

Can we talk about bladders and bowels? (SickKids VS Disconnection)

Mason Donkin: I remember before I wouldn't have sleepovers. I wouldn't hang out with friends. Because I had my special needs that my teachers needed to know, and I had my extra clothes in the bathroom, and I was the only kid that had to ask in the middle of class if I could go change because I had an accident...

Hannah Bank: Imagine being the only kid in class planning for an accident. And imagine coming back to school the next day after one happens. For years, that was Mason's life. He's 13 now, and has been part of the SickKids family since he was a baby. After seeing a range of specialists, he eventually landed in the office of Dr. Joana Dos Santos, a medical urologist here at SickKids. Basically, she specializes in pee and poop. She's dedicated her career to finding innovative treatments for kids who are struggling with both. Because she knows that when these systems aren't working well, it's debilitating. There's the pain and discomfort. And there's the social implications, the anxiety, the shame, the inability for these kids to just be kids.

Dr. Joana Dos Santos: There is a research published years ago that they asked school-age kids what was the most significant life event that they could remember in a negative way in their lives. And they ranked parents fighting as the first one and peeing their pants at school as the second.

Hannah Bank: Like many of Joana's patients, Mason had tried all conventional treatments for his bladder and bowels, but nothing gave him much relief. In 2020, Joana presented Mason with something as unique as him. If Mason agreed, he would be one of the first kids in the country to try it. He would be on a journey, along with Joana, of learning about his condition in a whole new way. The journey was an uncertain one, fueled by questions that Mason and his family were desperate to answer. The biggest question: Could this approach finally help Mason gain some agency over his body and over his life?

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

Jennifer Donkin: So Mason, as an infant, he was always very unsettled, would cry a lot, have a lot of projectile vomiting. We began taking him to doctors to see if we could actually figure out what the issue was.

Hannah Bank That's Jennifer, Mason's mom. Like so many kids with bladder and bowel challenges, Mason didn't get many answers at first. His symptoms fell under the umbrella of what physicians call "bladder and bowel dysfunction".

Dr. Joana Dos Santos: Essentially 40% of all patients that we see in the urology clinic, and we can see 10,000 patients per year, so 40% of them will have some degree of bladder and bowel dysfunction. The bladder and the bowel work together. So when kids start potty training and they start learning when to hold the bladder and to hold their bowels, they may start having issues with both. And they will present with constipation, poop leaks, urinary incontinence, so they will leak pee during the day or at night. They may have pain to pee, urgency and frequency, so they pee very often, or the opposite, they go into retention and they lose the ability of emptying the bladder effectively. The vast majority of patients with bladder and bowel dysfunction, they will get better just by treating the constipation and doing what we call retraining of the bladder. So we tell them to pee every two hours by the clock and drink more fluids. And eat more fruits and vegetables to increase the fiber in the diet and take some stool softeners. And average in three to six months, they get better. That will be 80% of the cases. 20% of kids, they need a little bit more of that as help with medication or physiotherapy of the pelvic floor and things like that. And 1% won't respond to any therapies.

Hannah Bank For most kids, it gets better. For Mason, it didn't. He is that 1%.

Jennifer Donkin: We went a couple of different places and he was diagnosed with GERD and acid reflux and lactose intolerant. But then finally at the age of 10 months, we brought him here to SickKids. And he had a little bit of a stay where he had treatment and bowel cleanouts to try to help with his overall impact in his stomach and his bowels. And then he began seeing Dr. Dos Santos and she started treating him with bladder medications, doing other techniques like time voiding, making sure he's drinking enough water, that kind of thing.

Dr. Joana Dos Santos: I know Mason for a long time, for 10 years essentially. I tried all possible treatments to the point that we were considering starting catheters at some point. And then at that time, we offered sacral neural stimulation.

Hannah Bank: Sacral neural stimulation, or SNS, had never been performed in Canada before, but it was something Joana had been following for a long time. And it had been yielding positive outcomes in other countries; in adults, and increasingly, in kids. SNS was a minimally invasive surgery focused on strengthening the connection between the mind and body. I asked her to explain how it works.

Dr. Joana Dos Santos: The bladder and the bowels, they are coordinated by nerves that come from the spine. We believe that kids that do not respond to anything, they have an issue, essentially a neurological issue with the way the bladder and the bowel are being stimulated so that they don't have awareness when it's time to pee or poop. So there are different ways to stimulate those nerves. There is a non-invasive way with stickers in the back, and we have an implantable device that will work just like a pacemaker for the heart, it's a pacemaker for the bladder and the bowel. It's very discreet. You cannot see anything, any volumes from externally or from the clothes. They are currently compatible with MRI. They can take x-rays, they can fly in an airplane, they can practice sports, so there is not a lot of restrictions with them. At that time, I talked to SickKids, to our leadership, and presented the data and wrote a business case. We are really highly supported for innovation here, especially if you're supported by evidence. So the Hospital was open to do a pilot with the first few patients.

