

# Life Rebalanced Live 2025

## BEYOND MEDICATION: EXPLORING ALTERNATIVE TREATMENTS FOR VESTIBULAR MIGRAINE

LIZ FUEMMELER: Good afternoon or evening, depending on where you're tuning in from And welcome to the first day of the Vestibular Disorders Association's fifth annual Life Rebalanced live. I'm Dr. Abbie Ross. I'm a vestibular physical therapist, a neuro clinical specialist, founder of Balancing Act Rehab, co host of the podcast Talk Dizzy to Me, and a proud board member of VeDA. Thank you all for joining us today. I'm so excited to kick off this week. Before we begin, I'd like to thank our sponsor who has made this event possible year after year. The James D. And Linda B. Hainlen Discovery Fund and the University of Minnesota's Department of Otolaryngology have generously supported Life Rebalance Live since its inception in 2020. A special shout out to Jim Hainlen, who inspired this event by holding his own vestibular conference in 2018 and 2019. Having experienced vestibular symptoms firsthand, Jim cares so deeply about supporting people on their vestibular journeys, and it was important to him to not only educate people about vestibular disorders, but also to provide a platform where people can connect. Now I'd like to introduce my co host, Dr. Liz Fuemmeler, a vestibular audiologist with Interacoustics and co host of the podcast in A Dose of Dizzy.

LIZ FUEMMELER: Thank you, Abbie, and hello everyone. We definitely want to say thank you so much to anybody that's contributed to this conference in any way, especially those at VeDA, donors, staff and volunteers. With their contributions, we're able to put a live version of this conference on at no cost to our attendees, which is amazing. If you want to gain lifetime access of these presentations following the live event this week, we will have them available for purchase for \$60, and your financial support helps support VeDA's continued mission to spread vestibular awareness.

ABBIE ROSS: Now, before we get started, I'd like to direct you to the poll questions. If you haven't answered them already for this session, please do so. Also, feel free to talk amongst yourselves in the chat and please put any questions that you have for today's speaker in the Q and A section and we'll do our best to incorporate as many as possible.

LIZ FUEMMELER: And just a reminder, although you're going to be hearing from healthcare professionals all week and especially today, none of the information that you hear should be taken as medical advice. Please make sure to consult with your healthcare provider before you make any changes to your treatment protocol.

ABBIE ROSS: So today, day one, one of my favorite, favorite, favorite topics. We're going to be talking about managing vestibular migraine. And when you think of managing vestibular migraine, you may think about medication as part of the treatment plan. However, today we're going to go beyond pharmaceutical interventions and focus on lifestyle modifications, nutraceuticals, exercise, neuromodulation devices and more.

LIZ FUEMMELER: It is my pleasure to introduce our guest speaker, Dr. Trupti Gokani. Dr. Gokani is a board certified neurologist, health and mindset coach, ayurvedic expert and master practitioner of neuro linguistic programming. And she has dedicated her life to developing a unique blend of ancient wisdom with modern approaches. Welcome, Dr. Gokani.

TRUPTI GOKANI: Hello. Thank you so much for having me. And thank you for that lovely introduction. So excited to be here.

LIZ FUEMMELER: Yes, we are so excited to have you. And we thought we could just start at the very basics so you can explain to us a little bit about what is vestibular migraine.

TRUPTI GOKANI: Sure, I'd love to. So when we think about vestibular migraine, we're looking at a profile of an individual that actually either currently has migraines or has a history of migraines and has this added vestibular component. And so these vestibular symptoms, and we'll go a little bit into what those symptoms are, they're often associated with some of those migraine symptoms. And the migraine symptoms, just to remind everybody, are symptoms such as having a throbbing headache, usually on one side of the head, experiencing some nausea, light sensitivity, sound sensitivity. So these are those kind of migraine features that are alongside the vestibular features. And we're looking for at least half of those vestibular episodes to be associated with some of those migraine features, at least a couple of them. And when we look at vestibular features, we're looking at symptoms such as the vertigo, dizziness, all of the vestibular kind of components that we've talked about or has been discussed in the vestibular component of imbalance. And the vestibular migraine is kind of this combination of both. It's experiencing vestibular, experiencing migraine. And at times the symptoms may be a little bit more migraine, at times the symptoms may be more vestibular.

TRUPTI GOKANI: That's what makes this a little complicated and a little challenging. Yet there are a lot of great treatment options. And now

there's a lot more awareness of this condition and we have a lot of tools to improve it.

ABBIE ROSS: Can you talk to us about the timing of symptoms? Is there a certain duration that people should be aware of in terms of their episodes? And can you clarify if a headache or head pain is necessary to make the diagnosis?

TRUPTI GOKANI: Yeah, great question. So the symptoms can vary from, as little as five minutes up to 72 hours. That's what makes it a little tricky, is that you can have this kind of range in terms of duration of symptoms. Yet when it comes to defining, you mentioned, defining that migraine component, a headache is different than a migraine. And it's really important to understand the difference in this. When you're looking at migraine, we're looking at disability, how much someone is struggling with the discomfort. And it's usually moderate to severe intensity. And I think about it's a pain that's stopping you from functioning, preventing you from really embarking on your day. Oftentimes individuals need to lie down, need to disconnect from the computer, from work, not make those phone calls. It's really disabling. It's not the same as just having a headache. Headaches are important to acknowledge too, because so many people struggle with headaches, yet migraine is different. This is

going to really impair one's functioning and impair one's well being. And that's why we really need to take it seriously.

LIZ FUEMMELER: Now, one thing we've learned just hearing your quick background, is that you're really big into the holistic approach of migraine. So before we get into some of those details, can you talk us through about what maybe a typical treatment for vestibular migraine as far as medication and what some of the limitations are of that?

TRUPTI GOKANI: Yeah. So, because this is a interesting complex array of symptoms that oftentimes we're trying to discover what aspect of the nervous system or the body as a whole is involved in this process of vestibular migraine, treatments can be challenging in terms of when a doctor is meeting the patient for the first time saying, okay, we're treating the vestibular component, we're treating the headache, are we treating the nausea, what component and what meds do we use? So as a neurologist, most neurologists tend to work with the migraine treatments that have been effective. So most of them, when they see this vestibular migraine individual will start with the traditional triptan medications for the acute attacks. And the triptan medications we're thinking about, there's so many out there now, many of them are generic, which makes it a lot, more accessible to obtain these, sumatriptan, known as Imitrex,

Rizatriptan, Maxalt, Sumatriptan, Zomig, maybe some of those more first line treatments that are used for the migraine component and hopefully can help the more vestibular symptoms also. I know a lot of physicians are trying the CGRP antagonist, the calcitonin gene related peptide antagonist that block that neuroinflammatory peptide that seemed to wind up the brain and maybe a part of that component.

TRUPTI GOKANI: There's been studies showing that there may be CGR receptors in the inner ear and within the neurons that kind of affect that inner ear. And so it's important to know that this CGRP peptide that many believe is kind of located at the trigeminal ganglion outside of the brain, may be actually working inside the brain and we can modify the pathways within the brain too from an external source. And then when you think about preventative medications, we look at a lot of the standard, again, medications that have been used for migraines, so beta blocker medications, tricyclic antidepressants like amitriptyline, seizure medications such as Topamax, topiramate. And a lot of it, like we do in migraine, is looking at the person as a whole saying, what specifically are we helping with and what else can we help with in the system? So for example, someone has a hard time falling asleep and has weight that's balanced, maybe amitriptyline may be beneficial because amitriptyline, one thing about side effects, can increase weight, yet it can help sleep

sleep. So we want to kind of think about the whole person when we're looking at medications and different tools, but everyone is individualized and it's all depending on the person.

ABBIE ROSS: Now how long do you recommend a person trials traditional medication routes before understanding whether or not it's part of their treatment concoction? And also, what do you say to people who say, I'm so sensitive to medications? Go ahead.

TRUPTI GOKANI: Yeah, hear that a lot. Hear that a lot. And my heart goes out to so many individuals that struggle with vestibular migraine because it is oftentimes individuals that have had migraine for many years and this vestibular component comes on. And we'll go into the whole, I'd love to go into Eastern medicine thoughts about it and vestibular looking at the functional medicine approaches to it. Western is still not quite there with really fully understanding it. And what we do know is that, your first question was how long do you try things? Because I'm a very holistic practitioner, I don't jump oftentimes to pharmaceuticals right away. I often try to improve the system first and if needed, will then use a pharmaceutical. And what I will encourage individuals to do is first start looking at some big things. But just to answer your question about how long to try things, if a medication is started, I often, for the preventative



daily medications, give it at least a couple of months if it's tolerated, and for an abortive as needed medication, at least two tries because the symptoms can differ based on the attack before we kind of finalize or decide to move to something else.

TRUPTI GOKANI: And it's hard for me to not recommend lifestyle changes with the prescriptions if I'm going to recommend a prescription. I don't think I ever recommend a prescription without something else in terms of a lifestyle, we can go into that. But I often find it's important to know that it's a holistic approach that's really important to help this complex condition.

LIZ FUEMMELER: I know in my market, many of the patients that I see, neurologists will recommend starting with some supplements before getting into prescriptive medications. And I think we actually had a question from the audience about they took magnesium for their vestibular migraine. So are there any other supplements to be aware of or to talk to their doctors about before using prescription, prescription medications?

TRUPTI GOKANI: Yes. Yes. I'm a big fan. At my early days, I had run an integrative center where we were doing IV nutrient therapy and following

something called the Myers Protocol, which was a Magnesium B vitamin CoQ10 kind of IV infusion for individuals with migraine, vertigo, fibromyalgia, all sorts of different kind of kind of neurological and pain syndromes. And what I discovered during that time is that there is no question that during an acute attack of a migraine, of vestibular symptoms of any kind of neurological event, the mitochondrial system is being taxed. And those mitochondria, which are those little kind of energy centers within the cells that are manufacturing ATP, which is a really important kind of energy molecule, we'll call it, to help our systems function, we utilize the mitochondrial energy, the ATP, very quickly and rapidly when we're in stress. And very often the base to create ATP are a few things. The nutrients, magnesium, riboflavin, which is B2. And we also need coenzyme Q10. We also need oxygen.

TRUPTI GOKANI: I need to breathe. And it's this chain called the electron transport chain. Won't get into too much hardcore medicine here, but what we're looking at is for us to create ATP and for the ETC, electron transport chain to work, the nutrients and oxygen are kind of base ingredients. And so some of my favorite supplements are magnesium in a chelated form, magnesium glycinate, magnesium malate, magnesium taurate, different versions of magnesium. Looking at that in addition to riboflavin, in addition to even CoQ10 and for some activated CoQ10

ubiquinol. So if something is not working, I'd like to encourage individual to look into the type of supplement they're taking, the quality of the supplement they're taking, the dose of the supplement they're taking and do they need a combination? Because the mitochondria often needs not only nutrients yet sometimes a few of them in addition to us taking a breath, dropping the shoulders and remembering to breathe. Because if we're on and constantly on in terms of stress, we're going to use up those nutrients a lot faster. So they don't work as well. And I saw that in the practice too that individuals sometimes came in for IV infusions, very often under acute stress. And so it's important to remember to manage the stress so we're not dependent on the nutrients, if that helps.

ABBIE ROSS: Absolutely. I think I need to take a nice breath right now and relax.

TRUPTI GOKANI: Let's all take a breath and drop our shoulders down away from the ears. So easy to kind of get into a state which we can talk about, share with you more about how I go into that when we get there. But yeah, but the big nutrients, magnesium, magnesium B2, CoQ10, those are probably the three, I'd say the trifecta are most important because they feed into the mitochondria, the energy centers.

LIZ FUEMMELER: What is your take on neurotoxins? For someone in our audience asking about Botox?

