

## **The Hearing Journal Dec 2021 PODCAST TRANSCRIPT**

### MAIN SHOW

**Speaker1:** Welcome to *The Hearing Journal* Podcast where we explore topics from the world of hearing healthcare— through conversations with incredible leaders, creators, and practitioners. We'll break down the stories, lessons, and truths of bringing better hearing to a world in need.

Established in 1947, *The Hearing Journal* continues to be the premier publication for hearing care professionals.

I will be your host. My name is Dr. D'Anne Rudden. I'm a doctor of audiology and a private practice owner. I coach other hearing professionals to build a confident presence by owning their authentic stories.

You can find me online at [www.dannerudden.com](http://www.dannerudden.com). Let's meet this month's guest.

Let's face it. Some level of painful personal trauma and tragedy – like illness or injury, death of a loved one, loss of a job, or an unexpected breakup of a relationship – is unavoidable. The question is: Will these private calamities erode your capacity to be happy or cause you to become stronger and better able to live a meaningful fulfilling life? Consider how differently carrots, eggs, and ground coffee beans are affected by the extreme adversity of being boiled. Like a carrot, adversity can soften you. You can emerge more flexible, understanding, compassionate, and grateful, OR you can let your life spirit turn into soft mush. Like an egg, boiling water can make you harder, stronger, tougher, and wiser, OR you can become more cynical, pessimistic, callous, and inaccessible. And like a coffee bean, once ground up, you can become transformed into something better OR lose yourself completely. But, resilience doesn't just happen. It's a mindset and a skillset. Resilience is built over time, often through significant difficulty --- with equal parts grit and grace.

Resilience has been called "ordinary magic" – while it can seem it is reserved for those navigating extraordinary circumstances, it is much more common than once thought. It's a human trait inhabited by all, but only used by some.

No one knows how to alchemize adversity and trailblaze through transition quite like Matt Hay. He is the current Director of Audiology Sales for Redux, the developer of a patented drying process for hearing instruments, wearable hearing devices, and personal electronics. Matt can often be found, in his words "slowly running, biking and swimming across the Midwest in support of non-profit hearing care and neurofibromatosis organizations. He is a frequent speaker, author, and podcaster on the subject of hearing loss and overcoming challenges. Matt's personal story of studying music leading up to his eventual deafness has been featured on NPR and optioned by Channing Tatum for Paramount Pictures.

On the podcast this month, I am so excited to chat with someone who may just embody every one of the positive qualities of being subjected to the boiling water of life, Mr. Matt Hay. Matt, welcome to *The Hearing Journal* Podcast!

**Speaker2:** [00:03:41] Thank you very much. I've been following what you do for a long time, so it is an honor to be here as well. And I know we're on audio, so everyone should just assume I look like Channing Tatum.

**Speaker1:** [00:03:53] It is true. We've been doing these by Zoom, but I was fortunate enough to have you in my backyard for at least the morning. So I will say I'm sitting with a much better version of Channing Tatum.

**Speaker2:** [00:04:10] That's how my wife introduces me to people.

**Speaker1:** [00:04:13] So perfect. Perfect. Well, Matt, for those of the people that might be listening that haven't heard your story, would you mind talking a little bit about your background—a little bit about your diagnosis, having neurofibromatosis, and the experience of having progressive hearing loss?

