

Transcript: SickKids VS Silence

Cold Open

Hannah Bank You're listening to a six-year-old boy named Jacob, who's playing the piano with his mom, Nicole. Music has long been a keystone in their family, going all the way back to a worrisome discovery before Jacob's birth.

Nicole Boucher We found out that Jacob has two large cysts that formed at the back of his brain, which caused the rest of his brain to form differently. At that time, we didn't know what that would mean, but it would mean that we'd have to be closely monitored throughout the whole pregnancy, and then at birth, "prepare for the worst and hope for the best" is what we were told. Being closely monitored, I think, well it was my first pregnancy. And being a first-time mom, you're hyper vigilant about all the movements, and is this normal? Is that normal? And any time we would go long periods of time where there'd be no movement, my husband and I would put on music, and we would notice Jacob would start moving right away. It was I guess our first clue that maybe music was going to be something special for Jacob.

Hannah And then he was born. What was that experience like?

Nicole I just got a glimpse of J when he was first born and kind of whisked away. He was having some breathing difficulties. We were very lucky—they rushed him over to SickKids. That was my real first introduction to SickKids, being wheeled over after giving birth to meet my beautiful baby boy. Seeing just this beautiful baby boy lying in the NICU and not knowing can I touch my baby, or can I not? And having the nurses be like, "It's okay. He wants to know you're there." And right away you know it was: Put the music on. Let's let him listen to the music, something familiar. That's when I start singing "You Are My Sunshine" to him, and that became a song that I would sing to him on numerous emergency visits to SickKids.

Hannah Jacob turned out to have an *extremely* rare genetic condition, which affects his development and leaves him immunocompromised. Once, when he was still a baby, Nicole was singing to him at SickKids, and a nurse noticed how well Jacob's vital signs responded to the music. So she referred Jacob to a music therapist named Carolyn Marshall. I was curious how those sessions unfolded for Jacob as a baby and as he grew older.

Nicole The one time we're up on the seventh floor and I had Jacob, and they were coming to do an ultrasound on his brain to check how big the cysts had grown. And he was screaming and screaming. He was just a little baby at the time, and I remember I was sweating. And he's crying and trying to get out of my arms. And Carolyn just happened to walk by at that moment, and she came in with the guitar. She had learned Yellow Submarine, which at that time was one of Jacob's favourite songs. And she sat down right beside us and started strumming. Jacob instantly stopped crying. I started crying because I was like, Oh my goodness, this person has just like went and learned one of his favourite songs and is playing it beautifully and at the most perfect moment. Jacob is, you know, now calm in my arms. I'm crying. She's dabbing my tears in between strumming the guitar. I think not only did it benefit him at that moment, but my stress levels went down as well and my anxiety came out as well.

I don't think I ever truly had a good understanding of what music therapy was, or how it could truly impact a child or an adult too. Once we started, I was like, wow, this is a game changer.

Hannah You're listening to SickKids VS, where we take you to the frontlines in the fight for child health. I'm Hannah Bank, and this is SickKids VS Silence.

Act One

Hannah You That's the soundtrack of the ICU. Those beeps. Those alarms. The beeps that constantly go on.

Hannah B. Meet another Hannah—Hannah You. Like Carolyn, she’s a Music Therapist here at SickKids, and she knows how tiring and scary it can be listening to all those beeps and alarms day and night.

Today, Hannah’s in the Cardiac Critical Care Unit. She’s about to use her guitar to create a new soundtrack for a baby who’s connected to a breathing tube.

Hannah Y. The way that I came in with the guitar was to first watch him. You know, I’m always watching what’s happening with him. Is he calm? Is he okay? Where is he looking? Is he uncomfortable? Are we trying to stay awake? Are we trying to go to sleep? And so in that moment, I was like, okay, we’re staying awake. I wanted to get a little bit of sensory, so the guitar comes in with not necessarily like sparse chords, but I was using different fingerpicking that was a bit more continuous. And, of course, mindful that the beeping would stay within the key of the chords I’m playing on the guitar. But I may just start, just start with a strum. And if the baby’s crying, I’ll do another strum. So notice it’s not a big strum—it’s very minimal, because what I’m looking for is, is this helping or is this adding to the stress? And then sometimes I’ll do a *[sings]* ahhh... Ahhh... Ahhh. Like I don’t know how you feel, Hannah, right now?

Hannah B. Amazing. So relaxed. Engaged.

Hannah Y. It helps relax.

Hannah B. Mmm hmm.

Hannah Y. And some of the chords I’m playing, I’m playing intentionally to leave you like, Oh that’s, that’s not complete. Like there’s something that’s supposed to come afterwards. It’s that. And so musically, I’m doing things, and when I can see that the baby is not more upset, but actually I’m watching the heart rate, I’m watching oxygen, and the music seems to either be helping or not making it worse, of course, then I’ll go into a "hello" song *[sings]*: Hello, my friend. Welcome to music. Hello, my friend, it’s so good to see you today...

Hannah B. So many things to think about and pay attention to, and I just love the idea of being able to learn about this while listening to you and share this. You know, for our listeners who might not know much about music therapy do you think you might be able to give us the definition according to you of what music therapy is?