TRUPTI GOKANI: I'm a big fan. I know it sounds strange. Here she is, this eastern medicine practitioner that does Ayurvedic medicine in western. But I have to tell you, my first paper back in 1999, 2000 was on the safety of botulinum toxin for headaches and safety and efficacy. And I was looking at the data, 25 years ago there wasn't as much data as there is now. There wasn't the FDA approval that we have now for chronic migraine. And it's interesting, the great thing is when I looked at it back then, I was curious, I was thinking, well, why does it help headaches? How could it possibly be helping headaches, those that have headaches? And in that early paper, I found that, the data was leaning towards this CGRP peptide way back in the day. And this interesting phenomena of when the Botox is injected, it tends to reduce CGRP. And yes, it does release a reduced acetylcholine, which then reduces the contractions of the muscles with those that get the botulin toxin to reduce wrinkles. Yet it's also working on different things like CGRP.

TRUPTI GOKANI: So there's a pain component along with that muscle relaxation component. And CGRP is working more on different neurons, like sensory neurons. So my answer is I like it because I see why it works. I

want to know why. We as providers should always take extreme caution when we're recommending different pharmaceuticals, injections, neuromodulation devices to understand what is it doing to the system, is it safe and does this tool make sense? And when you look at botulinum toxin, what we're looking at is this injection is blocking a peptide that very often, if you're making a lot of CGRP, it actually comes from the gut. The gut actually is the home of CGRP production. And what I find is that CGRP in the gut, if the gut isn't balanced, which a lot of people, in fact, I think pretty much everyone I see has a gut imbalance, then they're going to make more CGRP, wind up the trigeminal nervous system, and wind up that whole kind of activation system which activates the migraine center. And so what we want to do is think about, okay, if we can't then work on the gut right now, if we're not ready to do that yet, maybe the Botox can be something that can reduce that peptide and it's locally administered and doesn't interact with other medications that are being taken.

TRUPTI GOKANI: So I have been a fan for a long time because I started injecting back in 2000 and 2002 or 2003, got FDA approved for chronic migraine in 2010. And I think if done wisely and safely under the right practitioner, I would highly recommend someone that is an injector that knows the trigeminal vascular system and understands migraine. I wouldn't recommend going to a local spa or going to a dermatologist. I'm

just going to tell you it makes a difference if you have someone that understands pain, you can really get nice results in addition to doing some other things, such as lifestyle changes we mentioned.

LIZ FUEMMELER: Yeah, and of course, we've been alluding to it because it's the topic of the day. We want to look into these lifestyle modifications. We know that that's been a long time part of the approach for vestibular migraine. But we also know there's been a lot of changes in society recently. Just like increase in screen time, COVID, being out, working from home, food changes that everybody's eating. So given this shift that we've seen in society in the last few years, what lifestyle modifications are you using the most for your recommendations for your patients?

TRUPTI GOKANI: Yeah, and this is so important because I was practicing before COVID for many years and then took a little bit of a breather, focused on coaching, went back into clinical practice and I was kind of shocked after pandemic what happened. The number of vestibular cases went up dramatically. And I thought, what is happening? How come there's so many individuals that have this now where I wasn't seeing it for a good decade before? And I do think these are some of the key components you mentioned here is spending time and we were all

transitioned to the screens. We had no choice to stay connected, Zoom with our friends and families, Zoom with work, getting on. The computer was part of just connecting and we as human beings need to connect. And so this kind of interaction with technology in general, no question has activated our nervous system, hasn't given us a sense of off time. We spend so much time on, we've forgotten how to turn off. And then of course, social media, getting on social media on our off time. And it's concerning, it's extremely concerning because our nervous system isn't meant to take in this high level stimuli at all times.

TRUPTI GOKANI: It really isn't. And I'm in my 50s and I think back to the days when we didn't have the Internet. I know it sounds like I'm ancient, didn't have the Internet, we didn't have cell phones, we didn't have all this technology. And when I go to work, go to work, go to an office, finish, come back home, and then there was nothing. It was just me and myself and we had a few channels on TV to watch and that was about it. So the sensory overload, it's pretty dramatic. And I don't think the young individuals see it as much as some of us that are older because we see the difference between these two worlds that we've lived in and now live in. And so my encouragement is to know, number one, that there are tools that we can now go to, to break away, yet know that even making sure you don't have like, the blue blocking glasses and you're not kind of being

mindful of how much screen time, dimming the lights at night, even the lights in your home, all of this is going to tell the nervous system that you're awake, tell the adrenals to stay on, sometimes encourage the system to believe you're in danger when danger isn't present, this is all going to affect the adrenal stress response system, which is part of a lot of work I do with functional medicine.

TRUPTI GOKANI: And that's going to unfortunately worsen migraine and worsen the vestibular symptoms. That also plays a role in gut health, because I have this model I call the three brain model, where it's top down, bottom up. And the first brain is how we think and how we perceive stress. The second brain is how we feel the enteric nervous system. The third brain is the gut microbiome. And what I find is that if one is stressed and on and always turning on the nervous system, there's studies that actually show a stressed mind can actually impair your gut and create dysbiosis, abnormal bacteria and pathogenic bacteria in the gut by having the mind that's stressed. We're not even talking about what you're eating yet, we're just talking about what you're seeing and thinking. So COVID itself had its own effect on individuals, yet I think those that were more affected tended to be individuals that most likely had guts that were a little bit imbalanced. We can get into that a little bit, and more likely had a sense of stress and a perception of stress that was



turned up a little bit more. And I think it's important to acknowledge this is something that can be modified and shifted to improve the overall condition.

ABBIE ROSS: So let's talk about that person who has sensitivity to light, whether it's stores, on their screen. Aside from a couple of the tips that you mentioned there, what kind of conversation are you having to get them to better tolerate these types of situations, especially situations where they might not be able to just avoid it and actually do want them to even avoid it all of the time?

TRUPTI GOKANI: Right. And if you don't mind, I'm just shifting to ayurvedic medicine for a moment because it'll help me, as I say, I answer everything with a template of that knowledge and it'll help the listeners if I explain it. And I'll go into some more fine tuning because then everyone can kind of think where I'm thinking from. Right. And so ayurvedic, I'll just jump into that. I got into it way back when I was a first year medical student. A student because I was struggling. I had severe sleep issues and I did not want to take the prozac that the doctor recommended for me and he told me I was depressed. I said no, I'm not depressed, I just can't sleep and I don't know why. And it'd been three months. I was going to quit medical school and instead I ventured into the bookstores and I

found these amazing books on eastern medicine. And I knew nothing about Eastern medicine. I am Indian of origin but grew up in Chicago. So I did not have this knowledge base. It wasn't like this was something that was introduced to me at a young age.

TRUPTI GOKANI: So I was coming into this desperate, just looking for some answers, didn't know how to get better, didn't want to quit medical school. I worked hard to get there. And these books are really interesting. And so Ayurveda, what it means A-Y-U-R means life and Veda's wisdom. It's a wisdom of life, wisdom of longevity. 5000 year old science. And it's interesting because Ayurveda was basically a science that was discovered based on observation. It wasn't based on data and clinical studies and trials. It was, let's observe people, let's observe nature. Let's see what we kind of understand from those that we observe. And how can we make sense out of imbalances that occur in well being. And so what was realized is that there's three types of individuals. There is what we call the Vata type and there's, back up a second. All of us are made up of five elements. Air, space, fire, earth, water. Every living thing, be it a plant, be it an animal, be it a person. Five elements. Air, space, fire, earth and water. And what happens is we're born into a type, okay? And the air and space type, if you have that kind of those elements that make up your nature, you're going to be what we call the Vata.

TRUPTI GOKANI: VAT. Vata type. The Vata type is kind of someone that likes to move and go and do and kind of tends to be very active, active in the mind, active in the body, likes to talk a lot, like to be the life of the party. Vatas are very enthusiastic, like to take on different projects, very creative, very artistic, musical. If that's you, you're the Vata types. And Vatas are oftentimes thinner in their frame or have longer bones and tend to not really care for a circadian balance. Like don't to follow the rhythm of nature, they skip lunch, skip dinner, go to bed late. Different things. Like to be kind of in their own nature and their flow, great when it's in harmony. Okay. The Pitta is a fire and water type, a little bit more determined kind of type. Bae, competitive, muscular, can see how things need to be done. You think of fire giving the ability to see, kind of get that done. You can, great directing things? That's the Pitta. And the Kapha is the earth and water type. Bigger structure, bigger bones, little bit of a bigger body. Tends to be more calm and grounded. Kind of the opposite of the Vata. Doesn't like to be around a million people. Likes to be one on one, more intimate. Maybe be home on a Friday night reading a book versus being out at an event.

TRUPTI GOKANI: So in general, what happens is life, because life is such, we get pulled out of that birth nature. We get to Vata, to Pitta, to Kapha.

When you asked about light sensitivity, light affects the eyes, Pitta imbalance. When you're too fired up, it's going to give you more light sensitivity. So before I try to change the environment and change up, which I do want to do, I'm going to first ask about the person and say, are you feeling very Pitta? Are you really irritable, because Pitta is fired up. Are you angry? Are you maybe having challenges with reflux or nausea or diarrhea? Those are Pitta symptoms or rashes. So we're looking for, is there an energetic shift into that state? And what I try to do is kind of educate people to really think about that first. Because if we can start to get to the core of light sensitivity, we're not expecting all those tools out there.

TRUPTI GOKANI: And not that those tools aren't helpful, they're super helpful. But a lot of times people, I see those tools haven't worked or they stopped working. Like how come all these things aren't really working for me? What do I need to do? And I say, instead of looking out there, let's look in here a little bit. So that's my approach that take people in and I try to go into those three. Does that make sense? I went through it really fast, but it's a 5,000 year old science and it's really big. But just wanted to give a taste of it, a flavor of it.

LIZ FUEMMELER: Absolutely. And I can see how that would change how

you look at and manage different symptoms that you're hearing. Do you find, I know there's a lot of alternative treatments and therapies and exercise, do you find that there's some that work well, regardless of that core being that everybody is, or does it really depend on that type of person and what symptoms?

TRUPTI GOKANI: Yeah, I think everyone, every single individual would benefit from turning off technology, getting to bed and having a nice deep sleep pattern, because deep sleep and getting especially into deep sleep not only helps reset the hypothalamic pituitary adrenal axis, it also helps reset the microbiome and detox the liver. That's good for everybody. Practicing some breath work I think can help everybody. Of course, there's different type of breath techniques depending on the person. The Kapha might want to do a little bit more of an activating breath. They're a little bit more of the withdrawn types. They're the ones that are a little bit more prone to congestion and depression and heaviness. The Vatas, quieting the mind, really quiet breath work and the Pittas can kind of do in between. But breath work in general can be super helpful for all. And then really setting a circadian pattern for everybody. Turning off at lunchtime, stepping away from technology on the computer, sitting down to have lunch, sitting down to have dinner, making sure it happens around the same time every day. These are things

that everyone, if we can start to do that and then extra credit, chew your food really well.

TRUPTI GOKANI: We're often rushing and the salivary amylase is manufactured that, the ideal is a take 32 bites for every or chews for every bite. It can be hard to do 32. You can try it. It's hard, but maybe start with like 10 and 20. You'll be surprised. Some people, they'll tell me, oh my gosh, I just do a few bites and I swallow. Take your time, chew. What happens when you're chewing is simply that your body is starting to acknowledge that you're entering into a calmer, parasympathetic state. The brain can turn off of thinking about all the challenges in the world, which there's many things going on right now. Let's focus on us for the moment. It's not being selfish, it's self care. And start chewing. Get that salivary amylase to be released. When that's released, it'll break down your carbohydrates and then that converts to, that activates your gallbladder to release bile and your pancreas to release its enzymes and your hydrochloric acid release in your stomach. There are so many things that we can do and not get so fancy that don't cost money.

