[Snap Judgment intro]

[upbeat music]

**Glynn:** Snappers, do you remember those audio tests you had to do with elementary school? The ones where the tones change pitch and speed, and you raise your hand every time you hear something different? Well, for Matt Hay, this childhood rite of passage is where it all started.

**Matt:** I never raised my hand enough in the whole tone test. I can even remember sometimes raising my hand because I felt like it had been too long since I heard the tone. So, I was just making it up.

**April:** Matt faked his way through hearing tests for years as a kid, he just ignored the fact that his hearing was not as good as everyone around him. And then, when he was 18, he applied to West Point for college. He had to go to Fort Knox for the physical.

**Matt:** And I failed. I got a letter from the government that I had failed because of substandard auditory acuity.

**April:** But still, he ignored what was happening, until he couldn't hear people on the phone. He went to see a new audiologist.

**Matt:** And she said, "Your results just came back really weird. I'd like you to have an MRI." Nobody goes into an audiogram and comes out with a diagnosis of getting an MRI.

**April:** The scan showed two tumors in his head pushing up against his left and right hearing nerves. Doctors diagnosed him with a rare condition called neurofibromatosis type 2.

**Matt:** It affects 1 in 40,000 people, and we had never heard of it, because why would anybody have heard of it?

**April:** Within a year, he was basically deaf in his left ear. The tumors in his brain were getting bigger. A couple years after college, his right ear started to falter.

**Matt:** Everything grew really fast. I mean, it went from nonissue to major issue.

**April:** Matt went back to the doctor. At first, this visit seemed like all the others.

**Matt:** The same generic pictures on the wall, the same generic wax paper on the table that they make you sit on.

**April:** The doctor sat in front of him in the same white coat, on the same wheelie stool.

**Matt:** The doctor said, "You know what? You're probably going to lose your hearing. It's not that big of a deal," which is a bold statement for somebody that's not going to lose their hearing.

**April:** He told Matt that these tumors can grow anywhere and do way worse damage than hearing loss. He could become paralyzed, go blind, even die.

**Matt:** And so, this was really the first moment in my life, not a girlfriend breaking up or losing a basketball game, but the first real moment where basically it doesn't matter how hard you work and it doesn't matter how kind you are, you're going to be deaf.

**April:** The doctor said it could take a few years, or it could take 10.

**Matt:** When something takes 10 years to go away, it's hard to prepare for the moment. It's like waiting for a steamroller.

**April:** Matt was 22. He figured while he still had some hearing in his right ear, he'd sign up for a sign language course. Once a week, he filed into a makeshift classroom at the Chicago Parks Department.

**Matt:** Those old school desks with names carved on them. They had the little place underneath where you could put your Trapper Keeper. So, there was a little bit of intimidation of what was my first day of school.

**April:** Matt was not good at it.

**Matt:** It took me about six weeks to learn the alphabet. That's what, four or five letters a week. I also think most of the people in the room were there to learn sign language because it would be neat. I was there to learn it because it was a need. And it's not as fun to learn something out of need versus just a want.

**April:** He also started learning to read lips and developed a distaste for mustaches. But there was this other thing he did that nobody taught him, that there was no class for.

**Matt:** When you have a neurosurgeon say, "Hey, you're going to lose your hearing, but that's not that big of a deal," you very quickly want to start hearing things, like listen to those songs that that really meant a lot to you because you might not ever get to hear then again."

**April:** He started listening to his favorite songs on repeat, over and over.

**Matt:** When you think about getting a song stuck in your head, that usually just happens till you hear the next song and then that one gets stuck in your head. I found myself in a moment when I thought, "What songs do I want stuck in my head for the rest of my life?"

**April:** It was the late 90s. Between Matt and his two roommates, they had one computer. It was on a folding table in the corner of the apartment.

**Matt:** And we referred to it as the Portal of Knowledge.

**April:** Matt used it to look up song lyrics. He let his roommates fight over what to put in the Sony five-disc changer. And Matt read the words while he listened, etching the songs into his brain.

[*A Day in the Life* by The Beatles playing]

**Matt:** The Beatles was probably the first music I was a student of.

**April:** He and his roommates would geek out, counting the crescendos and deciphering hidden messages.

**Matt:** That was probably my first introduction into music is more than one layer.

**April:** He did a lot of his music appreciation work on long drives in his silver Dodge Intrepid rotating through Phish, The Beach Boys, or Prince.

It just feels like a very heavy choice to make, and I sort of see it as you're choosing the soundtrack for the rest of your life.