**Speaker2:** [00:04:33] Sure. So I had grown up around loud noises, lawnmowers, and cutting firewood. And I think in the 80s and 90s, the idea of hearing protection wasn't really top of mind. So I never had great hearing or we just assumed it was. That was why when I got into college, I noticed I started really having trouble hearing on the phone and it became a noticeable everyday problem. But I'm 18, 19 years old. I'm feeling pretty invincible; certainly, I don't have a "hearing problem." It got to a point where I did go to see an audiologist and the outcome of my audiogram was pretty convincing that, yes, I had significant hearing loss, but the test came back a little. So my audiologist referred me to an ENT, who then referred me to get an MRI to see a neurosurgeon eventually. And that MRI showed bilateral acoustic neuroma, which are tumors on your hearing nerves. And it's not terribly uncommon to have one side, but when you have bilateral acoustic neuromas, that's bad news because a lot of really important things happen on both sides of your brain stem. And that was what that led to a diagnosis of neurofibromatosis type 2 or NF2. So basically, that summary just covered a really terrifying 18 months of my life because I went from being that invincible 18/19/20-year-old wondering, "Am I going to live to graduate?" So yeah, my interest in the field of audiology was probably first piqued then because, I think back now and knowing what I do now, how fortunate I was to not have somebody just fit me with a hearing aid and instead say, "There's something a little different going on here. We want you to see an ENT." I don't think it's a stretch to say that an audiologist may have saved my life.

**Speaker1:** [00:06:34] Well, I mean, I think we often take for granted the life-changing effect that we have the potential of having on someone's life. So thank you so much for sharing that. Now you were given this diagnosis. I can't even imagine what that's like to be given [this diagnosis] that at any age but much less as a young person and then being told that you're going to eventually lose your hearing. At what point did the idea of an auditory brainstem implant come up and what was that journey like?

**Speaker2:** [00:07:18] So, our first step was to buy a dictionary because somebody says you have neurofibromatosis and bilateral acoustic neuroma and you need an auditory brain stem implant. You're like, Okay, great. Let's back away. I got a lot of things to learn here." I was fortunate to have a neurosurgeon who was very pragmatic and said, "You're likely going to lose your hearing. You need to begin preparing for that now. The time of being in denial is over. This is probably going to happen to you, though I operate." I needed to hear that because I was going to continue being the guy that said, "This is going to happen to me." And so as we started exploring what our options were because my hearing nerves were damaged. There's really nothing wrong with my ears. A hearing aid would have worked fine and gone down like sound going down a perfectly paved highway. But the bridge is out at the very end right before you get to the destination, which is the same for the case of hearing is your brain. So a hearing aid or even a cochlear implant wouldn't help. So, what he mentioned was an auditory brainstem implant, or an ABI, which had only been approved by the FDA a couple of years prior. I had to travel to LA to even have it done, and they sew electrodes directly onto your brainstem where they think your brain processes sound. And so I had the larger of the two tumors removed and the ABI implanted, and they said, "You know, we're going to turn it on in six or eight weeks and we'll cross our fingers and hope that you hear life sounds." At that point, my hearing had degenerated to a point where I was totally deaf. And when you don't hear anything, the idea of life sounds, which is like oven timers and police sirens, is pretty exciting.

**Speaker1:** [00:09:14] I think we take for granted that there are people that, like yourself, where hearing an oven timer might be the most exciting thing that happened to them all day. And for me, maybe that's the most annoying thing I could hear, but the richness of sounds in our lives and how important sound is in our lives to really create the best experience possible. I think that kind of dovetails really nicely into the part of your story that certainly resonated with me a lot when I heard you speak a couple of months ago. You talked about during that period of time and how you actively worked to remember the songs that were important to you, the music that was important to you. Why was it so important for you to store the soundtrack in your memory? And how did music play a role in your recovery?

**Speaker2:** [00:10:24] Sure. So my wife and I were newly married, and we accepted that the hearing loss was going to be a part of my future. And so living in Chicago at the time in Chicago, all the great bands come. I thought, "Well, what do I want to hear? What songs do I want stuck in my head for the rest of my life?" And that's a pretty heavy question. I mean, if you can only listen to one album, even if the greatest hits, what songs do you want stuck

in your head for the rest of your life? Because there's no guarantee that I'd ever be able to hear again the ABI would work. And so we set out, using every disposable income dollar, we had to see Paul McCartney, U2, Prince, and some of the great bands of our generation because that was the music I wanted stuck in my head. That was the music I resonated that resonated with me, and those are memories I wanted to recall 30 years from now when I was happy. I was sad, if I wanted to remember my mom and dad, you know, I wanted to be able to think back to the songs of Bob Dylan and Simon Garfunkel.