TRUPTI GOKANI: Really just self care. And self care to me is self love. And once you start doing that, it's really incredible how some of those things that didn't work before start working. And that's why I think it's really

crucial to pair things up together and to take a minute, just a few minutes to understand if tools aren't working, because I see so many patients where tools aren't working, let's think about what we can do for ourselves.

ABBIE ROSS: So I love the approach of starting within first and then adjusting outside of within based on your findings. So you start with setting your circadian rhythm, going to bed and waking up at the same time every day, getting that more restful sleep. To the patient who now has done that, what do you say if light sensitivity is still a thing? And actually we have a question about this in the chat, LED lighting is a trigger. What can you do in that case? Do you change the lights? Do you dim the lights? Talk to us about that.

TRUPTI GOKANI: Yeah, I mean, if light is, I mean, light is definitely an important thing. I mentioned that earlier, like the type of lighting, the intensity of lighting, the wavelength of lighting. So, yes, we want to then look at softer lights that don't activate the occipital lobe. And a lot of it kind of really depends on how much of that, I mentioned, that fire state. How much is that person caring? Right. They're really fired up. It's going to take very little to activate the state, which is why I work on that first and then say change the light bulbs. But you can definitely do both.

There's no question. But in terms of what type of lighting, some of those very simpler things is just dimming. Start with dimming the lights, don't have the lights on bright. I moved into a home where honestly, the mud room has fluorescent, those bright lights I walk in, I hear the buzzing, I see the light. I can barely even just walk in for just a moment going in and out of that mud room. So just softening, softening, dimming, having lamps, having lighter lighting, natural lighting.

TRUPTI GOKANI: So I'm in a room right now. I have a light behind me because of the recording. But normally it's just the natural light on my face. So it's important to acknowledge that connecting with that circadian rhythm and having that natural light is very good for the nervous system. So taking away the artificial, bringing in more natural, dimming it down, changing some of the bulbs out, and moving to softer lighting can make a huge difference on that visual sensory impact on the nervous system.

LIZ FUEMMELER: I thought I would step in a little bit to vestibular rehabilitation therapy. So this is something that is frequently recommended for patients that are experiencing vestibular migraine. And first of all, I wanted to ask about the timing of this. When do you recommend rehabilitation therapy happening in your treatment plan, and is it at the start? Should they wait and get migraines under control? And



what does under control really look like to you?

TRUPTI GOKANI: Yeah, typically I'd like to make sure that they have the right protocol of, we think of Maslow's triangle, the survival mode. Let's make sure we have the right medications, the right tools that are the needed tools. And those might be neuromodulation devices, definitely acute tools and preventative tools that are going to start to kind of stabilize the system. And of course, those supplements we kind of put in there too. And then once we feel that there's some settling and we have those tools kind of shortly thereafter, I think vestibular rehab is great to add on. There's no need to wait too long. I think it's so helpful to pair things together as long as the individual can do both. I don't want to overwhelm anybody. So I'm always trying to make sure we go slowly, methodically, because very often I do know that patients I've had before, they get a little overwhelmed with so many things to do at one time, even lifestyle changes. I'll just mention one or two that I think are key. Here's a med or two, just here, and then maybe neuromodulation device. Okay, let's give this a time.

TRUPTI GOKANI: Let's give it a month or two. Do you feel comfortable? Okay, now let's add on this other approach. So to me, that's very systematic. And then you can observe what's working. If we do too many

things at one time, you don't even know what's working. So sometimes, like, we want to layer things based on just kind of not reducing overwhelm and then making sure that the individual is ready to take on the next. And some patients want to start right away with vestibular rehab and don't want to be on the pharmaceuticals, for example. Great, let's go there. Some, I want to do pharmaceuticals first. So also, I wish this was so easy and cookbook, but at the end of the day, it depends. Oh, evidence. 20 years. It always depends on the person and the person's needs, a person's past history, the person's interests, what they've grown up with, what they believe in, what they think will work for them. That plays a huge role in outcomes. If someone tells me, I actually really don't think yoga and meditation, all that's for me right now, I'm not going to push them on that.

TRUPTI GOKANI: That is not the right way for me to go. Okay, let's focus over here then. And maybe at a later time you'll be open, maybe you won't, that's fine. Or if someone says, I don't want to take, like with me, my early story with my sleep issues, I didn't want to take the Prozac. Maybe there's someone else that would have been okay with that. I want to focus over here. So it's so important. This is where I think the art of medicine is really important, is that we need to take time and start to really get to know the person. I think as physicians, just speaking to the

choir here, you guys all I'm sure agree is that physicians really should be taking time with the patients. And as you're a patient seeing a doctor, make sure you're working with a physician that will listen to you and allow you to just explain what your desires and needs are, what your goals are, not what their goals are, what your goals are. Because that plays a role.

ABBIE ROSS: We always talk about you are your provider's teammate. Like you are a team together to determine the best treatment approach for you. It may change over time. It may look different from person to person, but you are an active participant in creating your plan. You started to allude to this a little bit, but let's talk about some other complementary therapies. So you had mentioned yoga. What about things like Tai chi, acupuncture?

TRUPTI GOKANI: Yeah. The easiest way to approach it is, is looking at Ayurveda, which you talked about and looking at that three brain model I was talking about. And I have an upcoming book, the StressRX, that's coming out in May. It goes into much more detail. But what I'll say is that I looked at patients over 20 years and said, okay, which patients are really doing the best? Which ones are having those outcomes that are just incredible? And I found that they were working on these three brains.

And so yoga, tai chi and all that. I'll share where it fits into this. So the three brains, I kind of mentioned it quickly earlier. I think about it as the first brain, is how we think, how you process stress, how you interact with events around you. And what is your model of the world. And a lot of that is based on your early programming. It's based on those early brainwave patterns with mom and dad. Mom and dad between, when we are between the ages of 0 to 10, if mom is saying, this world is a dangerous place, this world is a dangerous place, this world is a dangerous place, your imprint is the world is a dangerous place.

TRUPTI GOKANI: That is just what happens. And you wonder why you might get more reactive to something that you see or hear. It may be because of the early program. And we just have to understand that's a piece of this. The second brain is how we feel. It's the enteric nervous system. It's the nervous system that's in the gut. So many patients I have met over the years haven't had a chance to express their emotions. Either they've held back their emotions, or if they've expressed them, they haven't been honored. And so it's important to know that suppressing or not having that ability to express and share and even clear emotions that have been, maybe you've held onto for years might have been a trauma or something happened earlier in life can play a big role. Because the vagus nerve basically connects the gut and the brain. The vagus connects

the microbiome to the brain in the head. And what happens is the enteric nervous system, how we feel dictates how much cortisol release we make. And it's fascinating to see that there's more conversation from the gut to the brain than there is from the brain to the gut.

TRUPTI GOKANI: So the last piece of it is the third brain, the microbiome. So fixing the microbiome and diet is a big piece of it too. So what does yoga, meditation, tai chi fit in? Kind of to me fits in in the first and second, though it can help the third, too, because when you're doing yoga, and make sure we're doing yoga the right way, and there is a wrong way to do yoga, I've had patients that have gone into hot, intense yoga classes, back to the Pitta types, not a good idea to be doing hot, intense yoga when you're a fire type, you're going to push your adrenals, run out of hormones. You wonder why you're progesterone deficient and have hormone imbalances and menopausal issues. It's oftentimes because you're over taxing. If it's a Vata excitable individual and you're doing a vinyasa flow, moving a lot, doing a lot of running, that's going to actually activate the wind energy state. I'd recommend you do some restorative hatha breath based yoga. If you're the Kapha that's getting kind of congested and heavy and has more, we call them the sinus system kind of migraines or the congestive headaches, that individual may want to do something in a heated room, may want to move a little bit more, may

want to walk a little bit more, run.

TRUPTI GOKANI: So a lot of the exercises are based on that. So yoga to me it's also based on the typing. That's why I had to kind of give you that background because I never jump right in and say do this. So it's let me get to know you first. Know the person first. And then kind of jump into now this is probably the best technique for you. And then I love tai chi. Huge fan of anything that quiets the nervous system and allows kind of self internal connection. Because the key is to become a really good observer of yourself. How is your neck feeling today? How is your gut feeling today? How is your breath? How is your mind? Be so tuned in so that you know the moment you're starting to get pulled out of alignment, what was it that pulled you? Was it the phone call you just had with somebody that upset you? Was it the food you just ate that kind of got you feeling a little bit irritable? What was it? Was it maybe eating lunch a little too late? And then we can start to then naturally fine tune and then again back to medications and neuromodulation devices and all these things, they work a lot better when we work on that piece.

LIZ FUEMMELER: That's super helpful to hear. And I know especially in talking about the first and second brain, it's really an awareness, it's having that cognitive awareness. So do you find we know mental health is

obviously a huge component of overall wellness. Do you tend to make recommendations in the beginning for behavioral health counselor, therapists or are there any types of mental health therapies that you found to be beneficial to create this awareness?

TRUPTI GOKANI: Yeah, I've been kind of shifting my thoughts over the years in terms of which types of providers are best to recommend for the different patients, because each individual is different. So of course, one of the most important things for all of us to make sure when working with patients that have a history of vestibular migraine is, is there an early childhood trauma, something that should be addressed with trauma informed therapist? There's a questionnaire, the ACE questionnaire, adverse childhood events questionnaire, and really important data around that questionnaire. And it looks at, do you have certain elements in your early life that could signify traumatic events that have maybe had an impact on who you are and this component of pain you're struggling with? And if someone is sharing a little bit, if they're open to even doing that questionnaire, then looking at those numbers and saying for you, I'm going to refer you to trauma informed therapist that can truly help you with understanding, what was that trauma? What experience did that have on you and imprint on you? And then how can we shift you, and help you so you can clear the trauma, so you can clear and improve your

current situation with the vestibular migraine.

TRUPTI GOKANI: When it comes to someone that doesn't have the heavy trauma, working with either a therapist or a coach, I'm a big fan of coaching because that's what I do a lot of. Coach is a little different than therapy. Coaching is a little bit more action oriented. Having a patient reflect upon what they can change, getting them to see their truth, getting them to then want to. You kind of make some steps forward, like, oh, you know what? I'm noticing that this is a pattern I have and this is a pattern I should shift. So let's work on kind of getting that bedtime routine going. And a therapist does do that. But oftentimes a therapist I find that I've sent patients to, and this is shifting over time, tend to spend time talking about some of those early events. And sometimes in some situations I get just a little concerned to make sure we don't hardwire the story or hardwire the event. So then it becomes locked in, something that happened when I was younger. Maybe I had a relationship that was upsetting for me. If I keep talking about it and talking about and talking about it, sometimes it can actually hardwire it and make it more challenging for my nervous system to clear, versus, coaching sometimes goes a little bit more into what did you learn from that experience? How has that experience now shifted you? So it's really important, and a lot of therapists are doing coaching too.



TRUPTI GOKANI: So it's really important to just make sure you're moving forward. So there's that one category of individuals I work with, I kind of find who does. I often use blended because I blend myself a lot of ways. So find someone that does that blended approach. And if I'm not working with them directly, I'll have them work with somebody that can help them with those facets that'll help them, most importantly, clear the emotional baggage that's held in the enteric nervous system, that feeling, the emotional brain, and it carries in the physical body. That's why yoga, practicing yoga clears the physical. When we carry wind, excess wind, fear and worry, that's that windy energy, it kind of goes into your neck and we go into what, a state known as freeze state. Someone is really wind excess. I mentioned that windy kind of personality. But if you're too windy, moving, going, doing too much, skipping meals, talking too much, going too much, drinking a lot of cold drinks, having cold foods, you're known to freeze state. Well, then what ends up happening is your neck gets tight, your colon gets tight, you're having constipation, you're having fear, and you want to kind of start to realize, well...

