Life Rebalanced Live 2025

THRIVING IN THE REAL WORLD: STRATEGIES FOR NAVIGATING VISUALLY OVERWHELMING ENVIRONMENTS WITH VESTIBULAR DYSFUNCTION

ABBIE ROSS: Hello, everyone. We are back for day two of the fifth annual Life Rebalanced Live and we have more all star lineups of healthcare providers and inspiring individuals who will be sharing their vestibular journeys. I'm Dr. Abbie Ross. I'm a vestibular physical therapist, 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'd like to begin by thanking 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 '20. Having experienced vestibular symptoms firsthand, Jim cares so deeply about supporting other people with vestibular disorders, and it was very important to him to not only spread education about vestibular disorders, but 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 A Dose of Dizzy.

LIZ FUEMMELER: Thank you Abbie, and hello everyone. It's good to be back for a second day. We do want to make sure to thank all those that have contributed to this conference in some way. That includes VeDA's donors, staff and volunteers. And with these contributions, we can put on the live version of the conference at no cost to our attendees which is

amazing. If you want to gain lifetime access to the presentations following the live event this week, we will have them available for purchase for $60, and your financial support helps VeDA's continued mission to spread vestibular awareness.

ABBIE ROSS: Now, before we get started, I want to draw your attention to the poll questions. They should be live now. Go ahead and give those an answer. Also, feel free to talk amongst yourselves in the chat yesterday. It was very lively. Thank you so much for your participation. And don't forget to put any questions that you have for our speakers in the Q & A section and we will incorporate as many as we can.

LIZ FUEMMELER: And same reminder as yesterday, although you're going to be hearing from some fabulous healthcare professionals, none of the information should be taken as medical advice for your own plan. So please make sure to consult with your providers in your area before making any changes to your treatment plan.

ABBIE ROSS: So today, day two, it's actually another favorite topic of mine. We're going to talk about navigating visually stimulating environments. We'll talk about sensory mismatch, common triggers, and which vestibular diagnoses are commonly affected by this phenomenon. We'll also discuss tips that will help you in everyday circumstances like the grocery store or a busy restaurant, and how mind body connection strategies can help you manage symptoms.

LIZ FUEMMELER: It is my pleasure to introduce our guest speakers, Dr. Bryce Appelbaum and Dr. Amy Moore. Dr. Appelbaum is a neuro visual optometrist who is on the mission to change the way the world views

vision. Dr. Amy Moore, also known as the Dizzy PT, is a vestibular physical therapist who educates with entertaining videos on TikTok and Instagram. Welcome Dr. Moore and Dr. Appelbaum and thank you so much for joining us today.

BRYCE APPELBAUM: Such a pleasure to be here.

ABBIE ROSS: We're gonna.

AMY MOORE: Same here.

ABBIE ROSS: Yeah, we're so happy to have both of you and two different views for today's conversation. We wanted to start off just to get everybody on the same level by talking about the three contributing systems to our balance system and how they work together. So Dr. Moore, would you mind speaking a little bit to these three systems?

AMY MOORE: Absolutely. So the way I always give this talk to my patients in kind of patient friendly language is that your vestibular system is actually a system like any other system inside your body. It's a collection of organs that have a job to do and their particular job is your equilibrium. It's to tell you if you're in motion, to tell you what position you're in, and to tell you what muscular reactions you need to have with your eyes and your body in order to stay upright and pointing forward. Kind of gives you a sense of where you are in space. So the collection of organs we're talking about here is your sense of sight, your senses really, let's just kind of leave that on the side for now. There's three senses that talk to your brain. Your brain processes this information about motion

sensing, about position of your body and the environment. And then it sends the signals down to your body and your muscles around your eyes and the rest of your body to keep you upright. But the three senses we're talking about are your sense of vision, your sense of vestibular, which is your inner ears, your motion sensors, and your sense of touch and proprioception, which is your ability to feel what position your body is in and what position the surface is underneath you and whether it's moving.

AMY MOORE: So your sense of vision is really, really important in this balance because you're basing a lot of your motion sensing abilities and your positioning abilities off of the environment around you. If you were walking down a hallway, the visuals are passing you by at a certain rate, and that kind of gives you information about what direction you're going in and how quickly you're moving. And that's why it's really difficult to stand with your eyes closed or to walk in a dark room. People with vision problems or problems with dependency on their vision system will have these symptoms that we're talking about today.

ABBIE ROSS: So three systems. Your visual system, your proprioceptive system, and your vestibular system. What happens if one system isn't giving accurate information? Are there certain symptoms that someone can experience? Dr. Appelbaum, why don't you take that one?

BRYCE APPELBAUM: Yeah. When things aren't working well and there's not a happy marriage, I mean, it's complete chaos in your world. And I'm sure many people listening can attest to that when our. And I'm biased, of course, with vision, but vision is our dominant sensory system. And when it's guiding and leading, the world can be safe and amazing, and we can allow opportunities to achieve at our potential. But when there's disorder or there's chaos in place, we often retreat and the world becomes very

scary. And from a vision perspective, what that looks like is our pupils widen and we get this tunnel vision effect. And that tunnel vision effect makes us feel so lost navigating through space, whether it's in grocery stores or driving or walking down the hall, or even just organizing your room and trying to process all the information around you. So there's so much we can all do to use our eyes, to rewire the software of our brain to change how we're using vision, but to establish a lot more order from that disorder that you're speaking of.

LIZ FUEMMELER: Absolutely. And I think, you know, just to move into the conversation more about vision, it may be good for us to understand what that means to you. I think a common question that we hear is, is what is the difference between acuity, people that see really well and have 20/20 vision and vision? Is there a difference there for you?

BRYCE APPELBAUM: Yes. Thank you so much for bringing that up. So let's think of it as eyesight and vision, and think of them as completely separate entities. Eyesight is the ability to see. So that's letters on a letter chart. And when you're in an eye exam, street signs, when you're driving, if you're a child, to see what the teacher writes on the board in the classroom. And eyesight really is a symptom. Vision is far more complex. Vision is how our eyes move together and converge and track and focus and process information. How our brain filters and organizes the information our eyes are sending it, to then know how to derive meaning and direct the appropriate action. So think of eyesight as glasses. It's a symptom. Vision is brain and vision problems are brain problems. And there are solutions for these brain problems, many of which we'll talk about today. But I think the take home is there is so much more to vision than just 20/20 eyesight or 20 whatever eyesight.

LIZ FUEMMELER: I have a follow up question to that too because I am a vestibular audiologist and a lot of the testing that I do with my patients involves a pair of video goggles and looking at eye muscle move and what the eyes do. Does that help you as you're evaluating patients, that type of information or how do you use those eye movements to help with patient symptoms?

BRYCE APPELBAUM: Absolutely. So I mean eye movement, eyes are the windows to our soul that we've all heard many times. But in terms of how our eyes are focusing, which is the inside muscles of the eye, how our eyes are converging or coordinating, that's the outside muscles of the eye, how we're tracking, a lot of the tracking that we think about as kind of a cross midline here. So it's the x axis, but to me life takes place on the z axis and that's the inside and outside muscles of the eyes and how, how much they're in harmony. From an evaluation standpoint, we look at all the functional visual skills that none of us are born with that come through our life experiences that are learned. So our tracking, our focusing, our depth perception, our eye teaming, our peripheral vision, but we look at them in lots of different ways. And I think a really thorough evaluation is going to look at your tracking system, for instance, but it's going to look at it in three dimensional space, it's going to look at it on a 2D plane, it's going to look at it on a screen.

BRYCE APPELBAUM: It's going to rely on eye tracking software as well as objective measurements. Because very often when there are spatial mismatches and when we're using our eyes as if we're perceiving things to be in a different position and space and where they're located, the tracking system gets thrown off because we're literally attending to a different place than where we're asking our eyes to attend to. And that mismatch is the root cause of so many symptoms and behaviors associated with disequilibrium.

ABBIE ROSS: So that mismatch can occur in visually stimulating environments. We're talking grocery stores, sporting events, busy restaurants. Maybe you're looking out the car window when you're driving. Dr. Moore, what types of situations or what types of situations do patients often report most problematic, and what symptoms are they reporting?

AMY MOORE: Good question, Abbie. So when it comes to visual dependence, which is what this mismatch is that we would refer to, people who have visual dependence are heavily depending on their vision system in order to make decisions about where they are in space. Kind of similar to what Dr. Appelbaum was saying. We're trying to attend to what we think we're seeing. So things that will confuse your sense of vision are things that are going to be heavily in depth, like going to a stadium where you're really far away from things, or large big box stores where the ceilings are very high. Anytime they have any kind of lighting that is fluorescent or flickering that can really throw off your sense of vision. Any very busy or moving environments as well. Things like people darting in and out or moving back and forth, even things like scrolling on a screen can confuse your sense of vision. And when it comes to those things that confuse the sense of vision, the symptoms that a person might experience can involve your sense of equilibrium. So it will involve dizziness. Dizziness is a general term that means you're sensing movement that is not accurate to the situation, or your positional sensing is off.

AMY MOORE: So you might feel lightheaded, you might feel woozy, you might feel unsteady, or disequilibrium, or off balance. People often will get brain fog, difficulty concentrating pressure, or pain behind the eyes.

There's also different motion sickness like nausea or even anxiety that can come about as a result of these kinds of visual disturbances.

BRYCE APPELBAUM: Can I add something to that?

LIZ FUEMMELER: Absolutely.

BRYCE APPELBAUM: Just because everything you described really stems from kind of a mismatch between two different processing systems that we have, one that responds to central focal information and one that responds to peripheral ambient information. And the root cause of like 80% of motion sickness in my mind, and I know I'm biased again, is a disconnect between vision and the three pillars you talked about initially, where we're getting this sense of motion, we're getting the sense of dynamic changes, but then our central focal system is overriding static non moving changes, and our brain starts to freak out because it can't tell what's in motion, what's stationary, can't filter and process all of that information simultaneously. And then we get this sensory overload where we can actually teach people how to actively engage periphery, look soft, open up the world, especially when they're not trusting what they're seeing, which often occurs, you know, when we're driving and we're all of a sudden over a bridge, and then we're aware of what's around us that we weren't aware of, and we become even more central or the stadium. You talk about, realizing there's all these planes of information.

BRYCE APPELBAUM: I can't filter and understand where I am or where these different stimuli are in space. And so really the synergy between that, that central and peripheral processing can help eliminate so many of these mismatches.

LIZ FUEMMELER: I have two sub questions related to this. The first one, when patients are exposed to that visual stimuli, sometimes it's the speed or the intensity of the stimuli. So do you treat it differently, or do you help patients in a different way? When slow versus fast things impact them, or when simple versus busy things impact them.

BRYCE APPELBAUM: 100% for me, it's quality, it's quantity, and it's accuracy. So very often our eyes and our brains are functioning at different speeds. And that can show up with reading where we're losing our place, we're skipping words or skipping lines, we're not remembering what we're reading. But in this scenario, where so much optic flow is occurring around us, we can often allow wiring and firing to take place with new learning. That can desensitize the brain and actually allow it to have a larger, what I call just noticeable difference or larger threshold so that we can handle more without all of a sudden wanting to retreat and going into that fight or flight response. But speed, size, contrast, brightness, I mean, all of these terrible things can play a role in terms of how our brain is processing information. And because vision is represented in every lobe of our brain, not eyesight, but vision. And a lot goes into vision. And there's more areas of our brain dedicated to processing vision and all of the other senses combined. You can't have any type of inner ear issue, head injury, or acute acquired event and not have vision be involved. It's just a matter of at what level.