And so I became very intentional about listening to that music. What I did not expect, and I guess a bit of serendipity is in the process of trying to develop this soundtrack for the life, I hadn't gotten a chance yet to live that music became sort of the Rosetta Stone when my ABI did start to work. I pushed because I wanted to hear better. I wanted to hear more. Over the first 10 years, my ABI didn't do a whole lot for me and I could get a little better than life noises but couldn't use the phone. everything was still very muffled. It was music that allowed me to really move from B to C to really kind of for lack of a better analogy, turn my ABI up to 11 and really started to hear better. Because I could use those songs as a way of my brain telling my implant this is how things are supposed to sound. And so music really helped improve my hearing even a decade after I had lost all of my hearing and started to regain it with an implant.

**Speaker1:** [00:12:55] And talk about that story of the first time that you recognized a song when you shared that.

**Speaker2:** [00:13:10] So we had a CD from a wedding of a mixed CD called "Songs We Like," which was just songs we liked that we had picked for our wedding. And so that was music that I had studied over and over again trying to rehear it. And it still was just very garbled, and I might get a little recognition here or there, but it was just this cacophony of sound and it was too much for my implant to process. But I was trying. And one day we got in the car, and when I'm not with my wife, she rocks out to music, so we're getting her jeep, and she turned the car on the music's blasting and she immediately turned it down because she knows with music on, we couldn't communicate very well. And she immediately went to turn it down, and I grabbed her wrist and said, "Is that 'Crazy Game of Poker by O.A.R.'" which is a band we could listen to in Chicago just before losing my hearing. And it just in the midst of all of this sound, I very clearly heard the lyrics. I said, "Johnny, what are you doing tonight?" which is kind of a refrain and in that song? And I didn't really think about how powerful the moment that was. But I had fully prepared to never hear music again a decade earlier. And at that moment, I heard a song—like I totally, absolutely heard music and I still get kind of chills thinking about it now. And it took a second for us to realize how powerful a moment that was. And you mentioned a carrot before—that was the carrot that I needed of saying, Hey, this work that I had been doing to hear better has been very frustrating because it's not happening as quickly as I want. My ABI is not performing as well as I want, but I just heard music, man! And I never thought I'd be able to do that again. And that's a pretty great carrot to have. That was the motivation I needed to say, "All right, I can keep improving."

**Speaker1:** [00:15:14] Yeah, because I heard you say for 10 years, it really wasn't doing much for me. And I think this is where, when I hear your story and I think about the struggles that you've been through, the perseverance and the and the willingness to keep going, even though things are difficult, I think, you know, for me, that's an area of your story that is so motivating for me. And so, what would you suggest to anyone listening to help them overcome difficulties in uncertain times?

**Speaker2:** [00:16:13] Because so, to be clear, I'm not in any way professionally qualified to offer this advice, so I will just share my own experience. For me, it was finding the right motivation, because it's not a coincidence that around year 10, my kids were born. And as a dad, you want to be there. As a husband, I wouldn't be there, just put my wife. But then as a dad, all of a sudden I have these new people that I want to meet and get to know and talk to. And I could kind of remember what my wife's voice sounded like, but I had never met them--my three kids now, and I had never met these people, and I want to get to know them. At the time, we had newborn twins and I couldn't distinguish between their cries. And that hurt, and that was something that I knew I needed for my own sake to be able to do, but I had gotten lazy with my implant. I would say that it wasn't improving. But what work had I really done with it? I had worn it, but I hadn't really worked on it and practiced with it.