Jennifer Donkin: She gave us real life positive outcomes of children that had the device. And she openly just talked to us about her recommendations and what she would do to help us feel supported in making the decision. Because at the beginning, my husband and I were very overwhelmed and didn't know if this was the right thing to do for Mason. And we took it as, well, Mason, when he's down the road, like in his 20s, would he look back and say, well why did you do this? Like, now I have scars. So we were just very unsure.

Hannah Bank: Like with any new procedure, there was a lot of questions that just couldn't be answered yet, not to mention potential complications and risks. But with the novelty came something else: Hope. For the first time in more than 10 years, Mason and his family had hope that something out there just might help. They said yes.

As Mason waited for his surgery, Joana and her team had just performed the procedure on their first few patients. They were learning that the device worked, in Joana's words, "like a light bulb". Mason was patient number five, and he felt the effects right away too.

Mason Donkin: I could feel the pain in my bladder being relieved that I didn't even know I had because I had gotten so used to it, and I could it getting lighter and I could feel more comfortable with myself. It felt like I could be like everyone else because before I used to always feel like an outcast or I couldn't take a sleepover because I was afraid of wetting the bed at someone else's house. And so it felt like I could finally exist in my own body and start to be my own person and do what I wanted to do. Because I also was able to start doing my hobbies, because I didn't really have any hobbies before I got the implant because my medical conditions just took up too much of my time.

Hannah Bank: Slowly but surely, in the following days and weeks, Mason's life started to open up. Learning to trust his body took some time. At first, he leaned on patience, reassurance, and routine. Progress came in small victories, like a day at school without an accident, each one

building confidence with the support of his family and care team. For patients facing bladder and bowel challenges, holistic care is critical. Noreen, a social worker here at SickKids, helped me understand what that looks like. She follows kids like Mason very closely, and she knows firsthand that when treatments like SNS start to work, the changes kids feel are everywhere.

Noreen Goraya: I think one of the significant ones is a sense of confidence. And the other piece, I think a very clear understanding that everything that these patients and their parents or their families were doing to support them around continence prior to this device working, there was a reason why it wasn't. And it really comes down to this understanding of like, wow, my body really was behaving in an X, Y, Z way and I really didn't have control over it. And even this confidence around trusting yourself and trusting your body and the signal that it's giving you by way of this device is so powerful in terms of shedding from the shame that comes with some of those experiences of incontinence, any obstacles that have come their way in terms achieving continence really, truly wasn't about their capacity, but rather this bigger thing that they can control just propels their emotional development in a very different way. And it's very cool to see.

Hannah Bank: Mason also had control over the level of sensation he was getting from the device. He could operate it himself easily with a phone.

Mason Donkin: And it has different settings, so you can turn it up or down. And it has different placements. So there are places that the LED leads to because there are multiple LEDs. Because depending on who you are, you might need a different place to help it work better. And there's like a kind of menu that you can choose the setting you want and then you can choose the intensity. And then there's also a slide on and off button in case of emergency. So it's really easy to just power off, and then power back on.

Jennifer Donkin: As a mom, it was truly just such a heartwarming feeling. I still get a little emotional, I'm sorry. Because I saw Mason just struggle for so many years, and because he is the youngest of four, I always felt that he felt different than his brothers. And so when I saw that that was happening and he was able to just go out and play and not have to have an extra pair of underwear in his backpack or have special clothes at school. And have to even get picked up. He did get picked a few times from school because the accidents were that severe that he wasn't able to take care of it himself. It just was truly just a moment I'll never forget because I knew that Mason was on the road to feeling comfortable with who he is.

Hannah Bank: After suffering for so long, Mason and his family got the relief they had been hoping for. But one night, when Mason was at a friend's house, he could feel something in his body wasn't quite right. The area around the implant was red. And hot to the touch.

Jennifer Donkin: So he actually developed a soft tissue infection a month after the surgery. So we came to SickKids and right away they admitted him and were treating him with oral antibiotics for the soft tissue infection and he was admitted for 14 days and by the end of the 14 days they were not happy with the amount of the infection that was no longer there. So they decided to remove his implant.

Hannah Bank: Mason had gotten a taste of what it's like for his symptoms to ease, to start doing some of the things he loved without fear. And just like that, all the progress they made started to slip away. They felt like they were back at square one.