Hannah Y. Sure, so music therapy is using music in a therapeutic way within a relationship that’s therapeutic, with myself as a certified music therapist. We’re reaching really clinical goals, so nonmusical goals. That can look like anything from expressing emotions, it could be processing, it could be decreasing anxiety. And that’s to really support just wellbeing.

Jonathan I see music as a light spark that can lead to a positive change in human life.

Hannah B. That’s Jonathan Han, a music therapist who works closely with Hannah and Carolyn.

Jonathan That’s a spark that sort of invites us to a private place where we’re less traveled. And then that potential that music has is to create you know a safe space, safe zone where you can deal with these things that are difficult to, like, put into words.

Hannah Y. We really meet people where they’re at. And, so, if you can imagine having a really, really bad day—and you’re just tired, or you’re not feeling well—and imagine just someone coming at you and saying, “Here’s some fun music, let’s go!” It really just wouldn’t land. So we’re really able to see what the needs are, and then meet them where they’re at and use the music to do that and navigate where they might want to go. Either we sit together in that space, or we can get to a place that might be a bit better for their well-being and mental health. And so we really navigate together through the music. A lot of times our referrals come in for difficulty coping. Difficulty coping in the hospital, or other reasons would be assistance

of pain management. So a lot of times we'll be able to support, with music, nonpharmacologically. Other types of referrals would be to support with any sort of palliative or end-of-life situations, too, for legacy creation and meaningful moments.

Music therapy in itself as a field is quite young. So the first time a music therapist stepped foot in this hospital was 1999. Ruth Roberts is the pioneer of music therapy at SickKids, and she had just retired in 2021. I really have to shout that out, because none of us would be here as music therapists if it were not Ruth Roberts. She initially started off in the Haematology/Oncology program, and it was just her. That program grew to hire another music therapist. Some of us SickKids listeners here might know Carolyn, and so they were able to expand to different areas of the hospital. And now fast forward to right now, where we have four music therapists, and we cover almost every inpatient unit in the hospital.

Hannah B. Each year, Hannah, Jonathan, Carolyn, and another colleague you'll soon hear from provide around three *thousand* music therapy sessions across the hospital. Their work is part of the Creative Arts Therapy program at SickKids, which includes donor-supported music therapy, art therapy, therapeutic clowns, and virtual reality experiences.

Hannah Y. I think what really is incredible with our music therapy team at SickKids is that we're a very diverse staff, and so we're able to really support our children and families in different ways. And we're quite mindful of our different backgrounds and our different social locators and how we then approach the work and approach interacting with others. Not only has our team grown and our program has evolved, but the types of music therapy interventions we use have also evolved.

Hannah B. I want to hear more about how music therapy has evolved—and its potential for unlocking breakthroughs for kids like Jacob. So I turn to one of Hannah's colleagues to explain what's going on...behind the music.

Act Two

Emily My name is Emily Mostratos. I'm a certified music therapist at SickKids.

Hannah B. And can you tell us a little bit about how you got to where you are today?

Emily I went into music, and I studied double bass for a long time, and during that time I was able to do some psychology units, and music and health units. I was able to start exploring the therapy side of things and that really, really sparked my interest. After a little bit of exploration, and my mom found a news article about music therapy—I read that story and I was like, Oh, that's what I want to do. That's so cool. I can't believe music can have such an impact on people and on children in that way.

So I met this young girl who had an acquired brain injury. At that time, the assessment from her team was that she had no play skills, she had no social skills, and she needed full support for her daily cares and activities.

Hannah B. She was also assessed from a clinical perspective and determined to be unable to communicate in a meaningful way.

What happened once you started music therapy sessions together, Emily?

Emily She had a little bit of movement in one of her hands, and I wanted to see if there was opportunity to build intention and purposeful movement. So we got access to a switch, which is basically just a big button that's very sensitive to touch and you can record things on this button. So we would do a hello song at the start with the button and a goodbye song at the end of the session. She was pressing the button really consistently at very appropriate times in the songs when she was prompted through the music. As this was going on, she's getting even better at it, her time is becoming very quick with the button, everyone's really excited, and at the end of one session, I can see that she's gearing up to something. I can see her mouth is

moving, her tongue is moving. She's got this look in her eyes and then all of a sudden she actually sings goodbye, which was incredible. It was—really was a big moment.

Hannah What was that like for you?

Emily Oh!

Hannah What was that moment like for you?

Emily I still get chills thinking about it. It really impacted me, and it really helped me understand the way that music can impact our brain and influence the neural pathways in our brain when we know how to use it in a really meaningful, therapeutic way. And I think it's just such a great tool particularly for people who maybe don't have language or words to communicate what's happening for them.

Hannah B. This conversation got me wondering about Jacob's journey with music therapy. So I asked Nicole for her perspective on the process.

What were your initial thoughts and ideas and hopes around it?