And so I guess I just answered the question in a few different ways, so I break it down. I could be pretty persistent about stuff if I have the right motivation. The answer one would be to find the right motivation for what you want to do. It's easy to say what to do this thing, but you need to have the reason to get off the couch and do it. So identifying the thing is easy. Finding the right motivation for me was a little harder, but I found that motivation with the kids being born and wanting to hear that. Second is I started practicing with much greater intention, and I didn't know what that meant when people used to tell me that. But I would just have my eye on it and think that meant I was practicing with it. It was a practice that was just kind of going through the motions. But when I started breaking that down into instead of trying to hear the world, I wouldn't try to hear this one song over and over again, and that worked OK. But then I started working on, "what if I can hear just these specific sounds?" And people in the audiology industry would know that as phonemes. My hearing improved, even more, when I stopped trying to listen to the world and stop trying to listen to a whole song and broke it down into individual sounds and then celebrating those small wins. And the third thing is when you break things down and recognize the small victories, you know, like, even now, I can't casually talk to my kids on the phone. And so instead of getting discouraged about that, let's go back and think that once upon a time, I couldn't tell the difference between their voices at all. How it helps that they're now almost 16. My son and daughter don't sound alike. But the small world of being able to differentiate that we mentioned before a carrot on a stick, I'm very motivated by stuff like that. So, if I can find a lot of small wins even throughout the day, that helps keep me moving forward. It's easier for me to be persistent if I can celebrate those small wins. It's also a great way to avoid being frustrated because instead of saying, Well, I can't hear the world anymore, but I can tell the difference between Anna and that's a pretty big deal. And eventually, that's going to help me here the world, right?

**Speaker1:** [00:19:58] Oh my goodness. Matt, her time has gone so fast I can hardly believe that this first segment is over, but I don't want you to go away because we're going to dive in even deeper on the Aftershow. So stick around. Matt, hey, thank you so much for being here on the hearing general podcast and for inspiring us so much.

**Speaker2:** [00:20:21] I appreciate you having me. This has been great.

**Speaker1:** [00:20:25] Want to ask a question on a future episode or join in the conversation with one of our guests? Tweet us at @hearingjournal or @AudioDocRudden or shoot us an email with your thoughts. Until next time, keep your ears open and take care of each other.

## AFTERSHOW

Speaker 1 (00:44):

All right. Well, we are back on the hearing general podcast after show with Matt Hay, who, if you didn't listen to the first part, go back and listen to the first part because his story of being diagnosed with bilateral acoustic neuroma, the eventual loss of his own hearing, the implantation with an auditory brainstem implant, is just so incredible. And he's so engaging. And so Matt, I'm so glad that we get a little more time with you cause it 15 minutes is just frankly not enough. It's just not enough.

Speaker 2 (01:24): I'm just glad they didn't kick me out.

Speaker 1 (01:26): Not yet. Not yet, but let's talk about, cause you said something in that first segment, when you were talking about, you know, in your mind, in the mind of a patient, you said to yourself, well, I want to just be able to hear the whole world. So, and then that was frustrating because that's a lot to have that as the goal. I want to hear everything in all situations and I never want to have any problems. And then you said, okay, well, I'm going to break it down to something a little smaller and a little smaller and a little smaller. And you've talked about doing phoneme work, which for most people is probably like, oh, that's the, you know, like put me to sleep part of training your brain kind of thing. But the impact for you was actually really dramatic. I know that you have been working with Angela Alexander who is an auditory processing guru. She's just amazing. I'm such a huge fan of her.

and that's made a big impact on your performance. So talk a little bit about your experience with that and working with Angela and how that's changed things for you.

Speaker 2 (02:44):

So I met Angela, online through an audiology group and reached out to her just because I thought she was doing some cool things and just seemed like a neat person. And at the end of our conversation, our first conversations, she said, I would love to just do some testing to see how you hear things. And I very, I said sure, but very selfishly, because I thought, you know, Angela might be a friend out of this and then be able to introduce me to other people. So I had zero expectations and I didn't confess this to her, but I thought there's no way she's going to be able to help me. I'm on year 18 of my ABI and I'm already, performing better than fortunately, better than a lot of people that have an ABI not because of just what I do, but I was lucky that it was implanted in the right spot and that 12 of the electrodes worked.