TRUPTI GOKANI: What triggered me into that state. So it's important that the person is not just looking at that event, but looking at the whole picture of what is that event doing to you now, and work on clearing that.

ABBIE ROSS: So good. I love all the things that you're talking about are really within our control because when we think about vestibular migraine and triggers, we talk about some things that are within our control and some things that are outside of our control. So really taking the helm and changing your life for the better by looking at yourself individually like you're explaining, I think is so, so important. I want to shift gears slightly. It's going to touch on a few audience questions. Can we talk about neuromodulation devices? What are they? How do they work? Are they successful?

TRUPTI GOKANI: I love them. I'm a big fan and I'm so excited. I mentioned how I had gone, I'd stopped practicing, pandemic happened, and then came back to practice again. And what was happening in that time was not only I was seeing this vestibular migraine increase kind of tendency towards individuals coming to me with those symptoms of vestibular migraine, but also the advent of now more and more neuromodulation devices coming to market and getting FDA approvals. And so we've got some of my favorites, and I'm just going to say, based on clinical experience, each one works a little differently. And we want to be really mindful, of course, of how we're using them. So Cefaly, is probably the one that is most familiar to so many because it's been out for such a long

time. And originally it was FDA approved for acute migraine. It's working on the supraorbital kind of nerve. It's that transcutaneous super-orbital kind of stimulation and what it's doing, and think about even Botox being injected kind of in this region, the Cefaly is placed here and it's kind of delivering a certain frequency, which is a little uncomfortable.

TRUPTI GOKANI: I'm just going to share. For those that wear the Cefaly device, you can probably understand where I'm going with this is that there's an uncomfortable feeling, feels like answer crawling kind of up the head, and then there's like the sensation of numbness. And it's a fascinating kind of experience because what it does is over the course of time, it got eventually approved for daily versus using just abortive as a preventative for migraine. It tends to quiet the nervous system. And it's worn for about 20 minutes. And what's nice is that the individual, while they're wearing the Cefaly, I have them because I'm big on lifestyle just take a disconnect from the world and do a little journaling, do a little breathing. Just practice kind of getting connected with self. And that device, what I like to do is to use it and pair it up with the breath. And I find that it itself has an FDA peripheral migraine. It's not approved for the vestibular, it's approved for migraines. So keep in mind much more data around the actual pain component yet it's a nice tool that isn't going to affect the systems, your digestive system, the liver won't be toxic to the

body.

TRUPTI GOKANI: I do like it. I think it's incredibly safe. Gamma core is another one. That's vagal nerve stimulation. We talked about the vagus nerve. It's that nerve that's kind of giving us that parasympathetic response state. It's connecting the gut and the brain. And very often we get so sympathetically driven that we don't turn on the vagus enough. And having that vagal nerve stimulation and using that can actually quiet and help reduce the intensity of that sympathetic drive state that activates the vestibular component. And Nerivio is another one which I think is really cool. That's a remote electronic stimulation and that's kind of working on the ascending pain fibers. And it's another kind of tool. I actually used it the other day because I was moving houses, as I mentioned earlier. And yeah, I had a little bit of a headache the day that I moved and I said, I'm just gonna take a break. And I saw the Nerivio sitting there and I put it on, and it's nice because you wear it for about 40 minutes and it's kind of working all of these different pain pathways that are feeding into the nervous system, feeding into trigeminal vascular pathways and really kind of creating that on state, creating that hyper vigilant state.

TRUPTI GOKANI: So utilizing these, what I love is that in a way, when I talk

about, we talked about yoga and breathing and doing these things to quiet the nervous system down, these are some beautiful tools that can, in a very similar way, quiet the nervous system down. And you can pair all these things together. And I don't like multitasking in terms of working with these devices, but one can. So it is nice to know you can do that if needed. If you're in the middle of a presentation or you have to get something done, and I've seen this where people put on their Cefaly and present or they'll wear the device while they're doing some work. And we have to function as a society and sometimes work has to be done. It's nice to be able to pair these together, and very low in side effects, which is nice. But I will say Cefaly, unfortunately for a good number of patients, there can be a worsening of the dizziness component. I'm sure you've heard that. And I just want to be mindful and careful of these devices. Use them the lowest, lowest kind of frequency, very gently first and just for short duration, just to test it first.

LIZ FUEMMELER: Yeah, that's super great advice and thanks for running us through that because I think there's a lot of different products that come on the market and it can be hard to discern when they're appropriate. And obviously working with a provider is best for that. Quick reminder, we do have some polls posted on the Whova app, so if you haven't responded to them, go ahead and do that. I was going to ask,

there's some questions coming in about light therapies, red light therapy, green light therapy. Do you have anything to say on that or do you ever recommend them?

TRUPTI GOKANI: It's a fun story. The green light therapy. I was actually speaking to a physician who I guess is really familiar with the first researcher behind the green light therapy. And now it's Harvard and Barney Bergstein does a lot of work around it. But the initial, I guess this is the story behind how the screen light therapy was found to be effective was the initial researcher's, brother, I believe, was having migraines and would go out to the garden and sit in the garden and just started noticing that being in this green, really lush green garden, pain started improving. And then the researcher was like, I wonder if green light has something to do with the nervous system. And kind of came up with this idea that green light therapy can help. And so I did have a device at home to try a little bit. I am not sure my thoughts yet. I do think it's a really great concept. I think it would be helpful to have some more clinical data around it. Though I think it's a safe tool to use, I haven't had as many patient responses or feedback as I'd like, so I think I'm still waiting for more data.

TRUPTI GOKANI: But I think it's really beautiful to add that to a potential

tool to use for those that struggle.

ABBIE ROSS: We also have a question in our audience chat about discussing hormonal replacement therapy and especially in the world of women with the changes in menopause and menstrual cycles. Can you speak to that?

TRUPTI GOKANI: Yeah, it's interesting. It's one of the first things I mentioned, the IV nutrition therapy back in the day. I was also, this is like 2007, 2006, 2005 even. I was also studying hormones. And I went to some conferences back, I can't believe 20 years ago on hormones. I mean, it was so apparent, patients are coming to me. Most of them are women, and many of them were telling me that their migraines worsened during or before their menstrual cycle. So I said, there's got to be a hormonal component. This isn't rocket science. Let's figure this out. So I started doing some early training and functional medicine at hormones and how hormones can influence headaches. And I did a small little study in my clinic and I found that, a couple things. I found, number one, and this is, I think, interesting for vestibular migraine that 83 patients I looked at, I wrote about this in the Mysterious Mind book I wrote, which is about 10 years, 10 years old now, I can't believe, but in that book I looked at adrenal fatigue and whether or no migraine individuals had something

called adrenal fatigue is what it was called back in that time.

TRUPTI GOKANI: And we did a four point cortisol testing, a saliva testing to look at how is your cortisol first thing in the morning, how is it at noon, how is it at 3:00 PM and then nighttime? And ideally you want to have this nice beautiful lift of cortisol, wake up energetic, cortisol, drops, drops, drops, and you fall asleep and make melatonin and have beautiful sleep. Well, unfortunately with my patients, 83 of them, 90% of them had either moderate to severe adrenal fatigue. And then I thought, whoa, what's causing adrenal fatigue? And now it's actually called hypothalamic pituitary adrenal maladaptation. Basically, the hypothalamus isn't talking to the adrenals. There's a disconnect and there's a whole story behind that. Fast forward I went a little further and said, okay, we got this study on adrenal fatigue. Now let's look at hormones. Looked at estrogen, progesterone, looked at ratios and found that pretty much everyone I tested had low progesterone levels and was estrogen dominant. There's a lot to package in, but what I'll say is it was fascinating to see estrogen dominance wasn't simply because someone had more estrogen than progesterone. They could have had low estrogen, but they also had very low progesterone.

TRUPTI GOKANI: So their body saw more estrogen than progesterone.



Why is it important? Well, when you're low progesterone, progesterone is neuroprotective. Progesterone works on GABA receptors, estrogen works on glutamate. Estrogen excites the brain, turns on that migraine profile, turns on the vestibular, it turns on the brain where progesterone quiets and calms the brain. And that's why progesterone, theoretically, if taken the right way, can help one sleep. And oftentimes it's used for sleep. So what was interesting at that early time, I said, okay, let's try to fix this because we have this adrenal fatigue issue. We've got these low progesterone, imbalanced estrogen ratios. I worked the compounder for about a year and had all these patients. I started putting them into different hormones. Patients got better, but then sometimes they stopped getting better. They'd start feeling better, for example, on the progesterone, sleeping better, headaches were better around their cycles. Sometimes they just give them two weeks of progesterone per month. Then after a few months they said, now I'm starting to gain weight and I don't know why. Well, because there's a bigger picture to this. With hormones, you need cholesterol to make all the hormones in the body.

TRUPTI GOKANI: It's a precursor all the hormones. Cholesterol converts to pregnenolone. Pregnenolone then goes into one of two pathways. It goes into what we call the catabolic muscle degradation pathway where you're

going to actually move to progesterone and make cortisol or the anabolic muscle building pathway, estrogen, testosterone. And what happens is very often when body is stressed and mind is stressed, we move down into cortisol production and we start to run out of progesterone and we start to get this estrogen dominance. Hope that all makes sense. Talking kind of fast because I know we're short on time. But this is described a lot more in detail in that book I wrote. What I found was that as I started giving hormones, you can't just fix the hormones. I would love to just have stopped there, like back in 2007, but done, figured it out. This is the map. I realized there's more to the story, which is then why I realized the gut plays a role, the mind plays a role. To really get to the root cause of that, all those areas really should be addressed.

ABBIE ROSS: And I know we are running short on time, but because we've talked so much about the gut and the microbiome, any just quick high level things to look into or recommendations you make for your patients to improve their symptoms of migraine, especially vestibular migraine?

TRUPTI GOKANI: Yeah, I do a lot of testing. I do find that food intolerance testing is very helpful. I find that microbiome testing is helpful, of course, under a practitioner that understands how to interpret that, how to apply it though from a bigger picture just know that the gut microbiome, the

100 trillion bacteria are playing a huge role in how we think, how we feel, how we perceive. So we do not want to skip the component of the food. Ayurveda goes into the sixth tastes in every meal. Sweet, sour, salty, bitter, pungent, astringent. Very often American food, Western food is very sweet, sour, salty. We don't get the bitterest pungent astringents. So start thinking about adding more complexity, adding more interesting things, adding a spice or two in your meals, making sure you're eating at the right times each day, getting lunch in every day, and just be mindful of chewing and some basic things before we get fancy. I do have a stress quiz. I'll just say on my websites, this is just a stress personality quiz where people can kind of get a quick sense of are they windy, fiery or earthy.

TRUPTI GOKANI: They're welcome to go there, Trupti Gokani MD and do that stress quiz. But what I'll find is that because we don't have enough time to go into it, the gut to me is the part where physicians, I'm encouraging them as much as I possibly can as I speak, to speak to physicians at conferences, to spend some time here with their patients because it is challenging to choose change all of these dynamics of lifestyle. It may be challenging to get the breath work and yoga in every day. Yet we're humans and we're going to need to eat. We all need to eat. And when it comes to even what you're sipping on and drinking the

tea and what kind of liquids we're bringing in to what kind of food we're bringing in, the microbiome is dictating a lot. And if we don't improve that, unfortunately, most patients have imbalanced gut microbiomes that I'm testing and most have what we call leaky gut syndrome that needs to be repaired. And if we don't improve those pieces of it, unfortunately, again, back to those tools, the tools aren't going to work very well, and that's what breaks my heart, is that sometimes these things are simple.