AMY MOORE: I 100% agree. It's very customized to the individual, what their triggers are. It can be motor responses of the eyes, like ability to track. It can be convergence and divergence, ability to focus close and near, I mean, near and far. Or it can be just their specific triggers of movement in the environment and in the periphery, so it's customized to

the person.

ABBIE ROSS: Now, are there specific vestibular diagnoses that we tend to see this sort of presentation more commonly? And Dr. Moore, why don't you with that one?

AMY MOORE: Absolutely. The two big ones is going to be PPPD, which I know is a lot of letters. It stands for Persistent Postural Perceptual Dizziness, which is just a maladaptation of your brain focalizing on the visual components and basing your decisions off of it. And then vestibular migraine, which we had a great speaker yesterday that was talking about vestibular migraine. That's specific type of migraine that has vestibular components. Those people tend to be more visually sensitive.

ABBIE ROSS: And Dr. Appelbaum, talk to us a little bit about what your treatment approach looks like for this type. A patient comes to you, says, look, I have a terrible time. I cannot go out into my community without getting symptomatic. I can't scroll on my phone. I can't go enjoy a movie with my kid. What is your evaluation and then your treatment approach based on that evaluation look like?

BRYCE APPELBAUM: So really, the evaluation is kind of lifting up the hood and seeing exactly where everything is functioning, where the areas of opportunity are for improvement, and then designing that customized approach. Dr. Moore, you hit the nail right on the head. With this entire population, everything has to be individualized to the person, because when you've seen one person with vestibular dysfunction, you've seen one person with vestibular dysfunction. And there are, of course, similarities. But sometimes for somebody who's got a more sedentary

lifestyle, who is on screens all day long, they're going to show a very different profile between the inside and outside muscles of the eyes and how they're working or not working well together, which then is triggering the vestibular system. So for somebody to be on a screen sitting and static, but then getting signals of motion and of dizziness and of vertigo, I mean, that's crazy to even think about that the brain can be tricked into thinking that, but it so often is a way to disengage from the task as signs of you are asking yourself to do too much. So from a treatment model, I mean, I would say there's probably four areas we need to always hit hard.

BRYCE APPELBAUM: One is nutrition, providing the brain high doses of what it needs to heal and to function at its best. And that can be supported by supplementation. I think a big area also is lifestyle modification. And there's so much we can all do to just make every day more tolerable just by addressing that particular area. But then it's really the vision performance training, which is the brain training to really establish that eye brain connection that is solid under stress, not under stress with motion in static environments where we can arrange the conditions to raise somebody's awareness what they're doing so they can learn how to self correct and self monitor and can learn what it feels like, what it looks like. The depth that ensues when both eyes are pointing and acting like they're in the same place. The brain's turning on that information. We're seeing things in 3D and then being able to reproduce that as we're integrating all the other systems in life that heavily depend on vision. So our treatment in office always incorporates cognition, movement, balance, and of course vestibular input, because vision doesn't operate in isolation of these systems. So if we kind of look at it as you're trying to get in a really good shape, you're going to most likely get into the best shape if you're going to the gym, working with an expert, with all the equipment and access to the strength and the freeways and the cardio and the flexibility.

BRYCE APPELBAUM: And you're taking this kind of cross training approach. So from a vision rehab standpoint, absolutely, that cross training approach is ideal, but not everybody has access to that. So there are certain eye exercises that can be really helpful. There's certain online programs that can be really helpful. We have one called Screen Fit, which is awesome, and a game changer. There's also simple eye exercises we can do as just part of our daily routine to prolong the need for our reading glasses to have to increase or to make it so that we have better processing ability in dark environments. I mean, there's so much that when we know better, we can do better. But there's such a disconnect in the medical world with everything, but really with the eyes over a proactive approach and a reactive approach, or a functional approach and a structural approach. And so if we take that proactive functional approach, any brain at any age can be rewired and has neuroplasticity to climb out of this place of chaos that so many of us are in because our visual and vestibular systems are not best friends with each other.

LIZ FUEMMELER: Do you just taking a step backwards before a patient would come in for this type of program or to do vision rehab? Does visual acuity play a role in the success of that rehab? Or what other things may a patient consider before starting Vision rehab that should be under control or tested for.

BRYCE APPELBAUM: Yeah. So I mean everyone who's been to the eye doctor, the doctors on that heavy pursuit of seeing the 20/20 line and that's just one little piece to the puzzle. Not everybody has to see 20/20. Not everybody has to see the same. I always say let's shoot for 20 happy rather than 20/20, which is a balance of comfort and clarity with a balance between each eyes input where we're kind of in the weakest lens

possible, that gives the most improvement, but mainly that improves performance. So again, if we look at eyesight as a symptom, that's low hanging fruit that we can tackle before a program. But very often eyesight changes or is impacted because of vision problems.

BRYCE APPELBAUM: So this sounds a little hyperbolic to say and probably for most people hearing this, but as an adult, our distance prescription really should not change unless there's a functional problem. And we're adapting to the lens we're in because of the stress from our environment and not having the tools in place place to meet those demands. And then we need something stronger or different to maintain that same clarity. So very often with vision performance training or the right type of functional work, eyesight improves because we're addressing the root cause or the problem that's maybe a focusing stamina problem, a focusing flexibility problem, an eye coordination problem, whatever that may be, that's making the system locked up, stuck with up close under stress from up close we've developed better balance and flexibility there then that distance blur is less likely or not likely an option because we've developed a better rapport with space.

ABBIE ROSS: That makes a lot of sense. Now going back to evaluation and treatment. Dr. Moore, does your session with a patient who comes in with that same type of presentation look any different given that you're a vestibular therapist?

AMY MOORE: Actually his bone structure of we identify the problems and then create a structured treatment plan that is customized to the person is exactly the same with medical management all around because those are going to be your basic components. We're basically going to identify the problems and diagnose the severity of the problems and identifying

the triggers. We're going to suggest or provide medical management. So if a person needs prism glasses, that would be considered medical management, proverbial low hanging fruit or a medication for say migraine medications to help get this person over the finish line. We're also going to be implementing a structured routine to help them with lifestyle management, to help them with modification of activities. But we're also going to be giving them structured exercises to start building on these pillars, these building blocks. And that does include not just visual therapy with vestibular rehab, but also their balance and equilibrium, their ability to sense their position over their feet and make those muscular reactions with their eyes and with their body. But at the end of the day, just like a patient who would come to me with a balance issue because they had orthopedic issues like spine surgery, sprained ankles, bad knees, we are going to measure their balance.

AMY MOORE: We're going to customizea program to improve their balance over time. And then once we hit a plateau, if that person is still struggling with, say, walking up a ramp or moving over uneven surfaces, that's when we start to modify the environment and say, maybe it's best if you use a cane over those types of environments. So whenever we train anybody for any kind of condition in physical therapy, at the end of the day, what we're really focusing on is, can we get you there? And if we cannot, what can we modify about your activities and your body and your environment in order for you to be able to achieve those things? So there is a lot of activity modification at the end of the day to help these people be able to go to the concerts and be able to go to the grocery store to experience these things like a normal individual without these kinds of symptoms coming up. So it's kind of the same bone structure of we're assessing, we're customizing, we're training, but then we're assessing and modifying as we go as well.

ABBIE ROSS: Now, Dr. Appelbaum, you gave a buzzword. Actually, that is one of our topics coming up later in the week. Neuroplasticity. And going back to what you were saying, Dr. Moore, the dosage of the exercise or the activity that you prescribe or recommend matters. So can you talk to me a little bit about dosage?

BRYCE APPELBAUM: Yeah. So dose is very different depending on what we're treating. But I always say to my patients, like, if we're trying to get your blood pressure to a certain level and 100 milligram pill gets you there, but so too does a 10 milligram pill. To me, I'm always prescribing the 10. But then on top of that, I'm figuring out how can we not even rely on the medication and figure out systemically what's causing that. So in a customized vision training program, with every single procedure and everything we do, whether it's high tech like augmented reality, virtual reality, eye tracking, computers, or really low tech, we want to find the patient's limit, always stay below it, but then kind of massage it. And I always say as long as communication lines are wide open between the doctor and therapist and the patient, we could get close to it, but we're never going to go past it. And I have a particular patient that was probably with us a dozen years ago who says she threw up over 50 times in my office and somehow we didn't know about that. And this was on pace to be an Olympic athlete and someone who thought no pain, no gain is the only way to go through life.

BRYCE APPELBAUM: At least with my type of work, we don't want that mentality. We should be tired after treatment, but we shouldn't be able to not handle life. And so often we see patients, particularly those with traumatic brain injury or vestibular dysfunction, who have tried whatever types of treatment elsewhere and felt like the treatment kind of awoke a sleeping bear, where all of a sudden it was like, oh my gosh, my brain's freaking out. I'm asking it to do things it was bypassing or ignoring. And

now I can't even get out of bed or I can't even like walk down the stairs without feeling like I'm going to completely fall over and throw up everywhere. So from a treatment standpoint, we want to push the envelope, but in a place where everything we do is scored so we can see the level of response, we can see the scores improving, and we can also set clear targets for what we want the patient to accomplish with each and every activity or exercise so that hopefully they exceed expectations. But it's really putting your eyes and your brain and your body through a learning experience where it gets feedback, it self corrects, itself monitors, and it learns from it rather than just doing something with repetition just to get through it. That's not how we want to approach anything from a rehab or training standpoint.

LIZ FUEMMELER: And it may be beneficial. I know we're getting a couple questions about the differences between vision rehabilitation and vestibular rehabilitation. So it could be helpful and we can start with you, Dr. Appelbaum. But it would be helpful to look at like what a typical day may look like for a patient. Obviously we know it gets very customized, but frequency. Do they do things in your office, outside of your office? Both? What does that look like? Just in a quick description?

BRYCE APPELBAUM: Sure. So we do literally every frequency imaginable. So we actually have a guy here this week from Switzerland who's in town for a week doing a week long boot camp. And we have these boot camps for people we don't work locally with, which not every profile is successful with that. But we have a really clear filtering process to make sure the ones who do come in can handle that. Most of our local patients, and we're in Maryland, right outside Washington DC. Most of our local patients are once to twice a week in office, where the sessions are about an hour long. And then we have a really robust customized home program where we want the patient working at home, ideally 10 to 15

minutes a day on the days they're not in training with us in office. And then I always say work hard enough that you've earned a day off each week that you can take off. Our home program is the right sequencing of exercises and of procedures. We also have a customized virtual reality program which is an absolute game changer. Where they do the work in office. We give them then a headset to bring home.

BRYCE APPELBAUM: It's theirs to keep when they're done. And our doctors go in each week on the back end and adjust the settings where every time the patient goes in they play a game, whether it's chopping up fruit, flying at them or popping balloons. But we're taking measurements of how well they can converge or diverge, or how well they can kind of oscillate between near and far, or how much contrast they can still detect certain things in, or how much brightness. And then the training is done at certain percentages of what we find that first assessment on and then we kind of build from that. Home therapy can be helpful, but I think specifically for this type of population, and of course I'm biased again because we see really complicated patients, but typically there's not a whole lot of life altering treatment with just home therapy. Unless you are so compliant, so motivated, and there is nothing else more important in your life, in which case, of course there can be. But just like working out, it's hard to work out at home doing only body weight stuff to get into ridiculous shape, unless you are so laser focused on that.