I had very low expectations about what Angela was doing and I had never even heard of auditory processing training. , but I agreed to do it. And so for context, my unaided open sentence recognition, sentences recognition and quiet was in the mid-sixties. And, I think that's generally considered very good. So Angela and I started meeting for about two hours once a week, you know, for three or four months. And, and, and as it was happening, I couldn't really tell a difference either. I just knew I was really bad at those tests. I didn't like taking them because you'd have to really concentrate. And I, I, I don't like taking tests that I know I'm going to fail and it's, we went through a few sounds and I had never had anybody to test me on very specific sounds.

You know, like how a world as a guy, as a deaf guy with 12 electrodes. I mean, I don't actually even know my scores with her but I know I failed pretty, pretty bad. And after hours and hours of working with her, I just had my most recent having done nothing else different than the last two years. And I had my most recent map update. And the outcome of that was after my APD training was my hint recognition of the scores improved to 96%. And I was tested on AzBios for the first time ever and scored a 78%. And I could never hear well enough that my audiologists even thought to test me for AzBio. So there's a correlation causation thing. I don't know if it's because of the APD training, but I didn't do anything different and improved more in one year than I did in the first 17.

Speaker 1 (05:37):

I think that just blows my mind. I mean, you didn't say it like you've glossed over it, but you said it like, like, oh, this is something that 96%, I mean, like in my head, I'm like 96%. Like, I don't know if I can do 96% on those tests. That's crazy. That is so, so good. And I think that speaks to, you know, how we're learning more and more in audiology about the importance of, you know, the software, if you will, part of hearing, which has all the brain stuff. That is where the rubber meets the road, the ear I used to say the year just kind of lives. You know, we used to think it just lived on its own little private island and that, you know, it didn't really have a connection with anything else, but we recognize, and I think, you know, probably many of our research scientists would just be rolling their eyes right now thinking like, really, you, you didn't see that connection, but I think it's just being brought to light so much more now than it ever has been, especially in the last year.

Speaker 2 (06:49):

I can't answer this from the clinical side, but from a patient side, I'm pretty invested in hearing care and have worn hearing aids and now an ABI. I mean, I hear with my brain literally, and I did not hear the phrase brain hearing ever until last year. And so even if it's a really, you've never heard about that from your side, from a patient side, I can tell you that patients do not think they hear what their brain, yeah. With Dr. Carol Flexer—I had the opportunity to listen to her speak a few weeks ago—who said, “Your ears know nothing.” And she kept hammering home the point that your ears don't know anything. They are a conduit for vibration to get to your brain. And it's just fascinating to me and it, and from a patient perspective, I love that the industry, that's trickling down to patients now and that, my hearing care professionals are becoming much more aware of that too, and comfortable with it, that they are sharing that with me, and that part of my care now includes understanding the brain's involvement in listening.

Speaker 1 (08:04): Yeah. And you did all of this work via tele-health and that's for me also the really interesting part of, you know, the gifts of COVID and the last year that you could work with somebody who is literally in another hemisphere of our planet and still get the outcomes that you are getting that, how was that for you working online?

Speaker 2 (08:32):

I do most of my calls now over the last couple of years through the zone, because of my hearing loss, I also use Otter, which is artificial intelligent voice recognition software. But I promised Angela I wouldn't cheat. So I turned that, screen back when she and I were speaking and I bought her a really nice, speaker online on Amazon. , it was maybe a hundred dollars and the speaker quality was just better than my iPhone, but being able to see the person here through a good, speaker, and then if I need to be able to read what they're being said, what they are saying, the communication was actually, pretty simple. I would, I would tell Angela there's times where on a phone call that I forget that I'm deaf and I never imagined how it happened and just thinking about all of those different things. It's amazing to me to think what wasn't widely known or used even 18 months ago. , you're talking about tele-health, Otter via voice recognition, software, even video conferencing. Wasn't great. I mean, Skype had 20 years to try to get there, , what we're doing with APD, you know, , the data that we've gathered on moisture impact on hearing aids and what we can do to correct that, , artificial intelligence technology in hearing aids, all of this stuff is changing the way people operate every day. And none of it existed two years ago, or existed in the way that it does now. And I think that's should be encouraging from both the practice side and the patient side. Yeah.

