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My name is Harry Forestell. I'm a journalist with CBC Television. I've been a reporter and producer and host about 35 years. It's part of my work. I'm on television a fair bit. It was about in 2013, the year my mother passed away that I began to notice a tremor in my right hand. I'm left handed, so it didn't bother me that much, but it was noticeable and it was something that I thought I'd have that checked out. So the next time I was at the doctor, I did. My doctor at the time was uncertain what it was, whether it was something called the central tremor, which I'd never heard of, but it sounded pretty benign, or whether it was something more serious like M.S., illness or Parkinson's. So that was a bit of a worry. It took over the next two years, beginning to confirm the diagnosis of Parkinson's. And then that time my neurologist in New Brunswick, had referred me to Dr. Tony Lang and the team at Toronto Western Hospital, a movement disorder clinic. And that was where in 2015 I really had my diagnosis confirmed as Parkinson's. My symptoms at the time were mostly the tremor, and I was shaking my leg on my left leg alone at work. Now, I was always a leg shaker as a means to the expanding access. And I guess when I was young, so that didn't really worry me, but it was noticeable that it was doing it when I wasn't really intending for it to happen. And then the thing that really sort of blew my mind and frustrated me was that I was finding it was taking more and more focus and attention just to walk normally. Now I live on a hill, quite a grade, and walking up the hill after dropping my daughter at school became a real task because I was so focused on swinging my arms in time to the movement of my legs. And I thought, this kid, this can't be right. This shouldn't take this much time and attention. I'm just walking. It's very simple. Why is it so hard? That was really beginning to annoy and disconcerted me. Well, the team return to action is very, very supportive, of course, and they were very thoughtful and concerned about not just for me as a patient, but about my career, what I did for a living, and knowing that I had to appear on television on a regular basis, knowing that I still had some career ahead of me. And I was only 53, 54 years old, and I still had career ahead of me to go. And Dr. Lang said, "Don't worry, we'll get you back on the air. It'll be okay." So he was very reassuring. Nonetheless, the symptoms continued to grow. And that was dispiriting. However, I did notice that the use of drugs like levodopa especially was huge in terms of helping me deal with the symptoms that control them. But over time, as my volume of the levodopa increase, the side effects of that, especially dyskinesia, began to be more and more of a factor in my mental health and my physical health. I had heard sometime earlier that there was a thing called deep brain stimulation and I understood the broad principles of it, but I thought, well, that's, you know, brain surgery sounds pretty serious and it's nothing that I want to get into right now. And Dr. Lang, as we discussed it, don't think that, you know, we've got to see whether you would qualify for it or not. And as we got closer and closer and the symptoms closer and closer to the current time and as my symptoms grew more serious, it became more apparent to me that maybe DBS would be a, you know, a more appropriate solution, a longer-term solution and a more satisfactory solution. My DBS journey began with the trip to Toronto to see if I even qualified because of course, with deep brain stimulation. The issue is are you able to gain is much benefit from it as you are from the use of levodopa. So a good strong reaction to levodopa, positive reactions over levodopa is a good indication that deep brain stimulation, which really only modifies and addresses the mechanical issues of the body in the Parkinson's case that I was suited for that. Also, there is psychological and social what not measures, but tasks that had to be gone through. So I spent a weekend in November, 32 years ago, going through it to see if I would be a satisfactory candidate. And much to my pleasure and surprise, I pass, I guess, for want of a better phrase, and I was delighted with that. And has that prospect of another option rather than just continuing with the growing. We had talked about the use of an abdominal shunt to deliver levodopa directly to the digestive tract. I didn't like that,

wasn't keen on the prospect of that. So DBS, when it was suggested that I could qualify and that they would do the procedure, it was it was a delight. I came home and my wife and I hugged, and my neurosurgeon here came around the desk and gave me a big hug. She was pleased to that. I said that I had qualified. Then came about a year later. Then came the opportunity to actually have a seizure done. I went up to Toronto. I was there for about a month and I went in and I was impressed and surprised by how quickly and how little fuss was involved in something is what had always seemed to me to be as complicated as this brain surgery. I was quite chatty. Apparently, Dr. Kazan and Dr. Kalia both remarked on how my line of questioning throughout the operation surprised him a little bit. When they're doing brain surgery, they're more used to speaking to one another, and they're, I think, answering questions and being interrogated by the patient. But I was curious about what was going on. I grew up around hospitals. My mother was a clerk in a hospital in Saint John. So as a child I would go in to visit her and regular basis and I've been in hospitals for various treatments through my life. So hospitals have never really intimidated me or frightened me. I've been more curious about anything. And that was why through that period of brain surgery, I was so curious about what was going on, what they were doing. And