TRUPTI GOKANI: They're not that hard. I promise. Everybody start simple. Start with just chewing, start with sitting, start with making sure you get lunch in, then go into the fancier things. What can I add in? What are the things that are processed I can take away? And I won't go on the whole conversation on processed foods, but I'm very, very, very concerned about that piece of it because if we can't shift that over there, I think we'd all be a lot healthier.

ABBIE ROSS: Very, very good points. And even migraine aside, to be thinking about all these things for our overall wellness. Another question from our chats, going back to supplements, a couple questions, actually, one, what is your take on products that are marketed as all in one supplements? Instead of taking things individually, it's kind of a package deal. And also, how do you determine appropriate dosages for

supplements for people?

TRUPTI GOKANI: So this is coming from someone who had an all in one in my clinic. So I did have an all in one. It was only because it was hard to find these very specific types of magnesium and B vitamins and ubiquinol and petadolex that from Weber and Weber. And so I did have an all in one, I will say that. But I don't have it anymore. I did have it. If it's one that you can feel comfortable that these ingredients, like I was a neurologist practicing a clinic, seeing patients doing IV nutrient therapy, I really knew what was in that combination. You just want to make sure who's sourcing it. It's not some person on Instagram that's selling it. I'm sorry, no disrespect, but you have to be careful. Be very, very careful, because it may seem really great. The package may look really pretty and nice, and what's in there may not be that helpful and you're spending money on just really nothing that's going to help you. So just be mindful of who's manufacturing, what their background is, what their story is, what research they've done on it, and have they really gotten great feedback.

TRUPTI GOKANI: Is it, are these testimonials that are really true testimonials? We can all have kind of manufactured testimonials. I just want to be people to be careful because I've had a lot of people that have

just thought that they were taking the right kind of magnesium. They take it for 10 years and then they come to me and then I change it. So how come that's something that's working? Well because you were taking one that was from a manufacturer that wasn't USP certified, GMP certified, that wasn't well certified. And so sorry to get in my soapbox about that, but it's really important. It's very important. So all in one, if it's the right individual that's creating it, I do tend to now because I don't really love any all in ones personally that I found out there. So I tend to tailor and say this kind of magnesium with this kind of B2 and this kind of ubiquinol. Because the reality is some of us have different reactions. If your gut is a little bit more sensitive, magnesium may lead to diarrhea, may lead to loose stools. So you may need to tailor the dose.

TRUPTI GOKANI: If your gut isn't as sensitive and you have maybe a lot of anxiety or sleep issues, a higher dose magnesium in a certain form may be more helpful for you. So, it's really hard to do all in one. And then what was the second part of your question? I'm sorry, I was going on down there.

ABBIE ROSS: How to determine dosages.

TRUPTI GOKANI: Dosages, yeah, kind of along with that. So, like, for

example, I would have someone do a magnesium quiz. How many magnesium deficiency symptoms do you have? Same thing with either. I was talking about progesterone. Like, dosing progesterone. Oh my gosh. There's some that dose 400 milligrams a day. Some of it does 10 or 5. Some do topical, some do oral. I mean, there's so many types. But again, how many symptoms do you have that are suggestive of that being the key component to work on? So if I have a lot of progesterone deficiency symptoms or magnesium deficiency symptoms, I might take a little higher dose to help me with that. And each one of these pieces, though, I'm just going to encourage everyone, do one thing at a time. Just do one thing at a time. Give yourself the opportunity to respond. It can take, just like a pharmaceutical, it can take sometimes up to 2 months, sorry to say, to get the full benefit.

ABBIE ROSS: Man, we could go on and on about this topic. There's so many other questions that we just didn't have time to get to. But great questions. Thank you to our audience for participating. Dr. Gokani, thank you so much for your time today. You are an absolute pleasure and so knowledgeable about this very popular and common topic that affects so many patients in our population. So thank you for being here.

TRUPTI GOKANI: Well, thank you for doing the work you guys are doing. I

mean, this is such an important area and us as practitioners can't do this without the support of all of you to just increase, acknowledge the awareness of this disability, of this diagnosis. Because I think there's a lot of physicians still are not even making the diagnosis vestibular migraine. So I'm going to empower the people that are listening to share it with their friends and family and their physicians and let them just know that this diagnosis is a true diagnosis. It needs really proper attention and care and all of us are going to do our best to help. And thank you guys for doing the work that you're doing. I'm really grateful to be here.

ABBIE ROSS: Thank you so much. And for our audience, if you'd like more from Dr. Gokani, check out the banner that just popped up below or today's agenda. Also, we'll try to get those, the website that you had mentioned in today's talk into our chat so you all can find Dr. Gokani and continue your learning. And now we'd like to pass the baton off to Heather Davies and Holly Smith. They will be facilitating our patient panel today.

HEATHER DAVIES: Hi. Thanks, Abbie and Liz. Hi. My goodness, I'm so happy this is recorded because I want to go back and take so many notes. Thank you so much.



ABBIE ROSS: There was a lot packed in there and so much room to go. Hopefully you both can speak on the patient side of things and get to some of these topics that we didn't get to in this morning session.

HOLLIE SMITH: For sure. I love having a front row seat to all of this and thank you ladies, so much.

HEATHER DAVIES: Yes, thank you. Hi, everyone, I'm Heather Davies. I am host of the Meniere's Muse podcast and I too have Meniere's as well as vestibular migraine.

HOLLIE SMITH: Hi. And I'm Holly Smith and I co host the VeDA Retired support group, which we actually have this afternoon after today's session. And I also have vestibular migraine as well as superior semicircular canal dehiscence. So it's great to see you, Heather. And I'm so excited to meet our panelists today.

HEATHER DAVIES: Yes. Today we'd like to welcome our patient panelists, Alicia Wolf and Ashley Pernicano. I hope I pronounced that correctly Ashley.

ASHLEY PERNICANO: Pernicano. Yes.

HEATHER DAVIES: Great to have you guys here.

ASHLEY PERNICANO: Thank you for having us.

HEATHER DAVIES: So exciting. We're excited to talk about this. And Alicia, I was wondering if you could briefly describe your vestibular journey.

ALICIA WOLF: Yeah. So this year I will have lived with vestibular migraine for nine years. I started to have symptoms, I would say... Actually this month I started to have symptoms and I was having symptoms of dizziness and just feeling lightheaded and off sometimes. I would often forget what I was going to talk about or what I was trying to say. And as that would happen, I would go to see all these doctors and they would tell me, oh, you're just anxious or you're stressed or you need more sleep, or you just getting over this cold. And that's what it is. So I got passed around to a lot of different doctors. And this happened over the course of seven months. And over that course of seven months, I slowly got to, my symptoms got worse and worse and worse. And so I started to have vertigo attacks where I would be driving on my coworkers and I would go to park my car and I would feel like the car was moving forward and I was sitting still. And then after that, I really started to push my doctors and

got sent to vestibular therapy.

ALICIA WOLF: Even the vestibular therapist never brought up vestibular migraine with me, which is shocking to this day. But think about it. Nine years ago, I mean, it's still hard to get diagnosed now, and it was even harder back then. And so I was doing vestibular therapy and all these different things, and I just kept continuing to get worse. And I ended up in the ER one night with a severe vertigo attack, which was like the true spinning vertigo and not just like the feelings of dropping or moving that I was kind of used to. And they sent me home with a diagnosis of vertigo and gave me meclizine, which I think a lot of us have had that same interaction with the ER as well. And so I just got fed up and I posted on Facebook and I was like, I am just desperate. I'm about to lose my job. I don't know what I'm going to do. I am miserable all day, every day. I'm no longer safe to drive. I feel like I can't even walk down the street safely. Can anyone help me? And at the time, I had been on the waiting list for the Dizzy Doctor, which is now Dr. Shin Beh. He's my neurologist that I think a lot of us know and have read his books. But he was at the time at UT Southwestern, had this big, long, months long wait list.

ALICIA WOLF: And a friend of mine said he knew an ENT at the Mayo Clinic that I could get into over there. And so we drove 16 hours to go to

the Mayo in Arizona. And the ENT walked in and he said, you have vestibular migraine. And I did not believe him because I did not have head pain. And I always thought migraine equaled a bad headache. So eventually he was like, this is the diagnosis, but I cannot treat you because this is more of a neurology pathway that you need to go down. So it turned out one of my co workers worked with Dr. Bae at UT Southwestern, and he was able to get me in a little bit earlier than expected. And I met with him over lunch one day and he did all his tests and confirmed the vestibular migraine diagnosis. And now we think I had triple PD in there as well. But it just wasn't diagnosed back then too. So it had just, my vestibular migraine had gone on for so long, it kind of turned into triple PD. But yeah, I've been working at this for nine years now, so I can't wait to share all the things that I picked up today.

HEATHER DAVIES: Well, we certainly appreciate that journey. It is. Can be such a long one. So thanks, Alicia.

ALICIA WOLF: Yeah.

HOLLIE SMITH: Yes, and so relatable, Alicia. I think a lot of us were shaking our heads going, gosh, I know exactly what you're talking about.

ALICIA WOLF: Yeah.

HOLLIE SMITH: Well, Ashley, would you mind sharing a little bit about your journey with us?

ASHLEY PERNICANO: Yeah, of course. So I was diagnosed with vestibular migraine and MDDS about four years ago. So I was diagnosed in July of 2021. I started feeling symptoms actually a couple months before that. So in March I was at work. I'm a nurse, so I work in the operating room. I started having dizzy spells. Like I felt like I was gonna faint, but I never ended up fainting. And it just kept happening over and over and over again. So I finally, it progressively got worse over the next month. I had to take a leave of absence. I saw, I first started with an ENT. I was like, what's going on? They said, well, it could be something called vestibular migraine, but we need you to check, we need you to go to neurology and check your heart first, make sure it's nothing major. So I did all of that. I was able to actually get in. I also see Dr. Shin Beh. I was able to get in with him in July, so a few months later. And he did diagnose me with vestibular migraine then and MDDS. I had so many symptoms I could not drive.

ASHLEY PERNICANO: I was dizzy 24/7. I would wear like noise canceling

headphones all of the time because just the sound of my kids voices was super triggering. I had ringing in the ears all the time. I even had like a buzzing sensation throughout my body, which is kind of an odd sensation. But yeah. So I was diagnosed by Dr. Beh. I did not start on medication right away though. I wanted to try supplements. I felt like I still was not convinced that that was my diagnosis. Maybe I was in denial. I'm not sure. So I did the supplements until about December and that's when I was like, okay, I have, I am basically bedridden. I could not get out of bed. I couldn't be left home alone. It was bad. I just had no quality of life. So I started medication and then slowly from there I started to get better and better. I still have my days. I'm still not 100% but it definitely, it helped a lot. And here I am today able to sit here and talk to you. I'm not in bed, I'm here in the conference. So I have improved tremendously.

HEATHER DAVIES: That's fantastic. Are you still on meds, Ashley, if you don't mind me asking?

ASHLEY PERNICANO: I am, yes. I am on medication. I started off with cypheptadine, which is an antihistamine, and I just, I started that about three years ago and I just weaned off of it last October. And so far, so good. But I am also taking propranolol. I take that daily. I also take clonazepam or Klonopin, whatever you want to call it. I take that daily as

well because that's the only thing that will help with my dizziness. It's like considered my rescue med. And I also do the Emgality injection monthly. So I do take all of those and they've helped a lot.

HEATHER DAVIES: That's fantastic. I have to say that hearing you say that, because propranolol was my savior, also for dizziness. But saying this, everyone is different. So everyone listening, please. What works for me, what works for Ashley, may not work for you. So please take that with you. However you'd like to go. And Alicia, what about you? What about medication to treat symptoms and stuff?