SickKids breakthroughs are only possible with the incredible support of our donors. That's why we're proud to recognize CIBC as the premier partner of the SickKids VS podcast. The bank and its team members care about making a difference. CIBC has championed SickKids for over 30 years and is the largest corporate supporter of the SickKids Cancer Sequencing program. CIBC also generously supports SickKids through CIBC Miracle Day and an active employee giving and volunteer program.

Jennifer Donkin: And as soon as that surgery was done to remove the implant, we actually saw instantly that the symptoms and the incontinence for both his bladder and bowel did return. So we knew that it was definitely something that was helpful to Mason that was working. We had to wait for him to recover from that surgery and then wait a year later and we tried to do the implantation again because we were keeping a journal and we saw that the amount of occurrences were increasing and going back to prior to the first implant. And then as well as Mason's confidence and self-awareness piece was also hindered. So we knew that it was in our best interest and Mason's best interest to talk with Dr. Dos Santos and do the re-implantation of the SNS device.

Hannah Bank: There are still unknowns. There's still lingering fear. But for now, it's working. Mason's enjoying all the things he loves, especially musical theatre. And he's been able to peel back on so many of the other things he had been doing to manage his symptoms.

Mason Donkin: I'm still having a drinking goal, but that's just because I'm very bad at making sure I drink enough water. It's just that I have the device and I use that through everything.

Hannah Bank: Living in the unknown can be scary, but it's hopeful too. Something that's giving everyone hope is Mason's age.

Dr. Joana Dos Santos: For adults, it's a lifelong treatment. For kids, there is a lot of neuroplasticity. I have patients now that are from the initial cohort that are turning 18 and they are symptom free now. And then the question is, should we just turn it off? Should we take it out? And we don't know yet, but we are also researching that.

Jennifer Donkin: So for the future, it could get better. That's the whole hope from all of us is that this will actually retrain his bladder and bowel to work together with his brain and then will limit the chances of him having to have it re-implanted when he's older. Typically the battery will last for seven to 10 years, but Mason has had to have just an adjustment just because he had a massive growth spurt. So he did actually have to go in and have another little procedure just to kind of fix that, which that could still happen. But there is hope that all the symptoms will be gone without the implant.

Dr. Joana Dos Santos: To me, the most important point is getting the message out there that there is treatment and there is hope, because many families won't come up front to discuss that with their health-care providers because of the shame and stigma behind it. So it's great to discuss and to get the word out there, that you don't need to live with this.

Hannah Bank: Thanks to Joana, and families like Mason's, the word is getting out there. And that's a pretty powerful thing.

Noreen Goraya: It's something I say to my teens all the time is that when we see these kids either inpatient or clinic they're coming into this hospital with a very unique experience to how they're navigating what they're navigating. Even if we see hundreds of other kids with the same diagnosis as them, they don't know about those kids, they don't have any access to those experiences. And so it's a very, it's very isolating, and it can be very, very lonely. But to feel that experience being shared or to have the ability to just connect these families with other folks is just so rewarding in so many different ways.

Jennifer Donkin: While Mason had the second implant, a family member that was going to be going through the surgery reached out and connected with me just to see our story to help her feel more comfortable in agreeing to the surgery for her daughter. And when that happened, that just made me realize that it's truly so supportive for all of us to kind of stick together and share our stories. I felt really grateful that I had that opportunity, and that mom and I still do connect from time to time just to see how each other's child is doing with the implant. And so I feel that that is one of the biggest things that I feel works. And just from our perspective, the event that we started seven years ago was very small and very just community-based, but now it's like grown to something that

is bigger than I could ever imagine. And we have so many members of our community that come out and support us, and the event is just growing. Every opportunity we have, we try to advocate.

Hannah Bank: After all he's been through, Mason continues to show incredible resilience and strength. And he's broken the silence around a condition that is so often shrouded in secrecy. But the message he most wants to share is simple.

Mason Donkin: Just because you have a different routine doesn't mean that you can't have similarities to your friend and still hang out with them. Sure, you may know that what's going on is different between the two of you, but that doesn't make you technically different. It just makes you your own person with your own story.

Hannah Bank: From SickKids Foundation, I'm Hannah Bank. Thanks for listening. To support breakthrough research and care at SickKids, please visit [sickkidsfoundation.com slash podcast](https://sickkidsfoundation.com/podcast). And if you liked this episode, subscribe and rate us wherever you listen to podcasts. SickKids VS is produced by me, Hannah Bank, Liz Surani, Rebecca Ostroff, Jasmine Budak, Charlotte D'Arcy, Zeynep Kahramanoglu, and Neil Parmar. This episode was written by Rebecca Ostroff. Sound design and editing by Quill. Check out our show notes for related links and resources. Until next time.