**Matt:** I don't think that's like an overly dramatic way to put it because I didn't know if I would ever hear again. And so, what song do you want stuck in your head from age 25 to 85? [chuckles]

**April:** Matt went for a lot of greatest hits and a few besides.

**Matt:** It was one of those like, I really need to start cramming from Prince.

**April:** When his hearing went, he wanted to be able to hear the songs in his head, but also conjure the memories he associated with those songs. This one took him back to high school when he and his good friend, Stephanie, first got their driver's licenses.

**Matt:** And I've got great memories of driving down the highway on her Subaru Legacy with all four windows down on a summer evening. And just *7* turned up all the way and all of us singing horribly along with it.

[*7* by The New Power Generation and Prince playing]

**April:** Matt says he was really deliberate about choosing songs he associated with good times. He was not memorizing angsty teenage rock anthems or depressing ballads.

[*Good Vibrations* song by The Beach Boys playing]

**Matt:** I never connected with melancholy. That was just not how I've been programmed. If there was a song I associated with sadness or loneliness, it's not something I would have latched on to.

[*Good Vibrations* song by The Beach Boys playing]

**Matt:** When I think about *Good Vibrations*, I just think about the three buddies in an apartment. We're all working and getting a real paycheck for the first time in our lives and we've got our own place. And we're going out in the city and we come back from a night out, and just [chuckles] let's play some Beach Boys.

[*Good Vibrations* song by The Beach Boys playing]

**Matt:** At the time, I can remember thinking like, "But I don't think people appreciate just how great this song is." So, that became one that I thought I really need to capture that song.

**April:** Around the same time, all this was happening, Matt met a girl, Nora. He was at a New Year's Eve party in Chicago.

**Matt:** At some point in the night, got into this really great conversation with Nora, and was just really struck by her. She's incredibly intelligent.

**Nora:** He was funny.

**Matt:** I remember her just being this very joyful person.

**Nora:** He was kind.

**Matt:** She was also very cute.

**Nora:** And he was cute.

**Matt:** And so, I positioned myself to kiss Nora at midnight.

**April:** He got Nora's phone number and the next week he called her. Nora was in med school in Indianapolis at the time. And a couple of weekends later, Matt was on his way for a visit. He left work on Friday evening and stayed until 4:00 AM on Monday.

**Nora:** It was awesome.

**Matt:** So, we started doing that once a month. Then, it became every other week. Then, it became every week.

**Nora:** He had a good side. So, I would always walk on that side, talk on that side. It became habit. So, that was no big deal really.

**April:** She started going with Matt to his doctor's appointments and she started taking those sign language classes too.

[upbeat music]

**April:** They doubled down on music together. They went to concerts and festivals.

**Nora:** U2.

**April:** Paul McCartney.

**Nora:** Phish.

**April:** Camping at Phish shows.

**Nora:** Beck.

**April:** I can remember Nora taking a radio into the bathroom and smell her perfume and overhear the music she's listening to, as she's getting ready to go out.

[*Beautiful Way* by Beck playing]

**Matt:** *Beautiful Way* was always the song.

[*Beautiful Way* by Beck playing]

**Matt:** I go on and peek in and she's singing to herself and just probably having more fun, getting ready listening to music than she had going out.

**April:** Matt remembers this time Nora helped him and his friends move into a new apartment.

**Matt:** And I remember listening to Beck and being in our new apartment with boxes everywhere, and dancing to Beck. And it was the first time I told her that, "I think I'm falling in love with you."

[*Beautiful Way* by Beck playing]

**Matt:** I think when you have the right moment in your life and the right person and the right situation, the song that's there when that happens can become really powerful for ways that you didn't expect or maybe you can't describe. When I would think, "Oh, I'm losing my hearing," I would think Nora, I want to make sure that I remember what these sound like.

[*Beautiful Way* by Beck playing]

**Nora:** And he had a spinal tumor in his neck that became awful, to the point where he couldn't really move, sleep, do much at all.

**April:** Matt was going to need major surgery to remove it, but he and Nora had only been dating nine months.

**Matt:** I was like, "Hey, I get it. You don't owe me anything. I'm going to be in rehab. I don't know what life is going to be like for me. I totally get it if you-- this is more than you wanted to sign up for."

**April:** Nora dropped out of med school. She says her priorities shifted after falling for a guy with a disease that reminded her of how short life was.

**Matt:** We listened to this on the way to surgery.

[*Three Little Birds* by Bob Marley and the Wailers playing]

**Matt:** "Don't worry about a thing," is a good theme on your way to brain surgery.

[*Three Little Birds* by Bob Marley and the Wailers continues]

**Matt:** This is the song that we did do something other than cry. [chuckles]

[*Three Little Birds* by Bob Marley and the Wailers continues playing]

**April:** But the surgery wasn't alright. The doctor has removed the tumor from the top of his spine, but there was a complication.