BRYCE APPELBAUM: And then in office that's really where the new learning takes place. So I say the new learning takes place in office. Reinforcement of that learning takes place at home. And just like any newly learned process, the more you practice, the faster you see things changing. And it's really clear if you've set clear short term and long term goals together, how to chip away at those and feel really empowered from the work, so that you can see your hard work paying off. So to

answer your initial question of what is vision therapy? Think of it as physical therapy for the brain, but really for the brain through the eyes and addressing the visual component of getting all these sensory systems to communicate effectively, but then to get the eyes to work together as a team and to get the eyes, brain and body to be solidified with a solid connection.

ABBIE ROSS: And because your body is interconnected, there is overlap between vestibular rehabilitation and vision rehabilitation. But something I wanted to reinforce is that repetition is key. So to the individual who can't come into the office every day to get the tune up that you're speaking of, Dr. Appelbaum, at home, as long as they're doing that repetition, they should get some improvement as long as the dosage is correct. So when we say dosage to one of the analogies, I like to use the Goldilocks analogy where it's not too little because you're probably not going to see much success. It's not too much because your system is going to be overwhelmed. It's just right. And then you build upon what's just right for you as your tolerance improves. Dr. Moore, can you talk a little bit about the vestibular rehabilitation side of things?

AMY MOORE: I love your Goldilocks analogy there, because that's exactly right. And it's the same thing that Dr. Appelbaum was saying as well. We have a delicate balance between what's realistic on both ends. What's a realistic amount of time to spend on this every day? Most people have jobs, most people have kids to take care of, they have responsibilities. So what's realistic on this end versus what's realistic for getting better? To be able to tolerate going to a four hour concert, you might have to exercise for four hours. And that is the reality of the situation. So we have to balance that with the tolerance of the individual.

AMY MOORE: Typically with vestibular rehab, we are incorporating a lot of the things Dr. Appelbaum is talking about with visual therapy, but we're also incorporating it with the balance portion. So your ability to stay on your feet, your ability to feel where you are in spatially and be able to make your body obey your postural commands with those things in face. So there's a lot of things that we're working on all at once. Usually it's a 60 minute session and it is based on your tolerance with rest breaks, of course, we're not just killing you for 60 minutes.

AMY MOORE: And yes, we do get a little bit of the vomiting in our office too, but we try not to push it that hard. Kind of same answer as him. We try to find your tolerance level where we're just nudging you to the edge of discomfort and then letting you come back down off of it. On days that you're not in therapy, we are asking you to do several minutes in a row at least, of vestibular rehab exercises, because again, on this end, if you want to get there, you have to actually push your body and you have to push your brain. And it has to be consistent exposure over a number of weeks in order for your brain to be able to receive those adaptive changes and for you to be able to start tolerating things in real life.

BRYCE APPELBAUM: There's a lot of people, I'm sure everyone has heard this, that some people say vision therapy doesn't work or vestibular therapy doesn't work. And my response that's fairly new, is those are the same people that are saying normal exercise doesn't work, right? Like, you got to do it. You got to know what to do, and you got to do the right amount for you, but with the right motivation, the right compliance. Not only does vestibular therapy work, not only does vision therapy work, it changes your life. It gets you back to your old self or even to a better, new self. But you have to really make sure that you have a partner in it who's helping guide you in terms of what to do. And then having that right dosage, I think that's a huge take home from all of this.

LIZ FUEMMELER: Now that we have a better understanding of vision therapy and vestibular rehabilitation therapy, I think it could be helpful to go through. We're receiving a lot of questions about specific environments, so I thought it could be cool to do a little bit of a quick fire session. And we can go Dr. Moore and Dr. Appelbaum. But what do you say to patients who need proactive tips for. We'll start with screen time, computer, screen, or phones. What do you say to help those patients? We'll start with Dr. Moore.

AMY MOORE: For any activity. And that's. This is going to be for, I think, everyone that comes up. You have to identify what you can change and what you cannot change. Things that you can change, you have to be creative about what things you can modify about that from your end. And things that you cannot change. There are things you can add to this situation. So for screen time, you can affect your own screen brightness. You can affect where your screen is positioned and where your body is positioned. So you can also affect how long you stare at said screen or what things... How many breaks you take. So those are the things you're planning ahead for the Things you cannot change. Let's say you have to get something done for work and you're under a deadline and you're going to not be able to take as many breaks. You're going to want to keep your screen level low, I mean, I mean your brightness. And you're going to want to try to look away whenever you scroll or whenever you are make this font larger or the area bigger that you're looking at. Those are things that you can kind of start functionally incorporating.

BRYCE APPELBAUM: Screen time is easily the new pandemic. The average American spends seven hours and four minutes a day on a screen. The average eight to ten year old spends six hours a day on a screen. That's

average. As humans, we are not meant to be staring at screens all day long. Between the brightness, contrast, glare, high energy light, the two dimensional blasting of all this to our brains, that are not intended to handle, it's a big issue. Absolutely. Dr. Moore's ergonomic recommendations can be amazingly helpful. Taking breaks. Dr. Abbey posts this all the time on her social media. Breaks are so important. Everyone has heard of the 20/20/20 rule, which is not taking a break or excuse me, taking a break at least every 20 minutes for at least 20 seconds and look at something at least 20ft away. But for most people listening, 20 minutes is gonna be too long. We should be taking breaks probably every five minutes, even if it's just disengaging and coming back. Because if everyone were to squeeze their fists after a few seconds, your hands start to hurt when you let go of your fist and come back and let go and come back, you can kind of maintain that tension for a long period of time.

BRYCE APPELBAUM: When we are on screens, our focusing muscle, which is a sphincter circular muscle behind our pupil, it's locked in. And that tension over time that happens with the extended screen time is literally what's causing eye strain, headaches, fatigue, blurred vision, dry eye. I mean all these symptoms. And unless we're trying to get really buff, tension over time is not something we want with our visual system. And then so simple things we can do to help support that. There's great tints and filters that can be very helpful and specific wavelengths, specific colors for specific people can be really helpful. We prescribe digital performance lenses, which are glasses specific for screen engagement that are way more than just a blue light filter. They've got the right magnification, the right therapeutic lens in place, and power so that it doesn't do the work for you, but it gives the brain a better opportunity for the eyes to work together as a team. So often on interviews that I'm doing that are long, I'll even just shut the screen off and soon trust that everything is going to be on and we're going to have audio and video.

BRYCE APPELBAUM: But I look through the screen and I've done enough vision training that I can literally diverge my eyes, disengage, focus, and do that forever because it's no extra strain on my system. But I know what to do. Most people don't know what to do. The other piece that's really big is dry eye. The average person blinks 15 times in a minute. When we go to a screen, it goes to three times a minute, which literally means that your tear film is being replaced less often. The windshield wipers are cleaning off the debris less often. Your brain then understands there's dryness. It sends a signal to release more tears. But your tears come out in a more oily fashion... Excuse me, in a more watery fashion, less oily. And so your own tears evaporate faster than they would. And so it starts this inflammatory cascade. And then dry eye disease and computer vision syndrome and digital vision disorder all come into play. When all we could be, if we were just blinking more or taking the right supplements like Omega 3, or having the right nutrition, we could have a more robust tear film that's a little bit more protective for screen time.

ABBIE ROSS: I remember I interviewed you for a social media post and I was asking you about tips, and when you said blinking, I was like, oh, so. Why didn't I think of that? But you don't process that. You don't think about lock in, and you blink less. So that's always a good one.

BRYCE APPELBAUM: It's fascinating to just literally put your phone up, hit record, and just watch yourself on the screen. And after like 30 seconds, like, where's my first blink? Why am I not blinking? But nobody knows this. And people who are working all day at home or kids who are just in their basements on tablets all day long, I mean, dry eye is becoming a massive problem. And so much of it is too much screen time.

ABBIE ROSS: So moving away from screen time, let's talk about a busy environment. We have a question about family events, kids running around, dogs, noise, and then also maybe some similarities between that and a restaurant. Dr. Moore.

AMY MOORE: Well, when it comes to these kinds of environments, usually you have a little bit of control over the person that you're visiting. You can communicate with them ahead of time, communicate with them. Your triggers your comfort areas. Tell them that you may have to arrive late or leave early. If you're not feeling well that day, have them arrange for you a quiet area, a darker area for you to go in and rest your eyes and your brain so that you can do some deep breathing exercises. If you're getting stimuli overstimulated at the time or any increased symptoms. When it comes to restaurants, sticking to familiar restaurants, smaller restaurants, any crowded area. If you choose to sit near a wall, you're going to have less periphery to look at. Try to focus on one person at a time. Try to communicate to your relatives and friends that you need quieter sounds, that you need less movement, less flashing lights. Those are things that you can always communicate ahead of time and modify in real time.

BRYCE APPELBAUM: The seat placement is so huge. I mean, like, be the first one to the table and sit in the seat that faces the corner wall and doesn't face the rest of the restaurant. And I'm sorry, but that's not being selfish. That's looking out for yourself. That's a very different mindset. And then even at parties, I mean, I tell my patients all the time, fake a phone call. If you're not comfortable sharing anything. Just say, oh, I got to answer this, and go on a walk. Or if it's your first time at a social event after some event, or just getting back into the world for whatever reason, try five minutes. And no matter how you feel, stop after five minutes, go to the bathroom and just check in with yourself and say, okay, how did I

do here? All right, I think I can do another five. Or I can do maybe six now, and then just slowly kind of titrate back to feeling more normal. But those are simple kind of... Those are recommendations, I think having you can wear hats to block out junk lighting. You can wear certain types of sunglasses.

BRYCE APPELBAUM: You can wear certain clothes. I mean, you can eliminate certain smells. You can rely on essential oils. I mean, there's certain things that we can do to really help kind of calm our sympathetic nervous system when we need to.

ABBIE ROSS: I'm glad you brought up position about where you're sitting, because another thing is when you sit at... If you're sitting at a table and you're following conversation and looking side to side, if head movement is also problematic for you, then sitting at the head of the table while facing a more static background can be helpful, because when you're at the head of the table, you're not moving your head so much. But I also want to make the distinction. These are what we call coping strategies. These environments are problematic, but you're going to do them anyway, these are what you can do to help you get through. The goal is really to participate in vision or vestibular or maybe both types of rehabilitation and improve your tolerance to these environments. So we're not saying do this all the time, because it's going to be like this forever. These are just coping strategies to help you get through. Dr. Appelbaum, did you have something to add?

BRYCE APPELBAUM: And I think if, if you're under the right treatment path, I mean, I've yet to find somebody who couldn't make substantial progress in those scenarios. And it's because you've identified what's going on and most importantly, the plan and the path to climb out of that

situation.