ALICIA WOLF: Yes. So that's where initially where we started with my treatment plan. And I think I was the same way as Ashley. Like, at first I was really hesitant to believe my diagnosis, but then once I had two doctors I trusted confirm it, I was like, okay, I'm all in on this. And I just have to figure out like a way I'm just going to put all my eggs in this basket and try treatment. And it's a little scary, but if it doesn't work, then I'll keep searching for answers. And so we started, because I was so nervous to start medication, Dr. Bae gave me like a lot of different options, which is what I find he does for a lot of different patients to like listen to what your issues are and try to kind of cater his medication plan to work with other things he might have going on. So if there's a lot of

anxiety, he'll look at like anxiety meds and that sort of thing. So for me, because I was hoping to try to get pregnant soon in the future, we went with beta blockers.

ALICIA WOLF: So I actually did Timolol eye drops every day, which now I realize is like kind of a controversial plan. But the eyedrops, in the eyedrop form, it's a little bit less medication than you would get with like an actual beta blocker pill. And so I had no side effects with it so that was really easy for me to go on. I'm no longer on those daily, I've weaned off, but I was on that daily as well as Lorazepam daily to kind of calm down my brain, similar to Klonopin. And it was extremely helpful for me. And I would say that those probably got me about 60% better. And it definitely stopped my severe vertigo attacks, like the drop attacks, or like the feelings that I was muting when I was sitting still, or especially like the spinning vertigo. But what it didn't stop for me was the daily dizziness. And so I was on those along with supplements for about like six months. And then I was like, okay, what other natural treatments can I try or add in? Because we were kind of looking at maybe adding another medication. But, like, at the time, the new CGRP meds were just getting released, and you couldn't really take those if you were looking to get pregnant.



ALICIA WOLF: And so that's always kind of been a hurdle for me because they seem to work really well for people, especially with people at the end. But if I wanted to have a family soon, I couldn't really try those. So I really leaned in heavy to the alternative treatments and just kind of tried everything. And after I started adding some things in like diet, exercise changes, massage therapy, even some of the devices, I was able to get to symptom free days over time.

HOLLIE SMITH: And we're so excited to talk about those alternatives coming up. Thanks, Alicia, for sharing about the medication side of things. And as Heather indicated, all of us are different. And make sure you check with your personal medical providers. But we definitely covered both the preventative and the rescue medications, which so many of us with vestibular migraines need. I was wondering, Ashley, if you, as we look beyond just the medication, what alternatives to medication have helped you to feel better?

ASHLEY PERNICANO: So alternative therapies for me. So for me, my main trigger is stress. Like, I know that stress is my number one trigger. And then with the stress, I get anxiety. So for me, it was important to find treatments that helped reduce my stress load and helped calm my nervous system. So now this is for me. And I know everyone's different,

but massage helped me a lot. I know some people, they can't be like, touch the head, neck. But for me, it helped calm my body and my brain and my nerve nervous system. I also find that it's super important for me to get outside once a day and do light movement. I like to go for a walk, but when I walk, I have zero distractions. Like, I don't wear any AirPods. I don't listen to anything. I try and just be present in the moment, feel the breeze on my face, listen to the birds chirping, just try and be present in that moment. I also, I need to eat regular meals. If I skip a meal, I will get ill. I don't feel good at all. And sleep is important.

ASHLEY PERNICANO: I do need eight hours of sleep. I know it's hard to come by, but that's very helpful for me. Another thing that I find super important is daily visualizations. So, like meditation or visualization. But for me, I do at least 30 minutes of visualizations daily. So I take myself to a place that's super calm, like the beach in Hawaii. So that helps me tremendously. I took a neuroplasticity course last year. They taught the importance of visualizations. What I learned is that your brain doesn't actually know if you're really there or not. So you could be sitting in your bedroom visualizing you're on the beach in Hawaii, but your brain does not know that. So it's a super powerful tool to help calm your nervous system.

HOLLIE SMITH: We're excited. We have a whole session on that later this week. So for those of you interested in neuroplasticity, there's definitely more information to come. Ashley, there's a question that came up in the chat from another person who is a nurse, and they were wondering if, with your techniques and the medication and stuff, if you're able to continue working as a nurse or if you have had to scale back or stop nursing.

ASHLEY PERNICANO: I'm smiling because that's actually, yeah, I was at work. Yes, I did go go back to work. And when I was first diagnosed, Alicia was like the first person I started following. Yeah, so we go way back. Well, I go way back with her.

ALICIA WOLF: She worked in my appointment. She's like, hi, I know you.

ASHLEY PERNICANO: Yeah, I was like, I follow you. So, yes, I have been able to go back to work. I have not been able to go back to work in the capacity that I was before though. I was an operating room supervisor prior to this. I think that the pandemic probably played a huge role in what all went down with me. I was super stressed out, but I have not been able to go back to the operating room. I work in an infusion clinic now doing chemo infusions. So, yes, I can go back to, I can work. It's just

not in the capacity that it was before. And it's a choice I've made because I think the hospital is super stressed. Like I said, stress is my trigger, and the hospital is super triggering. For me, that's not the case for everybody, but for me it is. But there is hope. You can still go back to work as a nurse.

HEATHER DAVIES: Absolutely. I'm a nurse also, and I was able to return to work, but remotely. So it's whatever works. And stress is such a big trigger for me going inpatient, just the thought of it? No. I love you ladies out there and men that can do the nursing inpatient with these symptoms. Good for you. It's just not for me anymore. No. What was, Alicia, what do you think is the biggest payoff? I mean, if you could take all of your, all of the tools that you have, like your supplements and all the different modalities, what is one thing you would choose to just keep or to recommend to people to try as far as...

ALICIA WOLF: I would be crazy to not mention what a huge impact diet has had on my journey. I think that it was not only impacted, basically the straightforward of like what I'm eating. And a part of that was doing the migraine elimination diet and taking things out and then realizing I had certain food triggers and then bringing them back in. But then the other part of that was to just from the perspective of cooking more at home and using cooking as a tool to sort of gain my independence back when I

had lost so much, so I could no longer work at the job I was in. And they weren't accommodating to me at all. And so it was, stress is one of my bigger triggers too. And I just had to be honest with myself. Like, I couldn't continue the job in the capacity I was in and focus on my healing as well. So when I left, I was kind of, it was really difficult for me because I didn't know who I was anymore because my whole career was who I was.

ALICIA WOLF: And I had to kind of find myself again outside of just me and apostle in this watch design. And I had to find, like, who I was outside of that and like really consider what I like to do. And I just had all these thoughts like, who would hire me now, like living with this, I mean, who's going to understand what I'm going through when my own family can't even understand it? And so I just really focused my time on making my meals for my family and trying to get through grocery shopping, reading labels, that sort of thing, and contribute. It was like the one way I felt like I could contribute at the end of the day. And so I had a lot of joy when I was cooking and I have some culinary education and I kind of went back to that and really just leaned into it and it gave me a huge, not only is cooking can it be a very mindful activity, but it just gave me a lot of great self worth to sit together with my family at the end of the day. And it was like something that I could control that felt somewhat normal to me.

HEATHER DAVIES: Alicia, what is the name of your cookbook that, I believe you have two of them out there. I know the people in the chat would like to know what the name of your cookbooks are.

ALICIA WOLF: Yes. So my first cookbook is the Dizzy Cook and that one really focuses on my journey with vestibular migraine and it's very migraine elimination diet focused. So like it goes by the Johns Hopkins Migraine Diet, which has you eliminate like common food triggers. Now these won't be everyone's triggers. It's just sort of to help give your brain a chance to calm down and then you reintroduce the foods later on to see if they're personally an issue for you. And so that's what that book kind of focuses on. And it's like very comfort food based. And then my second book is actually with Dr. Bae. So we really wanted to take, it's called the Mediterranean Migraine Diet, and we really wanted to take like a science based approach to treating vestibular migraine in particular and focus on like foods that are good to include for your brain health rather than just like taking stuff out, but like what we should be eating and what has been proven to help with your brain health overall. And that's what this book really focuses on. So things like omega-3s, getting a balanced diet, protein fiber, healthy fats, focusing on additive free foods.

ALICIA WOLF: Kind of like Dr. Gokani got into a little bit just cooking more

from scratch, cooking more at home. And we cover some of the common triggers a little bit, but it mainly is like things to include that can help your overall brain health. So this is kind of what I recommend to people is if they're just starting, I recommend starting with the Dizzy Cookbook and then kind of transferring over to this. This is more of like a long term way of eating and this how I eat now. So...

HEATHER DAVIES: That's really helpful. I know for those of you that are interested in cooking, there is a meetup this week as part of the conference platform. I'm not running it, but someone else is and so it's something else. Thank you for sharing that Alicia. And Ashley, in the chat there was a question, I know you mentioned massage and I believe craniosacral therapy, but there was a question about acupuncture and is there something that your providers used and those alternatives, the massage and the acupuncture, if you could elaborate a little bit more.

ASHLEY PERNICANO: Okay. So for me, I did try acupuncture in the beginning and I realized within two treatments it was not for me. I don't know if it's where they stuck the needle. I mean, I'm not afraid of needles or anything, but I don't know if it's the spot they stuck the needle, but he put one in my head and it sent me into a flare. So I learned pretty early on that I couldn't tolerate acupuncture. But I do know people that it's

actually very helpful for. So I wouldn't just throw that out the window just because it doesn't work for me. I just know that massage is much better for me. Like, I can get a massage, it doesn't trigger me at all. And it just, it feels amazing when I'm done. Like I feel so relaxed that I hardly feel that those symptoms that I feel daily.

HOLLIE SMITH: And the craniosacral therapy is so unlike a traditional massage. It is lighter, like the doctor was saying in our first hour, a lot more calming to the body, for sure. Ashley, that's really helpful information. So thank you for sharing that.

ALICIA WOLF: Just to add on to that, something that my massage therapist does that helps me is she'll kind of wrap my head. So she'll kind of wrap the fabric like crisscross around my head and tuck it. Like it's, you could use like a towel or something else. But just like the security on your head sometimes, even if you brought like a migraine cap or something like that, it tends to really ground you in your massage. And so I found that incredibly helpful whenever I was like, with like feelings of being floaty or whatever, whenever they're doing the Actual massage. And then she always alerts me if she's going to move the table. So that way you're like prepared for it or you could even get off the table and have them move it. That way it's not so sudden and it kind of mimics those



symptoms that we sometimes have.

HEATHER DAVIES: I'll tell you. When I had cranial sacral massage, I'm not sure if any of you could relate to it. I almost was a little light headed afterwards, almost euphoric, but then it faded. The dizziness wasn't there, but just, I think for just all the fluids movement. But it was unlike any massage I've ever had. It was wonderful, but different than a deep tissue massage. And Alicia, I love that. I can't wait to try that. The wrap. It sounds heavenly.

ALICIA WOLF: Yeah, I'll have to try to post an example on my Instagram or something in case so you guys can see. But I think it's normal to feel a little bit dizzy afterwards. It's kind of like vestibular therapy where like the dizziness should eventually calm down. But my therapist, she never works like directly on my neck. If we do, it's like the craniosacral therapy moves where it's just like the light touch. But I think that, having someone that doesn't just, you should avoid anything that really like goes in heavy on your neck because I feel like that's what increases the dizziness too. Yeah.

HEATHER DAVIES: Alicia, do you still drive?

ALICIA WOLF: I do. I have no problems with driving anymore. I would say

that it took me about a year to feel comfortable driving again. But yeah, with my treatments and everything, I feel normal most days. So it's not bad for me to drive. The only time it kind of bothers me sometimes is at night, like with the lights. If people have like really those extra bright headlights now sometimes get me.

HEATHER DAVIES: They're awful.

ALICIA WOLF: Yeah.

HEATHER DAVIES: They are.

HOLLIE SMITH: And with that let me ask this to you. Do you still drive?

