

## Seizures

**Hannah:** Every morning Lori Dreher chooses a program for her daughter Andi's brain. She has four options on the remote control. If she chooses Program A, Andi can talk, but it makes it hard for her to walk, so she needs her wheelchair. That's a good setting for school. If she chooses program B, then Andi can walk and play with her three siblings, but she can't speak much. That's a good setting when she's at home.

This device is the only thing stopping Andi's brain from short circuiting. Without it, she can have up to 200 seizures every day.

[MUSIC]

**Hannah:** Welcome 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 Seizures.

## ACT ONE

**Hannah:** Our story begins when Lori is pregnant with her fourth child.

**Lori:** So when we were 20 weeks pregnant in one of the ultrasounds they noticed a mass in her brain and that's kind of what started it off. So during the pregnancy monitoring the mass went away. But then when she was born she was left with this brain malformation which is a closed lip shizencephaly. So we just kind of call it the dead space in our brain which happens to be over the speech and motor area.

**Hannah:** No one knows what caused this it or why the mass goes away. Doctors tell Lori that her baby also has an arteriovenous malformation, or AVM, where the brain forms in an abnormal tangle of blood vessels, causing issues with the blood flow from the heart to the brain and vice versa. It's like a big knot of wires that you can't untangle. Brain AVMs occur in less than 1 percent of the population.<sup>1</sup> And they're dangerous.<sup>234</sup> Doctors tell Lori and her husband Dane to be prepared that their baby will likely need surgery right away.

**Lori:** So it was kind of unknown what what was she was gonna be like, what functionality she would have. She came out and it was amazing. She was able to nurse and eat and drink and perform, what the Apgar test or whatever, passed that with flying colours.

**Hannah:** But the brain abnormality does affect her. She doesn't have much strength on her right side so it takes her a little longer to start sitting and standing. But Andi starts physical therapy and by the time she's a toddler, she's running and playing like most other kids her age.

She plays soccer. She cheerleads. She has lots of friends. She's happy—and sassy.

**Lori:** You would tell her she looks cute today and she would say, "I know." And I'm like, OK glad you like the outfit or the clothes you picked out, you know. So, she has the most personality of I think all of the kids and just very outgoing. You know one of the others said, "How come Andi always has friends?" Because she'll just walk up to you and say, you know, she would start talking and or play with you or invite you over.

**Hannah:** Then, when Andi is three, the family takes a trip to Tennessee to visit friends. Andi is out with her dad Black Friday shopping when she has her first seizure. It's a big one. And it terrifies Dane. He's right to be afraid.

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<sup>1</sup> <https://www.stroke.org/en/about-stroke/types-of-stroke/hemorrhagic-strokes-bleeds/what-is-an-arteriovenous-malformation>

<sup>2</sup> Come with risks of seizures and hemorrhaging but I think we want to save the seizure part until later to tease it a bit. <https://www.mayoclinic.org/diseases-conditions/brain-avm/symptoms-causes/syc-20350260>

<sup>3</sup> "They are the most dangerous of all the vascular anomalies." <http://www.sickkids.ca/PlasticSurgery/What-we-do/Vascular-Anomalies-Clinic/Vascular-Malformations/Arteriovenous-Malformations/index.html>

<sup>4</sup> AVMs disrupt the blood flow of oxygen-rich blood from the heart to the brain. These abnormal blood vessels connect arteries and veins that then bring oxygen-depleted blood back through to the lungs and heart.

Andi starts having these big convulsive seizures every six months. The kind you see on TV – where her muscles stiffen, she loses consciousness, falls, and twitches and jerks uncontrollably.<sup>5</sup> They leave her exhausted and disoriented.

**Lori:** It just breaks your heart to watch them go through it because there's nothing you can do.

**Hannah:** Andi is put on a bunch of medications to try and control the seizures. Each drug helps—but only for a little while. And the seizures start to change. Sometimes they're convulsive, others she goes frozen and rigid, or she stares blankly, drops her head, and collapses. Her doctors put her on the ketogenic diet, a low-carb, high-fat diet which can help control seizures in kids with epilepsy. But nothing stops them from coming. She's having hundreds of seizures a day.

When she's five years old, doctors in the US, where the family is living at the time, want to do a craniotomy.

**Lori** So they decided, we decided to try brain surgery to remove the dead space because that's where they felt all the seizures were generating from, is that area. So, they went in to try to do the surgery. They had to abort the procedure halfway through because of all the vascular malformations. They couldn't get to the area that they wanted to remove. So, we had to close her back up. We kind of called we had to put Humpty back together again and then so that option was out. And then we just had to regroup and try and find something else to do.

**Hannah:** Doctors insert a vagus nerve stimulator. The vagus nerve connects the brain to the rest of the body and sends electrical currents back and forth to the brain.<sup>67</sup> Lori has a magnetic device that she waves over Andi's chest to try and keep a seizure from starting. It goes off 150 times a day. But then that stops working, too.