**Nora:** He woke up from that surgery and couldn't walk. He had sensory loss from the waist down.

**April:** Doctors told him they didn't know if he would ever walk again.

**Nora:** The doctor casually said, "Well, wherever we are in a year, that's where we'll be." And that's all anybody really knew.

[*Three Little Birds* song by Bob Marley and the Wailers playing]

**April:** Matt moved into a rehab center and he was by far the youngest person there. The schedule was not designed for 23-year-olds. Lunch was at 11:00, dinner was at 4:30, lights out at 6:00. So, Nora would come, break him out of there.

**Matt:** And she'd take me to the mall and push me around on a wheelchair. And we got in trouble for staying out too late, which was like 5:30. 23-year-old rehab rebels.

**April:** Matt's already had a girl willing to give up med school to sneak him sandwiches, to snuggle in his twin bed watching the World Series. A girl who after visiting hours trained for a marathon to raise money for research into neurofibromatosis 2.

**Matt:** [chuckles] You can't not marry. You can't not marry the girl that does that.

[soulful music]

**April:** Two years after surgery, Matt and Nora got married and bought a condo in Chicago. Life was normal and happy. But Matt could no longer hear soft sounds, like the door opening when Nora came home from work or her heels on the kitchen floor.

**Matt:** Our system was when she would walk in the door to flip the lights on and off, because otherwise I'd be doing something, and all of a sudden, she'd be there, it would scare me.

**April:** Talking on the phone was a big problem. Matt couldn't follow conversation. So, it would only work if he asked the questions, simple questions. And remember, this was before texting.

**Matt:** For me to be able to call and say, "Did you need me to go to the grocery on the way home?" She'll say one for yes, two for no. She'll either say yes or no-no.

**Nora:** It was August 18th of 2004, and Matt had come home for lunch that day. We had lunch on our rooftop. I remember him walking away and I yelled to him and he didn't turn, which then with one ear, he could have, should have. And he went back to work.

**Matt:** I can remember being in the elevator in my office at work and somebody was making small talk. And for no reason at all, it sounded like they were underwater when they talked to me.

**Nora:** He called me and he said, Things are sounding weird today. It's tinny, it's muffly. Something's not right."

**Matt:** So, I hopped on the train and I went home. As soon as Nora got home from work, I said, "I think we're done." [nervous chuckle]

**Nora:** We were told this is how it could go.

**Matt:** And there was a place on Division Street, Adobo Grill, that has great margaritas and great guacamole, the tableside guacamole. We went and got guac. What do you do when you lose your hearing? You go get margaritas and guacamole. And I can remember walking there and just sitting across having margaritas and telling each other I love you.

**Nora:** He wanted me to laugh. He wanted me to laugh so he would remember that, and hear me say, "I love you."

**Matt:** You can mouth the words "I love you" to somebody, you can sign "I love you" to somebody. But I wanted to make sure I remember what it sounded like.

[*Beautiful Way* by Beck playing]

**Glynn:** If you're about to descend into total silence, what are the last words you want to hear? Matt's journey continues in just a moment. Stay tuned.

[*Beautiful Way* by Beck playing]

**Glynn:** Last we left, Matt Hay was come to grips with the biggest challenge he had ever faced. Snap Judgment.

[static sound]

**April:** A lot of people think being deaf is like living in absolute silence, but not for Matt.

**Matt:** I would have one ear that sounded like a roaring freight train and the other ear would sound like a cryptic organ. And it's constant sound coming in at different pitches and it feels like different volume. They don't exactly know what causes it but it's almost like phantom limb pain where your brain wants to hear something. And when it can't, it manufactures its own noise.

**April:** But in terms of the outside world, he got nothing. Even fire alarms, nothing.

**Matt:** I would leave doors open, leave cars running, burn pizzas in the oven.

**Nora:** I remember the first couple of days, I would forget. I would see something or I'd go to tell him something, or I'd say, "Matt, [shouts] Matt," and then I'd be like, "He doesn't hear me. It doesn't matter how loud I yell anymore." I remember sitting there in my condo looking right at him screaming and just being reminded like, "Wow, this has changed."

**April:** Matt and Nora had taken those sign language classes, but they never got past the beginner level.

**Nora:** When the time came when we needed it, that's not how we communicated. It was more fingerspelling or even charades.