LIZ FUEMMELER: Yeah, and I'm glad, Abbie, that you had brought up the coping strategies because especially as an audiologist, we hear a lot about sound sensitivity as a part of many of these disorders. And it's not really the recommendation to put earplugs in. Obviously, if you're in a situation that you can't avoid, it's something you have to do to get through that. But it's not the long term goal. We want patients to be participating in life to the fullest that they can. Let's do one more coping strategy suggestion because we hear a lot about transportation being difficult and trains, planes, automobiles, whether driving or not. What do you say to these patients, especially if they're in the acute stage of just trying to cope

AMY MOORE: When it comes to driving? Typically what we see, and this is not for everyone, but this is the most common pattern we see, is that when you are the actual driver of the vehicle and can anticipate the movements of the vehicle. So if you're about to turn the wheel, you know that the vehicle is about to tip this way, it's about to shift this way underneath you. That actually gives your brain a cue to help it tolerate these kinds of signals. So when you're the driver, you tend to have a little bit more tolerance. So we usually recommend that you try being the driver, if that's safe for you. When it comes to airplanes, we usually recommend things that will help you with your ear clearing. I'm sure that Dr. Liz up there can tell us a little bit more about that. But what I usually recommend is chewing gum and sipping water to keep those Eustachian tubes nice and open and clear so that you don't experience as much pressure with going up in the plane and then coming back down, landing. The typical thing that makes people feel the most dizzy on a plane, besides that ear pressure, is that you're inside of a tube. So if this tube is tilting or tipping underneath you, you're having to balance your equilibrium with that and feel that.

AMY MOORE: So sitting next to a window can really help. And being aware of the motion of the plane. Planes only have three planes of motion, which is tipping the nose down or up, rolling the wings to the left or the right, or turning the plane in space.

AMY MOORE: If you are kind of feeling for those motions and balancing your head against them. For instance, if the plane tips down, you're going to tip your head back to keep your inner ears at a more stationary position. Those can be really simple things to be doing while on a plane to reduce your exposure to those things. And also, no matter where you travel, always plan in breaks as you can, as you can control. And bring a rescue kit with you. And those are going to be your coping mechanisms. That's going to be your earplugs, that's going to be your sun visors, that's going to be your rescue meds, your sunglasses, your migraine glasses, anything that helps you in situations where you're totally overstimulated and cannot exit. Which I love the little white lie tip that Dr. Appelbaum gave. But if you can't get yourself out of this situation, bring a rescue kit with you always.

BRYCE APPELBAUM: Just to add to that, if you're on a plane, if you're in a car, if you're on a boat, if you're on a train, and you know motion sickness is something that you're concerned about or you don't want it to rear its ugly head. Do not read, do not pull out your phone. Do not sit there buried in a tablet, because that overrides that focal central visual processing we were talking about and tips the scale. So diagnostic for somebody who can definitely benefit from vision training in terms of motion sickness, if when you're driving the car, you're way, way less symptomatic or solid. But if you're in the back seat, if you're reading, if you're a passenger, it's worse. That is a disconnect between the visual

and vestibular systems, it can be fixed. Also, being a passenger up front, if you're way enough and are old enough and can sit in the front seat, like you said, being able to motor plan what's coming at you and really relying on what's in front of you is something that can be a game changer. We have patients who say their chief complaint is when I'm riding backwards on a plane reading on my way to work, I get motion sick.

BRYCE APPELBAUM: Well, the simple solution is, well, don't do that and then you're fine, or sit frontwards or just don't read. But pretty much any brain can get to that place where it can handle those demands. It just requires brain training and optimization and enhancement and arranging conditions to raise your awareness what's happening in that scenario, so you can develop the tools to self correct and self monitor and make it so that's doable. But I mean most motion sickness has at least a visual component and in all those cases, so much can be done to help.

LIZ FUEMMELER: I was going to ask a quick question for you, Dr. Appelbaum. I know there's a lot of products and features that have been advertised recently to dizzy patients who are visually stimulated in these motion environments. Like Apple came out with their motion sensitivity. So you can be on your phone and see the dots going down or those motion sensitivity sensitivity glasses to wear in the car. So do you have anything to say about some of these items and are they helpful to patients?

BRYCE APPELBAUM: I would say if there's a, a life altering pair of glasses or device or something out there, we wouldn't just be learning about it, we would all be having it and all of us at least would have very different populations that we're working with. So when something seems a little too good to be true, if it's relying on a specific product, in my opinion, it

usually is a little bit too good to be true. If it's relying on the right type of treatment, you better expect that there's going to be life altering improvement because you have the trust of the person you're working with and you're in the right place and there for the right reasons, then it should be too good to be true. And then the proof's in the pudding when you go through that treatment. So I will say that the glasses with the lick... The fluid in them that adjust and some have six circles with fluids, some have eight, some have four. I have a lot of people showing me them and saying, well, this doesn't work. And I say, well, okay, I wish it did, but I'm not against finding something that's going to help people out there. I just, I don't think we've found a lot of that yet.

ABBIE ROSS: Dr. Appelbaum, this question is also for you. And I get this question a lot. Anytime I post some sort of busy environment on my content and that is, what does binocular vision dysfunction have to do with this?

BRYCE APPELBAUM: So binocular vision dysfunction is BVD. And just like a lot of diagnoses, it's a label. It's a temporary endpoint. It defines kind of where somebody's functioning in terms of symptoms and visual behaviors. But essentially, it's the eyes aren't working well together as a team. And I would probably say that 100% of the people I work with have binocular vision dysfunction, which is really what we need to then utilize and benefit from in terms of the treatment, to get the eyes to work together as a team, to get the eyes, brain, and body to be on the same page with everything here. So it's usually, it's a cluster of symptoms and so often has to do with a spatial mismatch between the outside muscles of the eyes, the version system, the inside muscles, the focusing system, and adaptations to life where we start using our brain a different way than it's wired. And so when there's these roadblocks in place, unless we learn how to remove the roadblocks, those maladaptations or those bad

habits just become more and more embedded, and then it really limits us. So the right treatment can eliminate that diagnosis. There are certain types of glasses that can help support the stress associated with reading and screens to help with that diagnosis.

BRYCE APPELBAUM: But ultimately, it's kind of just an umbrella diagnosis of, yeah, the eyes don't work well together. Let's figure out what that looks like, and then what's needed to make it so that they can work together.

ABBIE ROSS: And can you speak a little bit? We do have a question about prism glasses, which many of people on this call may have tried or have heard about, or maybe not. So can you talk about what they are and what it's used for and when you like to use them with your patients?

BRYCE APPELBAUM: Absolutely. So prism is an optical device that just repositions where something is in space. So let's say somebody had a 20 unit iTurn, and it's 20 units. Whether. Whether they're looking near, far up, down, left, right, or the diagonals, we can literally move the world 20 units where the eye is and then a double image go single, and all of a sudden things are way better. Unfortunately, in most cases, there is a brain attached to the eyes, and it's not the same amount of magnification, of displacement at every distance. And what we have to do far away versus when we're converging it near is a different animal. So that type of prism I described Is compensatory prism. And a lot of people will talk about that as kind of a crutch in some cases where that becomes your new normal, and then you need that much more image displacement to maintain the same single image. That's most likely the case with base out prism, which moves the world in to help with somebody who has an eye turned in, let's say. But therapeutic prism can

be outstanding. And therapeutic prism means learning is taking place for the individual from that setup.

BRYCE APPELBAUM: So therapeutic prism we use all day, every day, in our vision therapy rooms. Yoked prism is one type of prism that moves the image up or down or left or right for the same amount for each eye. So somebody who has a visual midline shift to the left, let's say we can move their midline back to where their body midline is, or somebody who has stroke and there's a visual field deficit. We can take the world for where they're not aware of and then move it to where they are aware of so their whole world opens up. There's types of prism like microprism, where for somebody who has trouble converging the eyes, you move the world outward. So prism... I think the main goal of prism should be to improve comfort. And we should always just ask, what are the positives and negatives with any treatment and with anything we're relying on, and then the positives should outweigh the negatives. But then also figure out, what are the different choices? Because there are many different options for treatment, Especially in the vision space. And I'm not anti prism, but we want to go in with the right intentionality behind it and then also with the least amount that gives the most improvement.

BRYCE APPELBAUM: There's also a lot out there on prism that are kind of myths that are blasted all over the Internet. Like, patients eat prism, it creates dependence. They do harm. It's a band aid. It's a crutch. Vision therapy is always better than prism. I mean, all of these topics have different sides to the coin. So I think we need to be aware of just the specific situation and what that does for that patient in terms of the outcomes we're trying to achieve.

ABBIE ROSS: Back to that individualization of care. There's no one answer

fits all, unfortunately. I wish there were. Our jobs would be very easy. But this is what makes our jobs rewarding, is helping people figure out their certain situations, working toward their goals, specifically. Dr. Moore, this is a big one as well. The question is, what role, if any, does anxiety play in these disorders? So we talk about the dizzy, Anxious, dizzy cycle a lot. Go ahead.

AMY MOORE: That is A excellent question, Dr. Ross. So the way I describe anxiety when it comes to these kinds of symptoms is it's one of the five types of dizziness. Whenever we say dizziness, we're just saying a general term that makes you... Gives you a sense of discomfort about your equilibrium. So in that sense, anxiety can be a sense of discomfort that is coming from your discontent with where you're positioning yourself, where you're feeling, your position is. So when it comes to anxiety, unfortunately, it's a stimulation of the nervous system. It's a stimulation that can lead your brain and your sympathetic nervous system to start taking over and become overstimulated. The more anxiety you feel, unfortunately, the more it can kind of dovetail into more and snowball into more anxiety. So a large part of treating that kind of anxiety is not just what we're talking about this entire time, which is exposure therapy. Exposing yourself to these kinds of stimuli in small doses consistently over time so that you can tolerate it better, but also calming your nervous system. There are ways to expose yourself in gradients and gradual pieces that can help you control these kinds of senses and help you tolerate it a little bit better tomorrow, a little bit more tomorrow, and continue moving forward.

AMY MOORE: So all these coping strategies and rescue mechanisms that we're talking about are for you to be able to complete your task. We want you to be able to complete your task, but you also have to be realistic about do you ever want to complete the task without ever

experiencing these symptoms? If that's the goal, the therapeutic goal, you need to be gradually exposing yourself and gradually pushing yourself outside of your comfort zone, day by day, in order to experience these kinds of anxiety cycles, so that you can start trying to better control them. And so that's where the anxiety dizziness cycle kind of rears its ugly head with these poor people experiencing these symptoms.

LIZ FUEMMELER: And I think we've already learned this week that dizziness is very complex. It involves many different parts, and it's nice to consult with many different professionals to make sure what you're getting is appropriate for your care. Since we have a couple minutes left, Dr. Appelbaum, could you talk about how patients get to vision therapy when they're a candidate for vision therapy and how to find a vision therapist?

BRYCE APPELBAUM: Yeah. So there are so many areas of life that are impacted by vision that can be completely... Can be drastically improved with the right type of work. So avoidance of reading. Somebody prefers audiobooks rather than reading on their own or Resistance for with reading as a kid, trouble catching a ball, motion sensitivity, eye turns or lazy eyes, recovery from a head injury or TBI, poor eye contact.