ALICIA WOLF: Yes, I drive. The interesting thing is I was diagnosed with MDDS, so movement actually made me feel better in the beginning. So driving, I wouldn't feel. I didn't feel bad when I was driving. I did take. I mean, I had a lot of anxiety in the beginning, so I did take a, I couldn't even be left home alone, so there was no way I was going to drive a car. But yeah, no, I drive now and I, yeah, doing fine now.

HEATHER DAVIES: That's wonderful. And I know everyone's journey can

be a little different on the driving thing, and that it's great to check with your practitioners and to slowly work on those baby steps. Ashley, this is kind of a difficult question that's kind of coming in from the chat, but we've had, you mentioned anxiety, but someone's asking about if either of you, but this question's for Ashley, have suffered from depression. I know you mentioned anxiety, and then also if you've tried EMDR, any other therapies that have kind of helped with that piece of your healing journey.

ASHLEY PERNICANO: So, yes, I believe I do suffer with depression. I didn't before I was diagnosed, but, post diagnosis, I have had a hard time, especially because I've had, I had to quit my job, which was my livelihood, and then try and figure out some, just kind of like Alicia, same thing. You got to find your own path and what works. But I found, I did therapy for a while with a therapist that actually specializes. She has similar issues, vestibular issues. So I did therapy with her because she knew what I was going through, and I found that to be pretty helpful. I haven't tried the EM... I think you said EMDR. Is that what you said?

HEATHER DAVIES: Yeah.

ASHLEY PERNICANO: Yeah. I haven't tried that. But just the therapy and

talking to somebody who could relate to me was very helpful for me, and she had a lot of tools that she taught me. But, yeah, I mean, I still, I mean, to be honest, there are days where I'm just like, I'm crying because I'm like, this is hard. It's hard, but I try to find the good in every day. I mean, it could be worse. Like, I think it could be worse. So. But, yeah, I mean, I do struggle. I still struggle.

HEATHER DAVIES: Thank you for sharing that. I know that it's a common thing that gets discussed in many of the support groups. So at least you don't have to feel alone, whether you're with a therapist or with support groups. It's definitely not feeling alone in your journey is helpful. Alicia, what about you? Have you had the mental health piece of it as well? The anxiety, depression? Have you tried EMDR or cognitive behavioral therapy? Any of the...

ALICIA WOLF: Yeah, we focused more on CBT in my initial therapy, and actually, my therapist had, I brought up EMDR with my therapist now, we're looking at trauma from actually being diagnosed with vestibular migraine. Because sometimes I feel like the trauma of going through what I felt and losing my job and being diagnosed and just living with it. I sometimes wonder if I, like, carry that with me and I have health anxiety in other places, only to find out that I was very validated my current

health anxiety, because I was... I actually found out that I was struggling with low ferritin. And so I didn't know if it was like, maybe perimenopause symptoms, but again, I couldn't find a doctor to validate me. And so I'm like, is this really all in my head again? And so I asked my therapist. I'm like, maybe I'm, am I making stuff up because I went through this with vestibular migraine? Or am I just like, this pain, patient, just like, this big pain to everyone, like, just saying, hey, there's something. But so I ended up, by pushing and everything, I ended up finding that I had extremely low ferritin.

ALICIA WOLF: So something that I've learned in the past year was that my attacks started getting worse again after I had my last baby, Lila, and I just wasn't feeling like myself, and I was exhausted all the time. I never had energy, no matter how much I slept. And I was getting more painful migraine attacks around my cycle, whereas before, like, I was just getting more dizziness symptoms. And so I felt like my migraine attacks were changing. And no one really brought up to me to like check, a full iron panel with ferritin. And what I learned about low ferritin is it can often cause a lot of the symptoms of dizziness, vertigo, tinnitus, that kind of thing that also connects with vestibular disorders. So once I got connected to a hematologist and started getting infusions, which is how I met Ashley, I noticed my energy went up. I was no longer having those

attacks around my cycle coupled with I do vitamin E protocol that Dr. Bae has been on. And it worked wonders for me. And so, like, not everything is perfect now. And of course, I had vestibular migraine before I had the low ferritin issue, but it definitely helped me with like a lot of the symptoms that were, like, getting worse.

ALICIA WOLF: Especially around my cycle. So my therapist is like, this is almost like, a good thing that you are so in tune and you push for these things, and it's not really necessarily a trauma response that you're doing. So we tend to work more on just like talk therapy and CBT and visualizations and that kind of thing. She really has me to do a lot of like the insight timers at night, which is just like this... And you can type in, like, whatever you're dealing with. And so she has me do a lot of like the yoga nidra. Nidra? I don't know.

HEATHER DAVIES: Nidra.

ALICIA WOLF: Yeah. Okay. And she has me do those in the evening to kind of like calm my brain or if I ever feel like I'm frustrated or like getting worked up about something. And that's seems to really help me as well. But it's always...

HEATHER DAVIES: I'm so happy you said that. It doesn't only work for us, it works for our kids too. I have my daughter, she has a little anxiety at night and I plug on the insight timer and she just lulls her off to sleep. So.

ALICIA WOLF: They have great headphones too. Yeah. I love that you can find different ones. And I save the ones I like and I can't believe it's free. It's like such a great...

HEATHER DAVIES: I have... Are you guys, either of you and Ashley, are you medication free or are you looking to be medication free?

ASHLEY PERNICANO: Yes, that is my goal. I am looking to be medication free. I'm not medication free yet and I'm not ready to be medication free yet. That's the honest truth. I don't, my body, I'm not quite there, but that is my goal. So hashtag goals, let's be medication free soon, hopefully. But yeah, I'm not there yet.

ALICIA WOLF: I'm not either. I mean, I still use it to pre treat before I travel. I use acute medications to pre treat. I use them before my cycle to pre treat. And so a lot of times, I used to be that way too, where I felt like it was. I had to, like, I wanted to live without medication, but now I just kind of see it as a way. I'd much rather be symptom free than medication

free, if that makes sense.

HOLLIE SMITH: Absolutely.

HEATHER DAVIES: I agree.

HOLLIE SMITH: It sounds like you both have found like the right balance of complementary medicine as well as traditional medicine that works for you. A question that's come up in the chat. We'll start with Alicia. Are you able to go to the grocery store? Are you able to do those kind of things? And if so, what are your tips?

ALICIA WOLF: Yeah, I have no issues with the grocery store anymore, which is amazing because it used to be like a huge trigger for me. I used to go with my sunglasses and baseball hat. I would say that, like, if you're really symptomatic, I love grocery store pickup now. I mean, I still use it if I, like to me it's worth the extra \$5 if I, it saves me so much time with the kids and like trying to wrangle them. So I think if it's more about like taking the stress out of my life than like avoiding the trigger load of the actual grocery store. But I would say that a few things that helped me were like getting migraine glasses. So I'm a big fan of wearing migraine glasses. Like, it's a higher trigger day for me. And then just like, slowly



introducing this stuff, go for five to 10 minutes and make it go at like an off time if you can. So either, like later in the evening or, like, during the day, or even, like, I love to go first thing in the morning after I drop off the kids at school, or like if they're with me, I'll take them first thing in the morning.

ALICIA WOLF: And we sort of make it a fun event where we kind of like leisurely stroll and pick things out. Like, everyone gets to pick out a snack that they want to try. And I always like to look for new things for the website, too. So it's kind of like a, if I can make it a more. It's just like cooking. Like, if you can make things more of a fun event and relaxing versus like what I have to do and I have to fit this into my life, like very quickly and rushed and stress about it, then you're going to have a totally different connection with it than you do if you go. And it's like a more fun thing. Now, granted, we live in the town with central market, and so it's like a really fun grocery store. So I get, not all grocery stores are alive. If you want to... I feel like more people are having, like, local grocery stores kind of pop up or things where, like, people are starting to make their own things, like farmers markets or people who make their own bread or whatever. Going to check out some of those places can be a lot of, I think it's a good time.

HOLLIE SMITH: Yeah, absolutely. Alicia, thanks for sharing about the grocery store and how it is easier now than it used to be. And Ashley, while Alicia talked about the grocery store, I was curious if there was anything similar that used to be hard for you, but now you have gotten better at it or you've been able to gain those things back. And if you have any tips for our audience.

ASHLEY PERNICANO: Ooh. I feel like everything was hard for me, so it's hard to think of just one thing. I think the hardest thing was taking care of my kids. I hate to say that, but it was, they're they're very triggering. I mean, when I was diagnosed, I think my son was. Let's see, he was probably three years old, so I had like a, he was either three or four. And then my daughter's two years older. So I had pretty young kids. I mean, they weren't baby babies, but very needy. And so I told my husband, please don't leave me alone. Like, I can't do this. I can't do this by myself. So I can do that now. I mean, I feel more independent. I can take care of my kids. I can drive them to their activities. I couldn't even go to like a sporting event. I couldn't sit there and watch my daughter play soccer. Like, I couldn't do that. And now I can. So, yeah, there are definitely, there's a lot of things that I could not do, do that I can do now. So, don't ever lose hope. You will get better. I remember laying there, I'm like, I'm never gonna get better. I was laying in bed. I would say, that was the

wrong attitude to have. Let me start by saying that. I mean, let me be positive. But, I just felt like I was better and I could not picture myself like sitting here doing this right now back when I was really ill. So, yeah, I think taking care of my kids and just being present and being able to like not wear the big noise canceling headphones, that's a win. And I'm able to do it now.

HOLLIE SMITH: Little kids are hard with that.

ASHLEY PERNICANO: They're hard.

HOLLIE SMITH: Oh my gosh. And like, you can't just. And they're small. Like, you can't just be like, oh, be quiet or just stay over there. They don't get that. Yeah, I have those days too, where I'm like, I just can't stand.

ASHLEY PERNICANO: Parents deal with a chronic illness.

HEATHER DAVIES: My daughter was three also when all mine started. And she actually had her own set of earmuffs too, just because it was a game. I mean, she doesn't know... I know, but she doesn't know a life without my symptoms. So that's just a part of the way it is. Yeah. Yeah. And it is. You mentioned the change in perspective. When you're deep in the

darkness, it's really hard to see that there is another side. But once you find a community of your vesties, it's so much easier to vent to them and get past it. And then they can also say, pull you out of it when you need it.

ALICIA WOLF: I mean, I still will message Alicia. I'm like, help me.

HEATHER DAVIES: And now would be a good time to bring up. We actually have a support group for moms that are dizzy. It's called the Dizzy Moms Club. And there will be information on the chat. Kyler will put up the information for a link to the Dizzy moms group because having support for moms with kids is really important. So there is a support group that's right for you. Even if that's not the one for you, there is one that's right for you and we definitely encourage that.

HOLLIE SMITH: Absolutely. Well, are there any. Let's see, Alicia, do you have any words of wisdom for the people out there who are interested in alternative treatments but aren't sure if they're really going to make a difference?

ALICIA WOLF: Yeah, I would say that just pick one to start that feels like it would fit into your life. So I actually brought, I know Dr. Gokani kind of talked about some of the devices and when she did, I went, ran upstairs

and I bought my phone down here so I can show you guys. So I have tried like so many different of the devices because whenever I was pregnant, there's just like not a lot you can do when with like medications and I had very high risk pregnancy, so blah, blah, blah. But my doctors, both my OB, my maternal fetal medicine doctor and then Dr. Bae all approved the use of devices for me. And so really I struggled a lot with nausea during my pregnancy. And so Dr. Bae had me try non invasive vagus nerve stimulation. So there's a few ways you can do this in a few different products. There's the Gamma core and Gamma core, it just works by stimulating your vagus nerve. So you just keep it here and it's like two minute sessions each time. And this is actually FDA approved for migraine. And it can be, sometimes you can get insurance to cover this.