**April:** We're not just talking about, "Did you feed the dog?", "Will you get the mail?" They're in their mid-20s just building a marriage, and the only way they could talk about anything was to spell out every word they wanted to say.

**Nora:** It was super frustrating. And at a time when we needed them, I mean, we had to learn to communicate, but we had to learn how to fight too.

**April:** They couldn't yell anymore.

**Nora:** And it's hard to when you're mad to slow down and enunciate and keep eye contact, because sometimes you want to just throw something and walk out of the room, but you can't.

**April:** Matt and Nora were talking about massive decisions or doing charades about them. Like how Matt needed another brain surgery to finally remove the tumor on his hearing nerve. And there was an experimental part of the surgery too that really scared Matt. Doctors were going to implant a new hearing device right at the bottom of Matt's brain. It's called an auditory brainstem implant, or ABI.

**Matt:** One of the things that really scared me most through this process was, I'm in marketing research. I research things as a career. When I went to research the ABI or I want to talk to people about the experience, there was nobody to talk to.

**April:** At the time of Matt's surgery, only 200 people in the world had one of these devices.

**Matt:** And the one person I finally get in touch with was just miserable. They were really unhappy with their ABI. They were really unhappy with their experience. Even if it does work, you should expect what they would describe as hearing life noises, buzzers, alarms. And at that point, when you can't hear anything, that even sounds great.

**April:** There was only a 50:50 chance that the device would work at all. But those were better odds than not going through with the surgery and never hearing again.

**Matt:** Despite Nora's best efforts, it's still a very isolating lonely feeling because if I'm going to live my life deaf, I'm always going to be the guy that puts people out. I'm always going to be the guy that needs something captioned, I'm always going to be the guy--

**April:** He decided to go for it. So, a month after Matt and Nora sat over margaritas, saying their final I love yous, Matt had the ABI device implanted in his brainstem. And a month after that, the doctors file back into his hospital room and turned on his new ears.

[water running]

**Matt:** At first, it just sounded like water running, sounded like somebody smashing up newspaper or wrapping paper. Things were just very robotic. The sound you're used to, you can tell, you can locate noise, you can kind of feel noise coming in your ears. This was totally different because the sound came from the inside out. It went directly to my brain. So, it bypassed the feeling of being able to hear.

**April:** Normal hearing relies on 60,000 nerve fibers. Matt was down to 21 manmade electrodes. And all the sound coming through the ABI device was just gibberish. Everything sounded the same.

**Matt:** Clapping or a dog bark or an oven timer going off, everything just had the same kind of [onomatopoeia] [muffled voices]. Charlie Brown's teacher is probably the best analogy I can make. There was no clarity to anything.

**April:** But every couple months for the next year, Matt went to the audiologist so he could essentially tune the ABI. He would adjust each of the 21 electrodes until those sounds gradually came into focus. [clap, dog bark sounds] The guy to do that was Matt's audiologist at the House Ear Institute in Los Angeles.

**Steve:** I'm Steve Otto.

**April:** He's kind of like a piano tuner.

**Steve:** And I've been doing that for 30 years.

**April:** Making all the electrodes on the ABI device work together in harmony.

**Steve:** I test each one of the 21 electrodes and I'll ask the person, "Oh, what's the sound like? Is it low pitch? Is it high pitch?"

**Matt:** If anybody's gotten fitted for glasses, and you go in and they put the big discs in front of your eyes, and they say, "Which is better, this or this?" And the A goes from really blurry to being really crisp.

**April:** Once Matt was able to distinguish basic sounds, the oven timer from the dog barking, it was time to try a word test.

[smile word echoes]

**Steve:** And they hear the recording say a word and their job is to repeat the word.

[school word echoes]

**April:** This is really hard for new ABI patients to get right.

[think word echoes]

**Steve:** They say, "You know when you say 'mom' what I hear doesn't go with what I see on your lips."

[meet word echoes]

**April:** For those first several months after surgery, Matt was communicating one word at a time, and yet somehow to Nora and Matt, it seemed like the perfect time to talk about whether or not they should have kids. But Matt was coming off his second brain surgery.

**Matt:** Then, I start wondering, "Can I be a dad? Am I even going to be happy? Can I do all of the things that I want to do as a parent. Would I ever hear the sound, hear my kids talk?"

**April:** The power of that fear, the power of that longing to communicate with his own children could actually help him. Otto says having kids or a job are the main predictors for how well people do with the ABI. Six months after surgery, Matt was going to have both. He was back at work full time. His boss found him a new market research job that he could do online. And Nora was pregnant with twins. Matt says he wanted to hear his kid's first words.