BRYCE APPELBAUM: Balance issues, not feeling confident in space, even difficulty with social interaction. So there's so many areas that have a visual role, let's say to find out whether you're a good candidate. I think it's going to the right type of professional who can evaluate what's going on, but then most importantly have the right treatment options available. So there's an international organization called COVD, the College of Optometrists and Vision Development. And this is the international organization that board certifies doctors in this space. They have a

website, covd.org where you can type in under the located doctor section, your address, your zip code and set up a search radius for how far away people are within there. You want somebody who has after their name the letters either FOVDR or FCOVD, which is kind of being transitioned out in the old school way to do it.

BRYCE APPELBAUM: That lets you know that they're board certified in this. So from an evaluation standpoint, you are in great hands with anybody who is board certified in that space. For treatment. It's a little bit different. And unlike certain aspects of physical therapy and speech therapy, vision therapy doesn't really have a whole lot of consistency yet. So it's not like a sprained MCL where you get a dozen sessions if it's grade one and two dozen is grade two. And depending on where you go, it's kind of similar work. You don't have to be board certified to offer vision therapy. Lots of other specialties and disciplines are actually doing vision work because the need is so high. I look at it as, it's just raising awareness. It's awesome. But for the really complicated cases, you want somebody who has a team and ideally a doctor doing the work with you. Because we always joke and say we know what we're doing our first session and we know how things should look when we're done with all this. But how we get there, what we do each session is dependent on you, your responses and how much we're able to push you in terms of adjusting the level of demand so you can really engage in higher level thinking.

BRYCE APPELBAUM: So from a treatment standpoint, you want to definitely talk to the doctor doing the evaluation. What does treatment look like, who's doing the treatment, how often am I seeing the doctor? And if this type of work is not life changing, somebody's doing something wrong in the equation. And that isn't always the patient or the doctor. It could be a caregiver. It could be not supported. It could be a lot of things,

but there's just not the consistency yet that there needs to be.

ABBIE ROSS: Well, this talk was unbelievable, both of you. Amazing. If you want to Hear More from Dr. Appelbaum or Dr. Moore, check out the banner. It might pop up here any minute. There it is. Or today's agenda. Thank you both so much for joining us today. Incredible. All right, now we're going to hand the baton off to Heather Davies and Hollie Smith. They're going to lead our patient panel on this same topic.

LIZ FUEMMELER: I felt like that was a great, great topic. And I yesterday I was lowering my shoulders. Today I'm blinking and looking far, so I'm learning something new every day.

HEATHER DAVIES: It was awesome. And yeah, this is so new to me. I'm going to be going over to covd.org and finding a vision specialist. Thank you guys so much.

HOLLIE SMITH: Absolutely. What a great session. Thank you. Ladies.

HEATHER DAVIES: Hi, everyone. I am Heather Davies and I host the Ménière's Muse podcast. I have Ménière's disease and vestibular migraine, and I'm happy to be here.

HOLLIE SMITH: And I'm Hollie Smith, and I have Superior semicircular canal dehiscence and vestibular migraine. And I co host the VeDA retired support group, and I'm so excited for today to talk with our guests. What about you, Heather?

HEATHER DAVIES: I am, too. I'm excited because I was reading their bios and I can't wait to get in here today. We are excited to welcome our patient panelists, Sherry Martinez and Sarah DeSantis.

HOLLIE SMITH: Welcome, ladies.

HEATHER DAVIES: Hi ladies.

SHERRY MARTINEZ: Hi. Thank you.

HOLLIE SMITH: Sherry, I was wondering if you could briefly describe your vestibular journey.

SHERRY MARTINEZ: Briefly is tough, but I'll do my best.

HOLLIE SMITH: I know right.

SHERRY MARTINEZ: Mine kind of started off a little bit different than a lot of people. I had a vision loss event at work and had no idea what was happening. All I could see were colors and then my vision came back together. It was like literally watching two things come back into one picture. And so I had recently just gotten new contacts, a stronger prescription. So I just told myself that's probably me needing to adjust to the prescription. But things weren't quite the same after that. So I started

having difficulty with reading, focusing, some dizziness, like visual processing. And so I knew something wasn't right, but I tried to just manage it. And then one night at work, I had an event that it just felt like my brain flipped upside down in my head and I literally could not look at the computer. I couldn't read. I couldn't even get my eyes to focus on how you read left to right. I couldn't get them to go that way. Very, very scary. And that was my last day at work. So that kind of started the journey of getting properly diagnosed and treated, which I'm sure everyone can relate is a long journey.

SHERRY MARTINEZ: So initially my primary care said, let's get an MRI, let's rule out MS, scary things like that, tumors. But then ultimately I was referred to ophthalmology and ENT. And so I had gone back to my optometrist and oh, nope, you're fine, you're corrected to 20/20.

SHERRY MARTINEZ: Sure, we've heard that. And then I went to an ophthalmologist who said, no, the health of your eye looks great. Maybe go see a neuro optometrist. So I went down that route and initially with this particular neuro optometrist, we had difficulty getting objective findings. It was all subjective. So he did ultimately try me out in some different prism lenses and such. That did not help and oftentimes made me feel worse. So mind you, this is all during the height of COVID. So to get into a specialist is taking months and months. So I finally did get into a neurologist here in my city and he pretty much immediately knew I had a vestibular disorder of some sort. So he had asked me, have you been to the Heuser Hearing Institute, which is in my city in Louisville, Kentucky? And I said, no, but I've been to an ENT.

SHERRY MARTINEZ: He said, nope, have you been to Heuser? And so I said, no, I haven't. He said, you need to go there, you need to see Dr.

Edwards. And so there I went and this started the whole journey to getting properly diagnosed and down the treatment path. So initially I was diagnosed with bilateral multi canal BPPV and vestibulo-ocular reflex dysfunction. So in that they had referred me to physical or a vestibular therapist in the area to work on the vestibulo-ocular reflex dysfunction or VOR dysfunction. And multiple tests were being done at the institute during that time as well. So ultimately we found that I had bilateral perilymph fistulas. For anybody that doesn't know what a bilateral perilymph fistula is, it's just basically where you have fluid leaking into your inner ear space where there's not supposed to be any fluid at all. And it also affects your cerebral spinal fluid production, it starts overproducing to try to compensate for this leak. So everything in your head is off. So during all this testing, I had started seeing another neuro optometrist that did a test that I had not had before. It's called a VEP test, and it measures brain activity to certain visual... What's the word? Just looking at a screen that has like... Sorry, this is VM brain at its best.

HOLLIE SMITH: It totally is. The brain fog is normal for people with vestibular migraines

SHERRY MARTINEZ: Yes, the brain fog is real so. But no, it has a screen with like checkers that move and it measures your brain activity to different stimuli. And we discovered that I had... My secondary visual cortex function was completely offline. I had like, no brain activity when it came to that. So although it's hard to get all of these diagnoses and knowing what road is ahead of you, it was actually good because we finally knew. So down the road, I had both fistulas surgically repaired by a neurotologist in my area. And during all of this, I was doing vestibular rehab because even though I wasn't making progress, we didn't want to go backwards. We wanted to keep things working. We call it prehab. And we tried some vision rehab during that time as well. But it was really hard

because I had so much going on. And so we kind of took a break from that in between the surgeries and let myself heal.

SHERRY MARTINEZ: So that all was going on. And after I healed up for my surgeries, which is about year three, sorry if I didn't say that. I'm almost four years into this, like a month shy. Year three, I was able to complete a test at my neuro optometrist's office called Neurolens testing and was ultimately prescribed Neurolens, which is what I'm wearing now.

SHERRY MARTINEZ: So although I had tried traditional prisms and they did not work for me, these have been a game changer. They are progressive and contoured prisms that are made specifically for your eyes, and they have changed my life. Like, I have consistently been improving in vestibular rehab and vision rehab because of that. They've helped assist in where I am in space and having my eyes work together and seeing things more normally, where before I couldn't do any of that. So, yeah, huge working towards recovery. So.

HEATHER DAVIES: Wow, that's a lot there..

HOLLIE SMITH: Yup..

HEATHER DAVIES: Well, we're going to dive in a little bit more in your story in just a second. I wanted to hear briefly, Sarah, can you describe a little bit about your journey? And then we'll get. Get into all the nitty gritty of all the glasses and all the therapies.

SARAH DESANTIS: Yeah. Yeah. Wow. Sherry. What is... I'm wow. Your story is wow. And I am a terrible summarizer, so. And my journey started at...

SHERRY MARTINEZ: Same.

SARAH DESANTIS: I will try to summarize. I'm 38 now. My journey started at age 19. So a age 19. And I'm gonna try. I'm gonna... Oh, I'm gonna summarize. We'll try. At age 19, my first symptom was I was driving at night with a friend. We were on the highway, getting off the highway, and I felt like, I can't see this exit. And it was very scary. And I felt like, I can... I'm getting off, but I almost felt like I just... Something just didn't feel right. But at age 19, I'm thinking, okay, I'm just gonna keep going with life and brush it off. A few months later, I was sitting in a college class and my friend is next to me and I'm in the back row. And I thought, okay, I'm gonna just close my eyes for a minute and take a little... Take a two minute nap. And I sat there and closed my eyes. And when I opened them, I just... Everything looked bizarre. That's the only way how to describe it. Everything looked weird. I almost immediately felt the fight or flight kicking.

SARAH DESANTIS: And I'm like, what is going on? I feel so strange. And I remember looking at my friend and saying, do I look okay? I don't feel okay. And she was like, you look fine. But I didn't feel fine. I left class, I went home, trying to go about life, doing the day to day things and just feeling off. Went to Easter with my family, tried to watch the kids hunt for eggs. Couldn't focus on them. The lights were bright, the movement was... I just, was very... I was scared. So In May of 2006, they did find that I had a Cholesteatoma. So. And if anyone out there wants to chat later about Cholesteatoma, I. Because I don't find too, too, too many people,

but some out there. So it's a benign tumor/cyst, but it's destructive and it tends to eat away things in the middle ear. So it was eating away my hearing bones wrapped around my facial nerve, kind of invaded the mastoid process, which is just directly here behind the ear. So I went in for my first surgery, 2006, and afterwards I would go to my ENT and I can remember sitting there with him and him looking at me and saying, well, we took it out, so you should be feeling... And I wasn't. I wasn't feeling better. It didn't make a difference.

SARAH DESANTIS: And I can even remember sitting and trying to just sit there and make eye contact with him. I had to almost keep looking down. My system was just on fire. So I wasn't validated by my ENT for many, many years. And that's not to fault him. And I'm not here to fault anybody, but I wasn't validated. I was just told, you're just having anxiety. So fast forward 2007, 2010 and 2012, '14, the Cholesteatoma came back, had it taken out. It came back, had it taken out, had prosthetic hearing bones, had those taken in and out. And all the while I'm trying to go about life, trying to go and do things and not quite understanding why they feel so hard. Trying to go to Walmart and walking in and feeling like, I don't know what's. Why I feel like I can't handle Walmart and why can't I go to the grocery store and go up and down the aisles like I used to and not feel like I want to just get me out of here, basically.

SARAH DESANTIS: So in 2018, and again, I'm going through life, I'm trying, I'm doing my best, but I'm having all these strange symptoms. 2018, I woke up one day and the whole world was on an angle. I was working full time. I had to completely stop working, stop driving, and life just stopped. And it felt very scary and very... Just very scary. I took some time for them to figure out. The Cholesteatoma came back. So went back in for surgery. And in that surgery had a completely different type of procedure called a canal-wall-down mastoidectomy. So the previous ones, they left the canal

wall of the ear up, and this one, they took it down. Just because this had been such an aggressive. It just kept coming back. It wasn't behaving. It wasn't going away when they were... So, long story short, I did get in with an ENT who was also a neurotologist and an otologist. I found Dr. Bay. I found a wonderful vestibular. Her name's Emily. She's vestibular warrior on Instagram. I connected. I started putting the puzzle pieces together and got the diagnosis of vestibular migraine So I went quite a long time undiagnosed.