ALICIA WOLF: If you can't get insurance to cover this, and it's really expensive. What I ended up switching two was Truvaga. So Truvaga is like the same company, which is Electrocore, it does vagus nerve stimulation as well, but you can just order it online. And they have a 350 device and an unlimited device. So I started with the 350 which has like these bigger nodes to it. So sometimes I feel like it's a little bit easier to find. But I've had other people tell me it's harder. And it only has 350 sessions on it. So if you're someone who uses it, like every day, multiple times a day. So use this as a preventative treatment for me as well as acute, you could go

with the unlimited. The only thing I hate about this one is you have to use your phone to control it, but it's a lot smaller. So I travel with it and everything, and you can just carry it on in your carry on. And I've only had TSA be like, what is this?

ALICIA WOLF: Like, maybe twice, but, like, haven't had an issue with getting through. And then when I was dealing with like, the low ferritin, the head pain more often, And I know Dr. Gokani talked about this, but it's the Cefaly device. Like, both of these have been studied for vestibular migraine. So basically, like, you just take one of these electrodes and you put it on your forehead like this. And these are like, they come in like 30 and 60 minute sessions. So you can use this for preventative and acute as well. And you just kind of turn it on, it'll sit on there. I like to use this more whenever I'm actually in an attack or I feel really, really bad. I find this more helpful, whereas, like, I like this more preventatively for like stress, anxiety, nausea, that sort of thing.

HOLLIE SMITH: Alicia, the doctor earlier mentioned that the Cefaly device can kind of feel like ants. Does it feel like that to you? Does it feel like creepy crawly sensation or. Or is it something that you adjusted to right away?

ALICIA WOLF: So. So I think if you have it too high, it can definitely almost trigger dizziness or feel like, really uncomfortable. There have been times I feel like it's gotten up too quickly on me and I've had to rip it off my head because I'm like, this is too much. But with the Cefaly connected, you can connect it to your device and control the level on it. And so I keep mine at like 12% to 15%. So, like, extremely low, where you can like, almost barely feel it, but you can stop it at that level so it doesn't go up in intensity. If you let it go up in intensity, it's way too intense for me and, like, it's not comfortable anymore. So I would say just be, control it to whatever is comfortable for you, but if you leave it there, it's like a massage for your brain. It feels so good. And a lot of, like, after my iron infusions, I had a lot of like pain that would come up and pressure in my head. And so it kind of initially like, it kind of created an immune response response for me. And so I use this a lot and it just like helps so much with immediate relief.

ALICIA WOLF: And so that's the way I kind of use them. But everyone's different. So that's my spiel on. There's also a band that you can wear on your arm called Nerivio. And I don't know how that one feels like I've never tried that one. I'm about to have my yearly with I Dr. Bae, so maybe I'll go up there and try it at his office. But I've heard good things about that one too. And that's trigeminal too. So this works on your trigeminal

nerve which I think is more almost connected to like pain or like one sided facial symptoms that we can get from migraine. Whereas like your vagus nerve is, you're kind of responsible for a gut brain connection. So that's why I think like that can be more helpful for like nausea, anxiety, that sort of thing. So that's how I kind of use them myself. But everyone's different.

HOLLIE SMITH: That's really helpful. Thanks Alicia. I know one of the questions in the chat, Ashley, you mentioned earlier about your husband and asking him to not leave you with the kids by themselves, but how were you able to get your partner on board and your family on board with what you needed? And this specific person was finding that the partner thinks it's all anxiety and stress related. How did you help him and the rest of your family kind of understand your situation?

ASHLEY PERNICANO: So I'm just going to start off by saying my husband was very supportive from the beginning, but I know that's not the case for everyone. I think it's very important to, what I started doing early on was I started to include my husband in all of my doctor's appointments like so that I was not playing middleman, saying, well the doctor said this. And so he was hearing it firsthand from the doctor and he could process the information however he wanted to process it for himself. So I found that



very helpful. Like if he could sit in, hear what the doctor had to say, then he could understand, I guess, what it is I'm going through or I mean, he doesn't understand what I'm going through because he's not going through it. But he can hear the information from the doctor, not from me. So I found that to be super helpful. But it is a tough journey, to be honest. It's hard. I had to start thinking, like, okay, I was thinking, me, me, me, me, me the whole time. Like, I feel this. I feel that. I feel this. You know? But what about him? I had to start, like, thinking, he's like my caretaker. He's taking care of me, he's taking care of the kids. He's doing so much other stuff that I had to start kind of thinking about him as well.

ASHLEY PERNICANO: But just being him, being involved, I think the biggest thing, biggest piece of advice I could give is bring your spouse into the doctor's office with you. That's the biggest piece of advice I have. That was very helpful because we have had some times where he's like, well, I don't... The doctor's appointments that he was not in on, he was like, I don't get what you're saying. Like, he did not understand. And I was like, well, I wish you were there, because that would have been helpful.

HOLLIE SMITH: Absolutely, yeah. And for those of you who would like more support, there is a support group for people who are supporting someone with a vestibular disorder, and there's also a support group for

people who are living alone, living solo. So those of you who do not have a partner, Karen and Cheryl, run a great group for that as well. Heather, there's a question in the chat for you. Someone there is asking about the challenges of having both vestibular migraine and Meniere's. Can you talk a little bit about that?

HEATHER DAVIES: Oh, my goodness. That's a big, broad question. Well, honestly, the symptoms overlap, so I just kind of, you just have to go with the flow. I do find myself questioning, is this from my Meniere's or is this from vestibular migraine? But you just have to live. You just have to figure it out. It's a long journey, it's tough, it's not easy. It's trial and error. And like Dr. Gokani said, try one thing at a time, and if it works for you, great, stick with it. If it doesn't, move on. There are so many things out there that work well for me that won't work for Alicia. It's just finding what works and constantly finding those little glimmers in every single day. Even if I'm having a crappy day, I try to find something to hold on to. And it's usually my family, my daughter or something. It's not easy and I'm not going to sugarcoat. It's just changing my perspective and really finding what works for me and when I need it leaning on the vestibular community. I will tell you I have got a.

HEATHER DAVIES: I'm a weeper. I'm sorry, I'm trying not to cry, but I have

got so many wonderful vestibular vestibule vesties in the community that I don't know where I'd be without them. Find your people and hang on to them and yeah, that's a very difficult question, but best I could do.

HOLLIE SMITH: Definitely finding your people. And the name of that support group for loved ones is called Supporting Loved Ones. And I'm sure that will be in the chat as well. But you're right, Heather. Finding your people for sure.

ALICIA WOLF: I have a quick question for Ashley actually. Ashley does IV therapy. I am curious, like, do you ever do IV therapy for yourself during a really bad attack or.

ASHLEY PERNICANO: I would need my fellow nurse friend to come over to do that for me. Put in my own IV. But yeah, super helpful. Especially I didn't even touch on this. I. I wanted to touch on this. I actually when the one person asked if I'm working again. I do own a small business. I do IV vitamin infusions. So I own my own business and...

HEATHER DAVIES: Awesome.

ASHLEY PERNICANO: I do IV therapy, and it is very helpful. I mean the

hydration is great for people who have nausea and vomiting due to their symptoms. And the supplements and the vitamins are good. The vitamins, because if you're deficient in B12, B6, B2, vitamin D, magnesium, you're going to have, be more prone to migraine so attacks. So it's actually really helpful to have an IV done instead of, now you can take it orally but orally you don't absorb it as you don't, you're like leaky gut. You're not going to absorb as much of the vitamin that way. If you do it through the IV, you get 100% of the vitamin and it takes immediate effects. So yes, the IVs are awesome.

HEATHER DAVIES: How long do you notice that they last?

ASHLEY PERNICANO: They last, probably everyone's different. It's really hard to tell tell but like I would say like a week or so.

HEATHER DAVIES: Okay.

ASHLEY PERNICANO: Yeah.

HEATHER DAVIES: Wow.

ALICIA WOLF: That's interesting.

HEATHER DAVIES: That's awesome. You see that a lot more, the mobile IV businesses. That's fantastic. I had no idea you did that.

ASHLEY PERNICANO: Yeah, I do. I didn't mention that one to that person who asked if I worked still, I don't. Yes, I do. So I do both. I do that and I do the chemo infusion.

HEATHER DAVIES: Fantastic. Well, is there anything else that you guys would like to leave us with, Ashley, before we close out? Because we're getting close to time, we could talk, I know, for another couple hours.

ASHLEY PERNICANO: I would just say, like, if for anyone who's hesitant about trying things, I would say just go for it. As long as it's safe for you, doctor approved, you have no contraindications, especially with any of the devices. Just try it. You're not going to get anywhere by doing nothing and by staying stagnant. You're just, you're not going to progress. So if it's not going to hurt you, I would say try it. I feel like if I tried something, when I would try something and it didn't work for me, I didn't think of it as, oh, my gosh, I just wasted all that money or I just wasted all my time. I just felt like, okay, knowledge gained. Now I know I can check that off the list. That doesn't work for me. Let's move on to the next. So don't be

afraid to try things.

HOLLIE SMITH: That's wonderful, Ashley. And what about you, Alicia? Do you have any closing words for our audience?

ALICIA WOLF: I mean, that was awesome. I have the same sentiment, really, because, I get, I share a lot of what I do online, and a lot of times I'm sharing things as I'm learning about them like I did with my whole low ferritin thing and the iron deficiency without anemia. And I'm just sharing, like, my journey and I get a lot of opinions and it's like, well, that won't work, or you shouldn't do that, or you should do acupuncture. That's going to cure you. And I'm like, I've already done, like, I've already tried that for like a year. And you just, again, it's one of those tricky illnesses that you just, you have no idea what's going to do, what's going to work with it. I will say, really giving something at least like a four to six months shot is a fair shot. I don't think anyone should just try it unless it's like really causing you a lot of discomfort or anything like that. But even with like medications and supplements or whatever, these things really do take time. It's not really measured in days.

ALICIA WOLF: It's measured in months to years. And I would say that a lot of people don't think that I was as severe because now they see me and

I'm doing a lot better. But it took me like two years to even start having symptom free moments. And that was with working constantly at it. And so it's also a spectrum disorder where we have different levels of severity. So some of us, we find our magic combination and we're able to move on, whereas others of us, it takes a little bit longer and we kind of have to keep tweaking things. And so wherever you fall in in that category, there's someone else like you out there.

ALICIA WOLF: And you're not weird. It's just, you just have to keep trying at things and keep working at it. And you're not a failure if you don't get better by tomorrow doing all these things. It's just a learning, like Ashley said, it's just one more thing learned in the whole process of trying to figure this out.

HOLLIE SMITH: Great words of wisdom, ladies. Thank you.

HEATHER DAVIES: Yes, absolutely. Well, thank you, Alicia and Ashley, for sharing your very personal experiences living life as vestibular patient. We appreciate you guys so much for being here.

ALICIA WOLF: Thank you for having me.

HOLLIE SMITH: Thank you. And thanks again to the James D. And Linda B. Hainlen Discovery Fund and to the University of Minnesota's Department of Otolaryngology for sponsoring this conference.

HEATHER DAVIES: Oh, and as a reminder, you can purchase lifetime access to the recordings and transcripts of this entire conference at [vestibular.org/lrl-recordings](https://vestibular.org/lrl-recordings) and you can help make sure the valuable information that's presented here at this annual event remains free to everyone by making a donation at [vestibular.org/lrl-donate](https://vestibular.org/lrl-donate). Those links are also listed in the description box below.

HOLLIE SMITH: Oh, Heather, what a great first day. Thank you so much. And we both look forward to seeing you for tomorrow's session on navigating the visually stimulating environments. So thank you everyone. We'll see you tomorrow.

HEATHER DAVIES: See you tomorrow.