PATRICK PARKINSON: I'm blown away by both of them. So--

HEATHER DAVIES: I know--

PATRICK PARKINSON: --good.

HEATHER DAVIES: --both of them. Well, yes, all this amazing information. Thank you, our panelists, Kalyn and Lynn, for sharing so much of your journeys today. Cynthia, Elizabeth, Tyler, and everyone behind the scenes. As a reminder, you can purchase a lifetime access to the recordings and transcripts of this entire conference at vestibular.org/lrl-recordings. And you can help make sure that the valuable information that's presented at this annual event remains free to everyone by making a donation at vestibular.org/lrl-donate. These links are also listed in the description box below.

PATRICK PARKINSON: And I just wanted to thank, again, the James D. and Linda B. Hainlen Discovery Fund, and the University of Minnesota Department of Otolaryngology, Abby and Danielle, and their physical therapy practice balancing act rehabilitation, and the Academy of Doctors of Audiology for supporting this amazing conference.

HEATHER DAVIES: Yeah. Well, tomorrow is our last day. I hope to see all of you there. [LAUGHS] See you guys tomorrow.

PATRICK PARKINSON: Thanks so much, everyone. Bye. Thanks, Heather.