**Lori:** So unless she's sitting on the couch surrounded by pillows you can't let her out of your sight. So as hard as it is for us it was awful for her because she's you know seven, eight years old, nine years old and now about to be 10, and she can't even go to the bathroom by herself because you have to hold her hand and walk her there. Not to mention she can't really speak and tell you she wants to go either because as the glitches have increased her speech has gone away too. So I mean it's got to be hard for her for having, you know, having these skills and then losing them.

**Hannah:** Lori's mom has a special name for Andi's seizures—glitches. When Andi first starts having them, Lori explains it to her other kids using the movie Wreck-It Ralph. In the movie, Princess Vanellope, a video game character, sometimes glitches, becoming a twitchy mess of blue-tinged pixels. So when Andi's having a lot of seizures in a day, she's Princess Vanellope.

Then, a few years ago, the family moves to Kitchener for Dane's work. Andi's seizures are relentless. They've lost the Andi that they know. But the family refuses to give up. They find a neurosurgeon at SickKids who might be able to help. His name is Dr. George Ibrahim. He's a new recruit, doing world-recognized research into childhood seizures, and he's the only shot they have.

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<sup>5</sup> <http://epilepsyontario.org/about-epilepsy/types-of-seizures/tonic-clonic-seizures/>

<sup>6</sup> <https://www.aboutkidshealth.ca/Article?contentid=2103&language=English>

<sup>7</sup> <https://www.epilepsy.com/learn/treating-seizures-and-epilepsy/devices/vagus-nerve-stimulation-vns>

## ACT TWO

**Dr. George Ibrahim:** I'm George Ibrahim. I'm one of the paediatric neurosurgeons here at SickKids.

**Hannah:** In George's office there's a corkboard of photographs sent to him by patients and their families. One is of a baby girl wearing a flower crown with the caption "thank you for saving my life." Another is a baby in a onesie with the words "here today because of my neurosurgeon" printed across their chest. I ask him about the photos.

**Dr. George Ibrahim** Well, I think that's a very kind family that gave me that picture to remember them by.

**Hannah:** He deflects. He's humble when talking about all the lives he's saved, or that he was voted one of Canada's Top 40 Under 40 leaders, or the fact that he speaks five languages fluently. He doesn't want to talk about himself, but he does want to talk —about the patients he's still trying to help.

He's especially passionate about helping kids with epilepsy.

**Dr. George Ibrahim:** If you look at the population of children in the country, I'm sure someone knows someone that has epilepsy. It is a disorder of brain circuitry. And if you think about it in terms of electricity, it just means that the brain is firing electricity in an uncontrolled way. And what that leads to is seizures. So that is the predominant feature of epilepsy, that these children have recurrent seizures. And often these seizures are very well controlled with medications. But in an important minority of children, no matter what you do, no matter how many medications you give, no matter what you change in terms of their diet, in terms of, you know, various treatments that are available, you just can't control the epilepsy.

**Hannah:** That includes kids like Andi. But George has been researching a new type of treatment that might just change her life.

**Dr. George Ibrahim:** I think you can consider the brain as this very complex organ that is essentially a set of wires with electricity flowing through them in multiple different circuits that overlap at different time points and in different places. And sometimes one or two of those wires can be malfunctioning. They could be, you know, short cutting or just firing off in a very in a very abnormal way. And what you can do is tell those specific circuits to quiet down.

**Hannah:** To quiet down these brain circuits, George is investigating something called deep brain stimulation.

**Dr. George Ibrahim:** It's an invasive surgical treatment that's kind of like a pacemaker. So it involves implantation of an electrode deep into the brain, through the skull. And those wires, those electrodes are connected to a device that's like a pacemaker. It delivers electrical stimulation into the depth of the brain. And what that does is alter the brain circuitry in some way. And it's been used for a variety of conditions and most of the evidence for its use comes from adults.

**Hannah:** Deep brain stimulation—or DBS—has been used to treat adults with diseases like Parkinson's and epilepsy. But DBS has never been done on kids anywhere in Canada. And there's only about 40 cases where DBS has been used to treat children with epilepsy around the world.

**Hannah (talking to Dr. George Ibrahim)** But, were any of them similar to Andi in sort of the vascular nature of her brain?

**Dr. George Ibrahim:** No. None of them. None of them were like Andi.

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**ANDREW:** As Canada's most research-intensive hospital, our scientists pursue big ideas like deep brain stimulation – every, single day. Donations are what fuel that innovation. So, if *you* want to help kickstart the next big breakthrough in kids' health, visit [sickkidsfoundation.com/podcast](https://sickkidsfoundation.com/podcast) to donate.

### ACT THREE

**Hannah:** So George and a team of more than 20 SickKids neurosurgeons, neurologists, nurses, social workers, and psychologists start to work together to determine if Andi is a candidate for this new treatment. The device doesn't look that exciting – there's a small palm-sized pulse generator that's implanted in the chest that's connected to a few strings of thin wires that are implanted into the brain. It comes with a remote control that looks like a walkie-talkie.

**Lori:** We were just thankful for somebody trying to do something. You know I think that was the most important. Instead of just saying you're giving up and not doing anything else.