Nicole So I was thinking, at the beginning, how can we use this? You know, he had another couple of major surgeries coming up. How can we use music therapy to help in that area? I spoke to his O.T. as well who was working on some of the feeding. And I was saying, is there any way we can incorporate music therapy with feeding? I was just trying to find all different ways knowing that, okay, we've seen those little pieces where music's made a big deal, what other pieces can we incorporate it into to see what kind of results we can find.

Hannah B. I understand that you heard Jacob actually play a song on his own, and I am so interested in that story. If you can take me through that.

Nicole Yeah. So, Jacob he started off with drumming. That used to be his thing, and he would drum on anything and everything. *[Jacob drums on a tambourine in the background.]* And then he started to show some interest in this toy piano in the shape of a cat. You know it had the keys, but it also had music buttons on it to play songs. That came with us for one of our stays, and he was sitting there and he's playing and he's pushing. Like at this point I'm like, these songs are so annoying and I didn't want to hear another one. And so he's sitting on the little bench in the rooms, and all of a sudden I hear Twinkle. I'm like, that's not one of the songs. And I look over, and I'm like, Oh my goodness, he's playing Twinkle on his own. So I grab my phone. I'm like taking a video. The nurse was coming by. I was like, You need to come in here and see this. He's playing Twinkle. And we all just stood there: Oh my goodness!

Hannah B And how old was he?

Nicole He was almost four. So he just totally heard it by ear.

Hannah B You mentioned doctors weren't sure that he would communicate. Can you maybe talk about how music therapy has supported the way Jacob communicates?

Nicole Yeah. So it started by using some music to communicate how he was feeling. He would request different songs, and the way he would request is Carolyn would start playing something and he'd be kind of like, eh, I don't want that. So she'd try a different song and his music preference would kind of tell us how he was feeling in that moment. We started to kind of pair songs to different activities that we were doing, and he kind of took off with that. So if he wants to go in the bath or the shower, he would run to the stairs at home and start "If all the raindrops were lemon drops and gumdrops." And so we knew he wants to go up and have a shower.

For feeding, because of the multiple intubations that has happened in Jacob's short life span, he developed a really severe oral aversion. So in order to get him to eat and drink, which we're still working on, but we paired music with it. So we started with Carolyn playing along with the O.T. when he was working on some of the bottle sucking. That's when we noticed, Oh, look, it's bringing some of the anxiety down. It's calming him and he's able to take sips. Music is so powerful.

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Act Three

Hannah B. I'm interested in in some of the other innovations that are happening in music therapy.

Emily What we're seeing now is we're actually able to record what's happening in the brain when we engage with music, and so we know that music really does impact brain function, and it impacts our behavior, too. So music actually activates some of the broadest and most diverse networks in our brain. And I think that's so cool.

The more we understand this impact, the better we'll be able to utilize and harness music therapeutically in a way that, you know, that can now be measured, which is really great.

Hannah B. Nicole and Jacob taught me that not all medical instruments need to be surgical. After all, music therapy can support and advance childhood development in remarkable ways. The same is true for the infant/caregiver bond, when babies end up in the Neonatal Intensive Care Unit (or NICU). At SickKids, you need specialized training to provide music therapy in the NICU—to properly support infants with complex medical needs and families who've experienced stress, trauma, and anxiety.

Hannah Y. I have that training, and so I'm certified to be able to work in our NICU. And across Canada, there are other music therapists that are, you know, moving into the NICU spaces, which is very exciting.

Hannah B. The training has helped Hannah in sensitive situations—like the one she's about to open up about.

Hannah Y. I got a consult. The team put the consultation in for this family because this baby was born and the parents weren't able to really physically hold the baby in ways that other families might when they first have a baby. And so they really wanted to use music therapy as a way to enhance that parent/child bonding. I remember luckily I met them just as the mom was holding baby skin to skin. And I was able to support them and provide music. And not just music, but their meaningful songs. I remember I sang their wedding song and was able to sing that for them as a family and with their baby.

Unfortunately, things shifted medically, and they had to change their goals of care. And so they went into more of a palliative state, and I was supporting them for the baby to feel comfortable, and to really have a legacy created and to share these meaningful moments. So that entails me asking the parents how would you describe your child? What does your child love? What do you love about your child, and who loves your child? And of course, a meaningful message they have for their child. And with that, I was able to compose and create a personalized song for this baby. And then we also had the ability to have the baby's heartbeat recorded. *[Sound of heartbeat.]*

So I took the recording of the heartbeat and put it into the song to create what I call a heartbeat song. And it was so wonderful to be able to capture the essence, and capture this beautiful baby's life and how meaningful they were as a family in song—and supporting them through that last part of the journey. And, actually, I remember I was able to attend that funeral. When I walked in, it was the heartbeat song just playing over and over.

[Sienna's heartbeat song plays.] "Sienna, our brave, beautiful girl. Our guardian angel, you're God's gift to this world..."

Hannah: From SickKids Foundation, this is SickKids VS. Thanks for listening. If you want to support work like this, visit SickKidsFoundation.com/podcast to donate. And if you like this podcast, please subscribe and rate us on Spotify, Apple or Google Podcasts, or wherever you listen to SickKids VS.

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