SARAH DESANTIS: However, the symptoms hit a new high in 2018 and that's when I really started to work on the healing process. So...

HEATHER DAVIES: Wow, my goodness.

SARAH DESANTIS: Very long story, very short.

HOLLIE SMITH: Your story is so relatable for so many of our vestibular people and especially for myself on the long journey. And Sherry, your story is so relatable and the complexity and continuing to add things to it. At some point it feels like Alphabet soup, the amount of letters after your name. So if you're just new to this vestibular disorder process, just know that it can feel overwhelming. VeDA has great information and Kyler can put it in the chat as far as all the acronyms that people talk about because it can feel overwhelming when you're first getting diagnosed and you're like, what are all these things? There was a follow up question, Sherry, on the chat about if you could repeat the name of the test that showed your brain and vision issues and what the lens was, that was different. And also does insurance cover it? Because that continues to come up in the chat of how are you even affording this? So we'll let Sherry start with

that. But then that how are you affording this question's gonna also go to you, Sarah. Go ahead, Sherry.

SHERRY MARTINEZ: Well, the test I had that showed my secondary visual cortex function was like completely offline, is called a VEP. It's a visual evoked potential. And I had that test at my neuro optometrist office. And just to note, although it was 100% offline, after the first fistula repair, I was retested and it came back 50% online. And after the second one, it was back 100%. So we repeated these tests after the surgeries and saw the connection between the two. I was still left with like binocular vision dysfunction, which we continue to work on. But it's a very good test. And I actually wonder how many of us out there could potentially be dealing with that. It was my brain's way of shutting down something that was like a big draw on my system. It was kind of to protect myself, my brain's way of protecting my body.

SHERRY MARTINEZ: And as far as the glasses go, they are called Neurolens. You can go to neurolens.com and read more about them. I would recommend them for anybody who has migraine or binocular vision dysfunction, among other eye issues. They really do help your eyes work together. They lighten the load from your brain and they're made specifically for your eyes through a test.

SHERRY MARTINEZ: So they've been just an absolute game changer for me as far as affordability. The VEP test was covered, the Neurolenses were not. So I think I paid about 900 ish dollars for them and then plus the frames. So it's not cheap. But it was worth it to me to put that money out there and see I'm a firm believer in trying all the things because I really want to get to the point of being symptom free if that's possible and I hear it is so.

HOLLIE SMITH: Yeah, that's really helpful information that some of the things are covered and some are not. Sarah, what has been your experience with being able to afford this long vestibular journey that you have had since age 19? I mean that's, that's a lot.

SARAH DESANTIS: Yeah, yeah. Well, it was great back in the day being on my parents insurance. No, I will... Yeah, I will second what Sherry said. Some things are covered and some things aren't. So it's really because... And it can get overwhelming. I feel like there have been so many times you want to try all the things at once and for most of us that's not realistic. So just picking and choosing things to try, as you can. I think that that would be my best advice. Just taking your time picking and choosing and really advocating for yourself with your insurance companies. I know a completely unrelated thing that bill I had going on, but just calling and saying hey, like can we resubmit this? Really being your own advocate is so important because if we don't do it, no one's going to do it for us. So being an advocate for yourself, I think, is important too.

SHERRY MARTINEZ: I second that 100%. I feel like dealing with the insurance companies has been a full time job for me and I have multiple claims that get processed incorrectly or initially denied. And you just have to be proactive and advocate for yourself. Call the insurance companies, file appeals if you need to and just keep them doing the job they're supposed to be doing. A lot of it's automated now, so you don't... Yeah, it doesn't even go to a person. It goes through a computer and the computer says nope. So just have to...

HEATHER DAVIES: I will tell you. Absolutely. And on that note, because I

know that a lot of us lose our jobs or have to step away temporarily, I found being completely honest with the finance department or accounts payable that ask them for hardship, if they have hardship applications or anything just because a lot of it a Lot of them have that availability to write a lot of it off, but they don't know if you don't ask. So. Yeah, well, I know this. This comes up a lot, but when you first started experiencing dizziness and disorientation in busy environments, did you think you were crazy? I mean, really, that just goes through your mind and the anxiety. And just like you said, Sarah, your doctor did not give you that validation, Sherry, did you feel that way when you first began having these symptoms?

SHERRY MARTINEZ: I don't necessarily.

SARAH DESANTIS: Oh, absolutely.

SHERRY MARTINEZ: Oh, sorry.

SARAH DESANTIS: Oh, I'm sorry that you said, Sarah. Oh

HEATHER DAVIES: I'll come back to you.

HOLLIE SMITH: How about, let's go, Sherry first and then Sarah.

SHERRY MARTINEZ: Sorry. My ears are full today too, so it's a little hard to hear.

SARAH DESANTIS: And I don't hear much in this ear. So overall...

SHERRY MARTINEZ: Same, hearing aid. I didn't necessarily think I was crazy. I just was like, what in the heck is happening to me? And I didn't know, am I gonna die? Is this life threatening? Like, what's happening? There was so much anxiety and fear of, what is this? So I didn't really feel crazy, but I just. Just more needed to find out what it was. And it was very scary. Very scary.

HEATHER DAVIES: Absolutely.

HOLLIE SMITH: Absolutely... And Sarah, what about you?

SARAH DESANTIS: Yeah, very, very scary. I took some notes because I was like this, you know, I'm 38, so going back to 19 to when it all first started. I do remember just driving around in my town and just feeling like, why does everything almost look... The word I could think of was, like, foreign. Things looked foreign. They didn't look right. And like I said before, just trying to go and do normal things and being like. And. And, you know, your body. And that's something I want everybody to hear. Don't let anybody tell you it's just... Oh, it's just anxiety. It's just your body and when something is off. And I think me being a younger... I think if it would have all happened at an older age, I would have been able to identify more. But trying to explain it is very difficult. And yes, it was very scary. The symptoms were all... They felt all consuming.

SARAH DESANTIS: And yes, very, very scary. So, yes, there were times that I thought. And like you said, Sherry, it was something really, really wrong with me. Not that this. Not that this isn't wrong, but it's something really... It's very scary and not.

SARAH DESANTIS: And not being able to explain it. I had a terrible time even trying to explain it to my friends. And my family, even to my mom, I would say to her, I just feel almost like I'm out of my body or I'm high or I don't know how to explain it. And it was, it was very hard to explain to people.

SHERRY MARTINEZ: It's so hard to put words to.

SARAH DESANTIS: Yes, yes.

HOLLIE SMITH: Sarah, I have to say that I relate and I want to say this to anyone who's on the younger side. For those of us, you were a teenager. I was a teenager when I started going through it too. And it is hard for someone who is young to be taken seriously. And that's a real thing. And we just want you to know, to trust your body. And that advice that you shared, Sarah, was fantastic. What just popped up in the chat was for you, Sarah, when you stopped working, did you go on disability? The person that asked the question hasn't worked or driven in almost a year. So they were wondering what that was like for you.

SARAH DESANTIS: Sure. And it's interesting because I actually have talked with Dr. Bay about this. He's my neurologist. He's fantastic. Such a wonderful doctor and person. We talked about this when I was

completing because through all this I discovered, wow, I really want to be able to help other people. So I was able to finish my master's in integrative health and I was working on my... What's called... It was a thesis type paper and he was, he and I were discussing what would be a good topic. I didn't end up going with this topic, but we discussed it. Disability is so not set up for people with chronic stuff. It is not set up at all for people like us that our day to day looks different. One day is not the same as another. And I did apply for disability at the time but I was denied and to be quite honest, I had no energy to fight it. I was blessed to have a ton of family support and a wonderful husband. I feel for everybody that is dealing with this by themselves or not able to have the financial support.

SARAH DESANTIS: I can't imagine how difficult that is. And I think it's something that really needs to be examined in our system. Like we really need to have it be set up more for people that have chronic things going on. So I did take time off. I was off for about four years and during that time I did a lot of, of healing. And it is amazing how the brain can heal. It's amazing how much healing can happen. I'm still amazed at my brain. And I thank God every day for the healing that's occurred. But I was able to get back to work part time. I work part time in occupational therapy. So I am in person two to three days a week, which is great. And it works for me. We have to just do what works for us.

HEATHER DAVIES: Yeah.

HOLLIE SMITH: 100. Thank you, Sarah

HEATHER DAVIES: What about you Sherry?

SHERRY MARTINEZ: Yeah. I was gonna say I can speak on this topic pretty well. I am in a union position. I'm an aircraft dispatcher. And so I do have certain protections for my job. But initially trying to apply for short term disability and taking so long to get an actual diagnosis, I was initially denied. And they give you an opportunity to write a letter to reconsider. I was denied that again. So I actually got an attorney and he helped me tremendously. We were going to go through the appeals process and we had so much documentation on me at that point that we didn't have to. They reversed their decision like really quickly. So then I got approved for long term disability and I'm still on that. I'm almost four years out of work and we're working hard to get back. But yes, and if you ever are on a long term disability plan through your employer, at some point they're going to make you apply for Social Security disability. So I had to go through that whole process. And yeah, I'm just so grateful that it worked out in my favor because had it not, I would be out of my job right now.

HOLLIE SMITH: Thank you ladies for sharing that. And just to mention a couple of things, first of all, there are two support groups. One for people who have had to medically retire due to their vestibular disorder and another one that is meant for people who are trying to go back to work. So two different stages of the vestibular journey and there's support groups for both. Kyler will put the link in the chat for that, but that was my experience as well. I had to retire from teaching elementary school. I also applied for SSDI. I was approved the first time, but that was because my medical records were same. We're this long... My recommendation, if anyone in the audience is intending on applying, to get letters from your doctor and the most information as you can. VeDA has a great article called Vestibular Disorders Are Disabling. Kyler can put a link to that in the chat as well because that is something that you can submit right, with your paperwork, whether you're doing it through Social Security or your

long term care insurance, whatever is the case for you. But it's hard whether you have something or not to make it through this long process for sure. So thank you ladies for sharing that.

SHERRY MARTINEZ: Yeah. And thanks for sharing that because I wish I had known about that at the time. But that will help a lot of people who are trying to apply for disability.

HOLLIE SMITH: Absolutely.

HEATHER DAVIES: Yes. So Sarah, can you. Do you still have issues with things that are visually triggering in the community? What things are triggering for you?

SARAH DESANTIS: Yes. Yes. So basically Walmart is my nemesis. I hate to use the word avoid, but I do tend to not... And I should backtrack and say it really depends on the day. Like some days I feel like I can go tackle more than others. But I do really have trouble in the big box stores. They're very overwhelming to me. I still really do struggle with the big box stores. I much prefer shopping at smaller stores, smaller grocery stores, boutiques. Not worrying about trying to go to, maybe even like a TJ. Maxx where there's a lot of stimuli going on. Yeah. The other thing that's been difficult for me, it still is with driving. I have difficulty with traffic is. And night driving is still difficult for me too. So those tend to be some of my harder challenges. Yeah.