**Hannah:** George reaches out to the neurosurgery team at Toronto Western Hospital, just a few blocks away from SickKids. The team performs the most DBS procedures in the country – but they're all on adults.<sup>8</sup> George's team works with them for weeks, planning the surgery, mapping Andi's brain to understand precisely where to put each electrode and the safest way to get it through the tangle of blood vessels and into the deepest part of her brain. But no matter how much you plan, there's always risks. There are a ton of unknowns: Will they nick something on the way in? Will it cause a bleed? And even if the surgery itself is successful, will the seizures stop?

The surgery is a two-step process. First, doctors implant the electrodes deep into Andi's brain. Then, they have to wait until her brain heals before they can turn it on.

The day of the surgery arrives. It's October 1<sup>st</sup>, 2018. It's Andi's brother's birthday so the family tries to celebrate in the waiting room during the eight-hour surgery.<sup>9</sup>

**Dr. George Ibrahim:** And then when Andi came in, we used a frame-based system. So it's a kind of like a coordinate grid system that helps us place the electrodes. And we're able to do this with millimeter accuracy, specifically in the target, which in this case is the thalamus, a very deep structure in the brain that has very, very extensive connections throughout the entirety of the brain. And then we implanted the pacemaker in the chest and Andi stayed in the hospital for two to three days and then she was able to go home.

**Hannah:** A month and a half month later, Andi, her mom and the neurosurgery team gather at SickKids. And they turn on the DBS.

**Sara Breitbart:** Some of the things that a child may experience as we're turning on their device for the first time: they may see something like flashing lights. They may get funny sensations in one of their limbs.

**Hannah:** That's Sara Breitbart, a nurse practitioner in neurosurgery, and part of the team who works with Andi.

**Sara Breitbart:** They may have on rare occasions they can have an emotional response of fear or joy. So really it could be almost anything.

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<sup>8</sup> <https://www.cbc.ca/news/canada/toronto/9-year-old-girl-first-child-in-canada-to-undergo-deep-brain-stimulation-for-epilepsy-1.4943923>

<sup>9</sup> <http://www.sickkids.ca/AboutSickKids/Newsroom/Past-News/2018/Deep-brain-stimulation-release.html>

**Hannah:** With Andi, nothing really happens. Which is a good thing. Now that they have the electrodes in the right place, the doctors have to start fine tuning it. This can take a long time. And in Andi's case, more than a year later, they are still working on it.

**Dr. George Ibrahim:** You can think of it almost like medication. You know, there's a certain dosage of medication that you take and sometimes you're under dosed or you're overdosed. You have to adjust the dose of medication that you give. Electricity is the same way. Electricity is medication delivered directly into specific brain circuits. And sometimes that electricity is too much. Sometimes that electricity is too little. So you titrate the dose of the electricity that you give through the deep brain stimulator.

**Lori:** You know we're still in this gathering process and trying to figure out what works and what doesn't. Because sometimes we can decrease the seizures, but her speech is gone and she's just very lethargic and doesn't want to do anything.

**Hannah:** Every day is different, depending on the settings on Andi's DBS. But Andi can have a day where she has few to no seizures. It's a step in the right direction.

**Lori:** Ideally everybody's goal is it's going to we're going to find the right balance of keeping the seizures under control and still letting her talk and run and be engaged in school and do the things that she normally did. So that's what that's what we all hope we're going to get to.

**Hannah:** Since Andi's surgery, five more patients have been treated with DBS at SickKids. In fact, SickKids established the first paediatric deep brain stimulation clinic in Canada. It runs once a month, and sees some of the most complex kids. Kids with non-stop seizures like Andi's, or uncontrolled movements.

**Sara Breitbart:** So you know we have patients referred to our clinic for a number of different reasons. But in every case it's a child who is struggling with a very difficult to manage symptom that you know generally has tried multiple medications, possibly surgeries, and is still struggling quite a bit.

**Hannah:** It's not as simple as a one-off surgery. When I meet Lori, she has a beach bag with four huge binders in it filled with detailed, day-to-day data on Andi to share with the doctors. Families come into the clinic every few weeks. It's a huge commitment, but it's offering solutions no other hospital in the country can.

**Sara Breitbart:** I think that the possibilities for this program and for this clinic are endless.

**Hannah:** It's a week before Andi's 10<sup>th</sup> birthday. She's had the DBS for almost a year now. She's having a good day, with almost no glitches, so her family throws an impromptu party. They take her to an indoor playpark.

**Lori:** You know, you've got the 10-year-old that's in the toddler area. But she was done after 40 minutes. But we tried. We made her a Jello cake because she can't eat anything else. So we did a Jello tower out of Jello Jigglers and had a refrigerator full of like eight colours of Jello. She liked it. But that's you know, it's kind of hard.

**Hannah:** Andi's seizures aren't completely gone. But she gets to celebrate with her family. And as her mom says, Andi's always been a fighter.

## **EXTRO**

From SickKids Foundation, this is SickKids VS. Thanks for listening.

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