**Steve:** Just like anything else, practice, practice, practice.

**April:** Just as it was slowly taken from him, sounds, one by one, started to sound familiar again.

**Matt:** The sound of my wife's heels on hardwood floors when she would come walking in. So, I can hear the door open because that was a soft sound. But I would know she would be home because of the click, click, click of the heels.

**April:** There was one time he was coming back from the grocery store, walking up the stairs to their condo.

**Matt:** And I kept hearing this whoosh, whoosh, whoosh.

**April:** He stopped and looked around, he examined the heating vents.

**Matt:** When you only have one ear, you can't identify where a sound comes from. So, I hear this whooshing sound, but I have no idea if that's from above, below, right next to me.

**April:** He put the groceries down and retraced his steps down the stairs.

**Matt:** It wasn't until I had walked back down and back up that I realized it was the sound of the seam on the inside of my jeans rubbing against each other. It had been maybe 20 years since I had heard something as soft and subtle as the sound of your own pants rubbing against each other when you walk.

**April:** Then one day, he and Nora got into the car. Usually, they turn the radio off. But this time, Matt recognized a rhythm coming out of the speakers.

**Matt:** That first moment of hearing *Crazy Game of Poker*, it was like a little light went on. I thought, "You know what? Maybe this is going to be an option."

[*That was a Crazy Game of Poker* song by O.A.R. playing]

**Matt:** If you've ever seen the movie, *Pleasantville*, it starts out black and white. And there's a scene where something happens and one person is in color but everything else is still in black and white. And it's almost like, "Well, wait, what's happening?" That's how it felt to me.

**April:** He realized he could go back to the catalog of songs he had memorized to train himself how to recognize sounds. He decided to listen on repeat again. He'd go for drives and pull out his old CDs. Just the simple stuff. Songs with minimal lyrics and really clear rhythms.

**Matt:** So, I could say, "Hey, is this *Let it be*?" Because I got the like, "Bom, bom, bom."

[*Let It Be* by The Beatles playing]

**Matt:** Particularly, Beatles, that was just clean and an easy melody. Some of their songs only had 10 words.

[*Let It Be* by The Beatles playing]

**Matt:** I wasn't really hearing the music. I was identifying the music. Maybe I'm not getting the unique moments within the music but I need to manage my expectations.

**April:** But it was enough for Matt to realize that he might be able to recapture a fuller spectrum of hearing than he first thought.

**Matt:** After I lost hearing, my goal was to be able to hear people say, "Hello," and, "I love you." It gave me motivation to set that finish line a little bit farther out.

**April:** Because now, he and Nora had two little babies. A boy and a girl, Luke and Madeline. A couple years later, they had another daughter, Kate.

**Nora:** There was a moment when Luke and Maddie were babies, we had two rockers in the nursery. So, we'd like sit side by side and read and play The Beatles lullabies.

**April:** And in the middle of the night, when they were a bit older and couldn't sleep.

**Matt:** My mentality was, "Let's come up with a new song to sing."

**April:** So, he turned back to the repertoire in his head.

**Matt:** Prince, I can't really think of anything offhand that is going to console a crying toddler. Michael Jackson was next and working my way to U2. And so, I would sing and probably would butcher the lyrics but that's the beauty of singing to a 2-year-old. I can remember Kate, "Sing the U2 song."

**April:** He looked up the lyrics and read them while he listened back to the song, just like in his old apartment with the Portal of Knowledge.

**Matt:** When I listen to *All I Want Is You* now*,* the memory it takes me back to is Kate being an infant and toddler, and there aren't very many songs at all that I listen to now where my memory is of something that occurred after I lost my hearing. And I didn't realize that until right now.

**April:** Luke and Maddie are 11 now, Kate is 9.

**Matt:** When you go to bed, do you remember that song you asked me to sing?

**Kate:** Oh, yeah, that song I remember--[crosstalk]

**Matt:** You'd say, "Sing me U2 song." [humming *All I Want Is You* song]

[*All I Want Is You* instrumental]

**Glynn:** Thank you so much to Matt Hay for sharing your story to Snap. A version of that story first aired on KQED’s Q’ed Up podcast, go get that one. The original sound design was by April Dembosky. That story was produced by April Dembosky.

[upbeat music]

Now, Snappers, this is not the news. No way is this the news. In fact, you could dance to the beat of your very own drummer, not realizing that your very own drummer doesn't even have a beat. And you would still, still not be as far away from the news as this is. But this is PRX.

*[Transcript provided by SpeechDocs Podcast Transcription]*