HEATHER DAVIES: And what about you, Sherry?

SHERRY MARTINEZ: Yeah, I mean, I can mirror exactly what she said. The big stores, the fluorescent lighting, there's so many products surrounding all sides of you and it is so over stimulating. I tend to go to those stores with the ball cap on and sunglasses and I tend to try to focus for something that's ahead of me instead of trying to take in the whole picture. But yeah, and driving at night, it took me a lot of months of practicing driving. I am happy to say. I'm actually driving in the day now and we're still working on practicing at night. But night is tough because the lights are so bright and they just blind you and other things are like busy restaurants. So I tend to go when it's the early hour, when all the retirees are there. It's quiet.

HOLLIE SMITH: 1:30 is a great time for any vestibular person. Those I hours.

SHERRY MARTINEZ: It is. I mean, we'll do dinner at 3:00 sometimes just so I can go. And we often ask them to turn the music down and avoid places that have blinking lights. And yeah, I do still struggle too with bright lights or going from bright light to dark or vice versa. I kind of lose my sense of where I am for a second. So. But yeah, Costco is my nemesis.

HEATHER DAVIES: I wanna mention. So sorry, Hollie, I want to mention at the beginning, when I began my VRT, I had insurance only covered three visits, and one of my biggest things was Walmart, going into Walmart. But he had set me up to do a certain thing when I'm walking in Walmart, to hold on to the cart and to actually look at... Focus on one item on my left and then look to the right and as I walk slowly.

HEATHER DAVIES: So those are things that I had to do to get, to where I am today to be able to walk down an aisle. So definitely ask your therapist for those little exercises. They sound crazy. The first time I did it, my husband's like, what in the world are you doing?

HEATHER DAVIES: I couldn't do it a lot right away, but every time I went in, I made myself do those exercises. And now I can walk down there without being nauseous and without the dizzies and the. The sound and things still overwhelm you at times. But it is. Sorry, Hollie, go ahead.

HOLLIE SMITH: Absolutely. No, that totally makes sense. And you're right to ask your vestibular therapist on what is best for you, because I know for me, with the SSCD holding the cart, and I don't know, that might apply to you, Sarah, with a perilymph fistula, when I hold the cart, the bumps on the floor make it go through your bones, and you have that bone conductive hearing, and it makes it worse to hold a cart. So it's like, if you go in, it's just whatever you can carry. So it's those things that you make it work for you. But it's different for each of us in our own journey. And it's different in each season of your journey, for sure.

SHERRY MARTINEZ: Absolutely. And don't be afraid to. If you walk into a store and you're like, nope, today is not the day. I've done this many times. I turned right around and walked back out because you don't want to get so overstimulated or so symptomatic that now you're down in bed for the next day.

SARAH DESANTIS: Absolutely

HEATHER DAVIES: Dr. Appelbaum. That little white lie of faking a phone

call or have to go to the bathroom or something like that in a situation like that. That's how you get out of that situation. But switching gears just a little bit, there's been a question that has come up when in the chat, and I'll ask both of you. First for Sarah and then for Sherry. At what point did your doctors recommend therapy? As in like, cognitive behavioral therapy or acceptance and commitment therapy or EMDR or any of the other therapies? Were they recommended for you and did you find them helpful? So first for Sarah and then for Sherry?

SARAH DESANTIS: Well, of course, when I was first diagnosed and it was just anxiety, I was recommended. Yes, yes. For therapy and did go. It is a bit hard for me to remember at that point how effective it was. But I can tell you that when everything got really hard in 2018 and '19, I did go on my own. Nobody told me to go. I just innately knew the benefit of talk therapy and knew. And really, it's finding a therapist that believes you and understands that it isn't all just in your head. So I did. God is good. I found a wonderful counselor. And she and I have worked and we. I still see her. And I told her, I'm gonna just see you forever. Because I just love going to therapy now. And I'm such an advocate, or not advocate. I'm such a... I'm so excited to tell people, healthy people go to therapy, not only just vestibular patients, but... So it wasn't recommended to me when it got super, super hard, but I knew it was going to be beneficial because having that.

SARAH DESANTIS: And again, finding somebody that really does understand and believe you. I did have a therapist before that. I knew, didn't believe what I was saying and was throwing things around like, oh, I think when you're going into stores, you have agoraphobia. You're just afraid to go. And. And I said, no, no, I'm not afraid to go into these stores. I never was afraid to go shopping. I loved shopping. But when I get to the store and I'm trying to do these things, it's not feeling good. So I think it's

really also finding your person that you can really just let it go and be yourself and just... And it's been extremely beneficial for me. Therapy has been wonderful for me. We did recently start trying some EMDR just to try to help my brain to recalibrate and relax a little bit in those really triggering situations. So stay tuned on that.

HOLLIE SMITH: That's wonderful, Sarah. And when you find the right person, it makes all the difference in the world for sure. Thank you for sharing that. And what about you, Sherry?

SHERRY MARTINEZ: Yeah. When I got referred to the institute for all of my vestibular testing, I was... It was also recommended by them that I see their integrative therapist that happen to be in the same building, which was fantastic. It's one less place we have to go to because we know going to places is really hard when we're first going through all of this. And so she was amazing. I connected with her right off the bat. She does kind of traditional CBT therapy, but also comes from a more holistic approach. And she taught me a lot of different coping skills and did some holistic practices on me as well. And I still see her to this day, and I adore her and love her. Thank you, Barb.

HOLLIE SMITH: That's wonderful.

HEATHER DAVIES: Hey, I'm curious, Sherry, since you mentioned the coping skills, what is in your little toolbox? If you come upon a situation where that is triggering that you weren't expecting? Can you share a little bit about that? Then I'll ask you, Sarah.

SHERRY MARTINEZ: I typically, like, if I'm triggered, I typically will just stop for a second or a minute and just figure out what's going on, because oftentimes when you're triggered, you don't really understand in that moment what's happening. So I will just kind of stop and evaluate and assess, what's happening. If it's something that I can... If I'm out and about and I can try to handle. I do certain breathing techniques, box breathing, for example, just to try to engage the parasympathetic nervous system and naturally calm my system down. Havening techniques is another one. If I am at home and it's more than... It's going to require more than just that. I will typically go take a reset break, lay down. I'll do maybe some vagus nerve stimulation or a guided meditation or coherent breathing, which is something that I've just learned. I took a class on it. Good stuff. And I recommend it. Again, all of these things to activate that parasympathetic nervous system, to calm ourselves down naturally.

HEATHER DAVIES: Oh, those are all great things. Thanks. The havening. What is the havening?

SHERRY MARTINEZ: It's another technique where you use breathing, and touch. And you might do both sides, or you might work on your face or even your hands together. And it's just a method that calms the brain down. It calms our system down. I was taught that by my integrative therapist. So there's a lot of different tools that are out there, and I would just say find what works best for you. And the whole goal is to calm your nervous system. So whatever activities will. Or exercises that will activate that parasympathetic response.

HEATHER DAVIES: Beautiful. And that's something you can take with you all the time.

SHERRY MARTINEZ: Yes.

HEATHER DAVIES: And what about you, Sarah?

SARAH DESANTIS: I totally. I love that, Sherry. The activating your parasympathetic rest and digest.

SHERRY MARTINEZ: Yes.

SARAH DESANTIS: That's such a huge... Because really, it... And I think they did talk about it just before we were in our, in our patient panel here about that cycle of the anxiety and it. The vestibular and it's making it, it just makes it worse. So whether or not you're presented with either one first, it's going to make it that much harder. So I agree with you like it. And it depends like you said, if I'm out and about taking a break is a huge thing. Even driving has been one of the harder things for me. So when I'm driving, if I'm presented visually with something that looks difficult, whether it's long and winding or if my world seems to be going on a tilt, I will just pull up. If I can safely pull over over, I will, I will just pull over, take a break. And I've really seen that, like just taking that break sometimes. Then when I start to drive again, everything looks better. So just giving your... And like you said, deep breathing. I love box breathing. I like alternate nostril breath, which is a breathing... A technique that helps to calm the nervous system.

SARAH DESANTIS: If I'm home, I will do exactly what you said too, Sherry.

I take rests. I take nice naps. I'll put cefaly device on which accesses the trigeminal nerve. I know, we all know the cefaly device.

SHERRY MARTINEZ: Love it.

SARAH DESANTIS: Me too. Yeah, me too. So I'll usually do like the acute setting if it's a symptomatic day. There are so many things if... One of the triggers too for me has been the weather changes. Oh, these weather changes just get me. So I'll put in my WeatherX earplugs and I'll try to look at my WeatherX app and try to... But we do our best and I think that's something else I wanted to say today is it's just we are all doing our best and I think mindset for me has been one of the biggest things. So if it's a really, really hard day, having gratitude has been huge for me. Not comparing myself to other people, not thinking, oh, well, so and so is traveling to Europe tomorrow.

SARAH DESANTIS: And I'm laying in bed and everything feels funky. I have a warm bed. I have a roof over my head. I have food in my fridge. I have people that love me. What is more important in life? That I'm seeing the world or that I'm taking care of myself and I'm calm in my heart and for me, I'm a Christian, so Jesus has been my foundation in this whole journey. So really just finding gratitude, I mean, really, to me that's been huge. So even on a bad day, what in my toolkit is gratitude?

HOLLIE SMITH: I love, Sarah, how you brought up. It was Abbie that talked about the dizzy, anxious, dizzy cycle and then they kind of expounded upon that. But I love how you took it from that to using all these tools and then being able to find that gratitude just in the simple things of being safe. Even if you're just in bed, you're safe and...

SARAH DESANTIS: Right. Right.

HOLLIE SMITH: Kind of go along with what we've been talking about. One of the questions that's popped up in the chat was about sometimes when you are visually dependent and you're trying to drive and all of that's new, you get a lot of tight neck, shoulder pain. Do either of you have that? What have you been able to do about it? What's been helpful? So first to Sherry and then to Sarah. So, Sherry, have you had tight shoulders, neck and what's been helpful?

SHERRY MARTINEZ: Yes, so I do get regular massage. I'm lucky in my area. I have a great massage therapist that comes to the house and my vestibular therapist is trained in doing dry needling. And so I get that frequently just to release the muscle strain and stress that we're carrying. She'll do like gentle manual manipulation of my neck. So those are some things. I do now have a heated pillow that goes around my neck. So I'll do heat and yeah, the neck pain is legit and it's been a part of my journey since the beginning. Our poor heads are trying to manage all of these symptoms and your neck is directly affected, so. Yes.

HOLLIE SMITH: Absolutely. Well, those are great techniques. Have any of them been covered by insurance?

SHERRY MARTINEZ: Yeah, the dry needling has been covered by insurance. Not the massage, unfortunately, but... And then the vestibular rehab. The stuff that she does with my neck is covered by my insurance.

HOLLIE SMITH: Perfect. Thank you for sharing that. Great tips for sure, Sherry. And what about you, Sarah?