Dr. Kalia and Dr. Fasano both were humorous, they were supportive, and they were informative during that process. I appreciated it, and oddly enough, I enjoyed it. The recovery was very quick. I didn't know how long I would really have to wait, although in retrospect, I think I was told it would be 2 to 3 weeks at least before the devices turned on. But I was at the hospital within 36 hours with my implant and the neurotransmitter in my chest and all the wires connected and everything ready to go. But they wanted me to hear a lot. Of course, I spent, I think, three weeks in recovery in Toronto on my own. I could probably have come back to New Brunswick earlier, but I wanted it to heal up there. I did that, returned to New Brunswick, and continued on my merry way as my social life and requirements ahead for events at work. I didn't return to work, but there were certain events that I had to attend that I did. There was sort of a honeymoon, in fact, that allowed me to spend almost two weeks without the symptoms of Parkinson's because of the operation, which is delightful. In fact, I almost didn't have to take any medication during that time, so I was a bit of a foretaste of what life would be like when this was finally turned on. But then again, the symptoms of Parkinson's began to pay for, and I had to go back on my regular medication. So that all happened from the end of September to the end of October. On December the sixth, they returned to Toronto and spent a week there. I had the device turned on and I was not alone. I was in front of a bevy of clinicians when it was turned on and the impact was immediate and very, very pleasing. My tremors, my shakes abated completely with the bonus that they didn't have to experience the dyskinesia that goes along with the increasing doses of levodopa. And that was a real-life changer. So, I came home to New Brunswick, and since then I've had, I think, three sessions with the DBS clinical team to set the device. And because it very much involves my training, tweaking here and there to ensure that it delivers the best result that is possible. Up to this point, the use of device has allowed me to return to work, not only to work in the office but in front of the camera, which is a huge bonus for me, and I can't say enough about how it has returned my life to me. My daughters were impressed, my wife even more so because she is the person closest to me and sees all the minor issues that I may have from one day to the next, even with PBS. So she's quite tuned in and quite an acute observer kind of things that are going, and she has been very, very impressed. Now, I subsequently did a story on my treatment and included in it an illustration of me turning off my DBS and turning it back on. And I recorded that with a colleague of mine at work. And then I sat down and watched the video that he put together. And even though it was me, even though I recorded it, knew what I was doing and even though I knew what was coming was very emotional moment for me to see how vulnerable I am without DBS. The fact of the matter is that video has probably gone around the world and has just led to an avalanche

of inquiries and encouragement and good wishes from friends and family and people I've never met before. I would like people with Parkinson's to know first and foremost that there is hope. It may not come in the form of deep brain stimulation for them. It may come, you know, through other treatments, but there is hope. This is not by any stretch necessarily a death sentence or even a life sentence. There is work being done every day to encourage people to live full and wholesome lives with movement disorders. So, the team at the Krembil Brain Institute are doing a remarkable job. And, you know, if I am an example of the work that they're doing, so be it. I'm impressed by my treatment and where I am right now. I know this may only give me another 10 to 15 years, but holy smokes, 10 to 15 years can be a lifetime. To improve my quality of life as much as this has is truly a remarkable circumstance. And for that I have to thank them. I can't say enough about the care and the quality of the treatment I received, and I just hope so many other people have the opportunities that I've had with the result that I've had. The reality of my life is that I have lived for the past 35 years telling stories of one sort and another. The fact that I'm at the centre of this story really is neither here nor there. It isn't about me, it's about the treatment, and it's about the remarkable result that can come from it, and that gives comfort and direction and hope to others. And my job is done. The benefit of me being at the centre of this story is that I didn't have to chase around and find someone who is in this situation because I'm right here. So, you know, I know the stories about me, but I've tried to find a way of telling that story from a more scientific and clinical point of view, as well as a personal point of view. It's important, I think, for people to remember that this is not a solution for everyone that it has to be remembered that deep brain stimulation works. For some, it may not work as well for others, depending on your age, depending on co-morbidities or other conditions that you have that might conflict with the treatment that you receive for Parkinson's. And expectations are a huge part of evaluating whether or not is suited for this. But if you're not suited for it, don't lose hope. There are other solutions. There are other treatments. And even though those treatments may not be as successful as DBS has been to me, they are all a step in the right direction. We just have to keep on keeping on and hoping and not forgetting to sign the papers so that when that moment comes and you're done with your brain, somebody else can make good use of it. The research that needs to be done at places like the Krembil Brain Institute.