Speaker 1 (10:14): It's really, for me, what continues to make me excited about working in audiology is that, you know, we are evolving into a much more rich profession than I think we could have even imagined a few years ago. And I really appreciate you sharing your perspective as a patient as well, because sometimes, you know, we, we get a little lost in our own, in our own bubble, and we forget about how that's actually impacting our patients so significantly. I want to circle to this idea of moisture because I know that's where you hang your professional hat, and it's an area of interest. You're doing research in this. And I want you though to start with yourself as a patient, because you came to this profession, not just because of the acoustic neuromas, but this has now become a career for you. And because of a very specific incidents where I think you were skiing and you maybe had a wipe out, is that true? Did I remember that correctly? Talk about that story.

Speaker 2 (11:32): Yeah. So skiing with my family in Michigan on day one, like run one wipe out. And because it shouldn't be a shock, but if you have bilateral acoustic neuromas, you probably also have some vestibular issues. So I didn't belong on skis, but I lost my implant in the snow. And by the time I found that it was frozen, I mean, water was literally frozen; it had drops coming off of it. And it was dead. So no amount of rice or hand warmer in the bathroom was going to bring it back. And so I found a company that was drying cell phones, and they put my implant in there. They were local, and I put my implant in there and 12 minutes later they brought it back to life. And so that in itself was a wow moment for me because, I mean, my hearing aids have evolved, and its awesome. I think hearing aid technology is just mindbogglingly cool. And so when people complain about their Bluetooth connectivity, I'm like, are you kidding? You realize how much that thing's doing in such a small space. The only problem I've ever had with them is I always got wet. So the opportunity to go work for somebody that was maybe fixing that problem, because it wasn't just a sound thing. But when I have to send my implant back half a day off work, paid apart, pay a copay, I'm without it for a week, which means I either go back to one that was programmed 10 years ago. That sounds terrible, but I'm deaf for a week. It's a significant physical, mental, financial difficulty. Every time I, my implant would get wet. So the opportunity to help remove that hurdle and the hearing care process was, I mean, I, the day they dried it for me, I said, are you hiring? Because I thought this is, this is the kind of company I want to be a part of that.

Speaker 1: I certainly take that for granted that if someone's device is malfunctioning and it needs to be sent off for repair, for you that's misery. That's devastating to have that happen. And to think that you could have had that situation, but instead you, in 12 minutes, you were back in business. I mean, that's, that's ridiculous. So you were motivated to continue to see this type of technology be available in the world. And so you've been doing some research, so there's not a lot, I mean, moisture in hearing aids, I think, what did you tell me earlier that there hasn't been a new article on research in hearing aids and moisture and things for how many

Speaker 2 (14:18):

Years, like decades? Like,

Speaker 1 (14:21):

It's just not all that sexy, right?

Speaker 2 (14:24): And to be clear, my intention is not to be a commercial about that. I might request, I guess, for this audience would be the best thing you could do for a patient is just be open to new ideas. And you might try something and not like it, send it back, give it to you, you're not committed to doing that thing. Or you might get research more on APD and decide that's not really gonna fit in my practice. , and you don't have to do it. So I wouldn't ever, expect anybody to adopt all of this new stuff, because you're already busy, but I do believe it's in my best interest as a patient, I would want my practitioner to at least try it, or to explore it, to see if that is right for their practice or their patient or their organization. I hope it's not a place to make, go make that request. But I look at things from a patient view and I would want that, you know, then maybe it's not the right fit, but why not try it?