SARAH DESANTIS: Yeah, the neck pain and it definitely... And this is not just vestibular patients either. But when we're stressed or more in that heightened state, my... It goes right to that, right to the neck area. So yeah, massage is awesome. I love massage. Of course not covered by insurance but so good and so beneficial for the body. I've also found chiropractic to be helpful and also just to have this communicating better with the brain, getting the spine aligned. I've also enjoyed an acupressure mat that also has like a wedge that you can lay under your neck and just letting the body relax and hitting some of those of those pressure points. I found yoga to be helpful to help release some of that. And I do like to also use essential oil sometimes if I'm not having a professional massage. If I'm just having my husband rub my neck for me, we'll add some nice essential oils into the lotion. Like maybe some petite green. I really, really, really, really liked for anxiety or some of like the more woodsy smells to really ground me because I love being outside and being in nature has been really, really helpful for me especially walking and things like that.

SARAH DESANTIS: So getting those smells to just to relax everything and posture has also been important. I think. So remembering to... I tend to want to slouch so no reminding myself to... Yeah but. And right. We can't avoid stress in life.

SARAH DESANTIS: We can't avoid. So I know that it's, it's going to happen, it's going to get tight. But yeah, all those things have been really beneficial for me.

HOLLIE SMITH: So we got the posture, the blinking, all the things today we're learning. Breathing. Yeah.

SARAH DESANTIS: I forgot to mention I just started also trying and again not covered by insurance, but facial reflexology. I recently started trying and when I leave I feel very, very relaxed and my practitioner has noticed it also with me just during our session that it seems to be beneficial for me for relaxation.

HOLLIE SMITH: How did you find someone? I've never heard of that. So for anyone wondering in the chat now.

SARAH DESANTIS: Yeah, so she's a practitioner at a functional medicine practice. So that's where I found her because I had been going there for some other things. So she works at this practice.

HEATHER DAVIES: Oh, nice.

SHERRY MARTINEZ: You reminded me of something else that I've recently tried at my vestibular therapist's office. I don't know what it's called. I'm sorry. But it is, she'll put electrodes on the back of my neck and on the bottom of my feet. And it will send, like, frequencies through my body.

HEATHER DAVIES: Like a tens unit?

SHERRY MARTINEZ: Sort of, but much different. Like different frequencies

and stuff, I think. But it's a de escalation thing. And so I always feel better after I have a treatment of that and I combine it with box breathing or whatever breathing technique I want, and it really, really kind of resets your nervous system. I have left feeling significantly better, and it is covered by insurance. And I'm sorry, I don't know the name of it, but...

HEATHER DAVIES: We'll be looking it up.

SHERRY MARTINEZ: Yes.

HEATHER DAVIES: Sounds lovely. Let me ask, when you guys started VRT, was it overwhelming? I mean, did you start out slow? I know a lot of people are like, I feel worse when I go, which I did too. But as I continued going, I. It got better. But any advice on anyone that wants to start VRT? And did you find it overwhelming, Sherry? I'm sorry.

SHERRY MARTINEZ: Oh, that's okay. Absolutely. It was overwhelming. When we started, I didn't know I had the fistulas, so I would have the... Like, constant bobblehead. My whole body would be spinning in circles. And so we had to start very, very slow, like at ground zero and build off of that. But as time went on, we realized, we're keeping things status quote. We're not going to let it get worse. Now we know what you have to have done. And so after the surgeries, it was extremely helpful. Now, was it easy? No, it's hard. And you need to do it in a way that my vestibular therapist recommends not going above like a three or four above your baseline because you don't want to overdo it. Now you had steps backwards and then you're miserable. So, yeah, we started slow and just built on it and built on it. And over time, especially once I got these glasses, I just started progressing much more rapidly in vestibular and

vision rehab. So definitely do it. My biggest advice is to find a vestibular therapist that understands vestibular migraine or whatever the diagnosis is that we have, because I found a lot of them are initially just trained to treat BPPV.

SHERRY MARTINEZ: And so for me, I was very, very lucky in that my vestibular therapist understood more than just BPPV and the things that were so complex that she was a go getter and went to the people she needed to go to to find out what. How do I manage this? And...

HEATHER DAVIES: That's Fantastic.

SHERRY MARTINEZ: Oh, I feel so lucky. I can't even express how lucky I feel, but absolutely do it. It helps. I had no sense of where I was in space. I had VOR dysfunction. Plus my ears and the secondary visual cortex function not working. So it took a lot of work. And you just don't give up, you know, find a good therapist. Don't give up. Keep going. It does get better. Yeah.

HEATHER DAVIES: Yeah. Thank you. That's all so true. Absolutely. And what about you, Sarah? How did you feel?

SARAH DESANTIS: I would say Sherry hit the nail on the head. I don't have a lot more to add to what you said, but to keep at it. I wanted to mention that being kind to yourself, starting slowly, don't avoid things. Don't avoid because it feels bad. Keep at it. In 2018, when everything got really difficult for me, I would put on my ball cap, my FL-41s which we didn't talk about, but the light blocking glasses, take a cane and walk to my

mailbox. That was my therapy and keeping at it and listening to your body cues. And I think finding balance can be difficult because sometimes I'll think, I think I can go do this today and then I go out and I find no, I can't. And that's okay. It doesn't mean you failed. It doesn't mean that you're not getting better. The brain is amazing and I believe that we all have such capacity to continue healing. But even if your day to day looks like walking to your mailbox, that is huge.

SHERRY MARTINEZ: That's a big win.

SARAH DESANTIS: Yes.

HEATHER DAVIES: Yes, absolutely.

HOLLIE SMITH: Absolutely.

HEATHER DAVIES: Fantastic.

HOLLIE SMITH: And as we're getting closer to wrapping up here, just wanted to give both of you a chance to talk more about, the baby steps you took towards regaining your driving, your visually stimulating environments and for Sarah, what does that look like for work with you? So what things haven't we talked about that you would really like to get the message to people who are really struggling today in our chat as we've had so many questions come up and I wish we could get to them all. So just what haven't you gotten a chance to talk about that you think would be most beneficial for our audience? We'll start with Sherry and

then to Sarah.

SHERRY MARTINEZ: Sure. My biggest advice is do not give into this like because you feel so bad that you are spending a year or two years on the couch or in bed because you are only hurting yourself, it's only going to get worse. So as much as it hurts and as hard as it is, get out there. Figure out what tools work for you. If it's a ball cap and sunglasses, or the FL-41 glasses, earplugs, whatever you need to get started. Get out there and do the things. And because the more you do it, your body and brain are going to have a chance to acclimate and desensitize to these things. The less you expose yourself to, it's just gonna get worse. So don't make the mistake I did because I just didn't know. But yeah, the more I do, the better I feel. And so I think that is something we all share in common. And don't... Oh, gosh, advocate for yourself. Don't give up if one doctor tells you, sorry, I can't find anything that's wrong. You're just dealing with anxiety. Be the best advocate for yourself that you can see multiple doctors until you create a team surrounding you, that it's working from every angle and they're working together.

SHERRY MARTINEZ: And I'm not just talking like medications or surgeries. I mean, look at the outside stuff, like, meditations, guided meditations, breathing techniques, exercise, diet, hydration, proper sleep. All of these things play a big part in our recovery. And we need to do all the things, but you just have to do it in a way that is best for you. And you'll find that out as you start looking into all these different ways to help yourself.

HEATHER DAVIES: Absolutely.

HOLLIE SMITH: Absolutely. Those are great ideas. Now, do you

recommend going slow so that it's not so overwhelming, or do you recommend going faster? What worked best for you?

SHERRY MARTINEZ: For me, it was very slow. So, if I went into a store I was always with my fiance, and we would just go slow until, it was like, nope, I'm done. And whether we got the stuff we needed or not, we were done. And we just built off of that. So I would say that's the same. And like, even therapies, you start slow and you build off of that. Because what you're trying to do is increase the threshold of what your brain can handle, and you're not doing anything. You're not going to increase that threshold. But yeah, definitely start slow. Listen to your body, go in the way that you need to. That's best for you. Because we're all different. And although we share a lot of the same symptoms and difficulties...

HOLLIE SMITH: Yeah, it looks like Sherry froze, but she had some great ideas with the whole baby steps. That's such a big thing, right?

HEATHER DAVIES: Yes.

HOLLIE SMITH: And then what about you, Sarah, as we're wrapping up, what advice do you have for everyone on the driving, the working, the therapy?

SARAH DESANTIS: Yeah, yeah. Well, can I just say it was just such an honor to be here with you ladies today. And with driving, yes, exactly what Sherry said. I definitely day one was not out, it was driving around the town with a support person. And again, depends on the day. Do not go push yourself on a day that is a bad day. Now sometimes we have to

push to get to an appointment or do something and I understand. So use your medication and do not feel bad about using medication. There is nothing wrong with... Just doing whatever you need to do for yourself. I think there has, there's a stigma sometimes about like, not wanting to medicate or trying to. And again, we all are different. So everybody take this with a grain of salt. But for me, I had to work on that knowing that I will use my rescue medication when I need to and I'm not going to feel bad about it. And in terms of working, yes, finding and maybe it means not going back in person if you're able to.

SARAH DESANTIS: For me, I have to kind of be in person. So it's knowing that I'm not going to be full time and that is okay. I'm grateful for what I can do. And like I think Dr. Appelbaum talked about too, when you are able to be in a spot that like, even if I'm standing in a room, maybe a certain angle I'm, I'm standing at is visually overwhelming. Okay, let me change my position. Let me turn towards the non busy wall. Maybe there's some wallpaper that doesn't look good. Turn your body, and so what if you're facing away from somebody and looking like this while they're talking? It doesn't matter. Do what's best for you. Do not... I would say too, don't worry so much about what other people may think. Do what's best for you. Love yourself through this journey. It is a journey. But don't stay home every day. I made that mistake many times. And I think when you stay home and you don't work your system, it gets worse. You can decompensate and I've experienced decompensation multiple times, so I actually have felt worse the less I work my system.

SARAH DESANTIS: So for me right now, walking is like the best thing ever. And I'm again going back to mindset. I'm like, oh, this is so great. I'm walking and I don't have to use a cane. And that has been such a, such a healing therapy to just getting out in the sun and getting, getting the fresh air and taking a walk. But everybody just keep at it. Advocate for

yourself, be kind to yourself. And VeDA is so awesome. They have been such an awesome research and I'm so grateful for them. And I'm grateful for all of the wonderful people that you can connect with because there is so much healing too, and knowing you're not alone. So, yeah.

HOLLIE SMITH: That is beautiful.

HEATHER DAVIES: Beautiful. I love that. I love that. What a great way to end this session. Thank you so much, Sherry and Sarah, for sharing all your personal experiences living with life with vestibular disorders.

SARAH DESANTIS: Thank you so much.

HEATHER DAVIES: Also, Sarah has offered if you would like to follow her journey, please find her Instagram handle right here at the bottom of the screen. And you can also find it in the link in her bio. Thank you again, Sherry and Sarah. Have a great day.

SHERRY MARTINEZ: Thank you, ladies.

SARAH DESANTIS: Thank you. Bye. Bye.

HOLLIE SMITH: And we would like to say thanks again to the James D. And Linda B. Hainlen Discovery Fund and to the University of Minnesota Department of Otolaryngology for sponsoring this conference.

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

HOLLIE SMITH: Oh, Heather, I'm so excited to see you for tomorrow. Tomorrow's session is on the Power of Neuroplasticity and we can't wait to see you then.

HEATHER DAVIES: Bye.

HOLLIE SMITH: Bye, everyone.