Speaker 1 (15:31): So give a little tease about some of the things that you are learning in your research with moisture and electronics and how that's what's coming up.

Speaker 2 (15:42): Well, we know that 98% of every hearing aid or implant or hearable that comes out, that right now, as much from it, 98%, there, there's a lot of effort to improve moisture resistance in age right now by manufacturers, which is great, but they wouldn't be putting all that energy into it. If the hearing aids weren't having a significant problem with moisture. So we're seeing that it's not geographical, it's not seasonal, you know, and I even talked earlier, you're in Northern Colorado. Do you really have moisture issues in November and Northern Colorado? And that's not the geography that matters as long as you put a hearing aid in an ear that is hot and wet and has no airflow and then compensation happening over and over again. , that's, what's getting them away. And, so for sending some, some of that new information and I in two weeks at the ASHA conference in Washington, DC.

Speaker 1 (16:44): Fantastic. Fantastic. Well, I want to flip the script a little bit to get just a little more personal, because I did say in the introduction if you didn't listen to that Channing Tatum is playing you in the movie of your life potentially. That's pretty cool. But what else do we not know about Matt?

Speaker 2 (17:17): Oh man. And I'm getting put on the spot. I would say that some of this is all very surreal to me because until two years ago, I was in a marketing research job where I think my hearing loss was tolerated. And so it's very new to me to be sharing, and I'm comfortable doing it. I just didn't have anybody asking, asking me to share. , it's very surreal to me to have an opportunity to share some of this experience that I have sort of accidentally gathered. , and I'm very proud and honored to have the opportunity to do that because I know not everybody, with hearing loss maybe has the microphone in front of them that I do right now. And I, until I take that responsibility very seriously. , and you know, I'm a dad and a husband first, that, yeah, the Channing Tatum thing is cool. There's no guarantee that happens. But aside from being a cool story at a party, that doesn't really change anything in my life.

I'm trying to get a little bit more confidence in sharing this experience. And only because, I had a moment and I don't know if you've heard this story, but I do a lot of NF-related fundraising and events. And I questioned, I thought it was very self-involved to get in front of a microphone and share this like, whoa, why I thought it was very egocentric. And so I resisted doing that for a long time for that reason. And I went into a conference when you sign in, you got the black survey and you're filling out your stick on a name tag, and a mom with a boy there looked at me and said, do you have NF? And I said, yes. She put her hand in her son's head and said, "I'm just so glad you exist." And I didn't know, is that a compliment? I don't know. But she wasn't saying you're a good guy or you're a terrible guy. She was just so glad that I exist. And so she went on to explain that her son was recently diagnosed and she's been doing scrolling; she falls asleep at night with her phone trying to figure out what she could do as a parent for a kid with NF and trying to learn about all of this stuff that most parents would feel when their kids are diagnosed with a disorder they never even heard of or can't spell. And she said I wonder, like, how are we going to get through today or the school year? And to see a 40-year-old walk in here who has an implant and facial

paralysis, but you drove here and you walked in here and your wife is behind you. "I needed to know that you exist." And so that was a pretty big moment for me because maybe the egocentric part wasn't getting up and talking, the egocentric part was not doing that. So that's been a big, motivator for me to try to get out and do more of this is why I was so grateful when you asked me to do this because our lives kind of crossed at the right point, where you had an audience that maybe wanted to hear a certain kind of message and I was just getting the courage to start sharing my own experience.

Speaker 1 (20:59): Matt Hay, I'm blown away by you.

Speaker 2: Thanks!

Speaker 1: It just leaves me absolutely speechless and profoundly impacted. And I am so grateful to have had some time with you and for you to be willing, to be so open, and to share some of the challenges in your life, but to also provide that layer of hope. And I think that's more than any of us could ever ask for. So I expect us to have many more conversations as you get out there and shine your light. Thanks again for being here.