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MJFF: Welcome to a recap of our latest Third Thursday webinar. Hear directly from expert panelists as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at michaeljfox.org.

Larry Gifford: Well, hello everybody. Thank you for joining us. My name is Larry Gifford. I'm a proud member of The Michael J. Fox Foundation Patient Council. I'm the president and executive director of PDAvengers.com, and I host the podcast “When Life Gives You Parkinson's.”

Larry Gifford: Today, we will be talking about who should consider getting DBS, deep brain stimulation. It's a surgical procedure for Parkinson's, and we'll cover how the procedure works, what someone may expect after the surgery, and the latest advancements on this DBS research. There's a lot of cool things that are happening in the DBS world.

Larry Gifford: We have a lot to discuss, so let's get started. I want to introduce you to our panel today. Dr. Kelvin Chou is the Clinical Professor of Neurology at the University of Michigan Medical School. He is also the site investigator of The Michael J. Fox Foundation's landmark study, the Parkinson's Progression Markers Initiative, better known as PPMI, at the University of Michigan. He is a DBS researcher and has written a book on DBS. Welcome to today's webinar.

Dr. Kelvin Chou: Hi. Thanks for having me.

Larry Gifford: Jim McNasby is Chief People Officer and General Counsel at The Michael J. Fox Foundation. He was diagnosed with Parkinson's disease in 2000 and had DBS surgery in early 2019. His spouse, Donald Moss, an animal rights advocate, is also here with us today. Welcome.

Donny Moss: Hello.

Jim McNasby: Hi, thanks.

Larry Gifford: And we have Dr. Joohi Jimenez-Shahed, medical director of the Movement Disorders, Neuromodulation, and Brain Circuit Therapeutics at the Icahn School of Medicine at the Mount Sinai in New York. She leads the registry for the advancement of DBS in Parkinson's disease or RAD-PD. We'll talk more about that a little bit later.

Larry Gifford: Let's get started with the questions. What is deep brain stimulation? Dr. Shahed, maybe you can start with that, and then Dr. Chou could take over from there.

Dr. Joohi Shahed: Sure, absolutely. Thanks for having me on this webinar. I think deep brain stimulation is a very exciting therapy. It's actually been around for a long time for treating Parkinson's disease, but what it is is a surgical treatment that is actually the most common surgical treatment used these days to manage Parkinson's symptoms. It's like a pacemaker for the brain. So if you think about a pacemaker and the heart, the wires are in the heart to regulate the heart circuits. But here we have a deep brain stimulator that delivers a small electrical current into those deep brain structures that are controlling movement, and by doing that, it can really block the signals that are associated with some of the symptoms of Parkinson's disease, like tremor and stiffness and certain walking and balance problems. When we get that stimulation just right for an individual patient, we can see all kinds of improvements in not only just the primary Parkinson's symptoms, but also some of the treatment complications, such as the dyskinesias and the fluctuations and maybe even the tremor that wasn't responding well to medications.

Larry Gifford: Okay, then Dr. Chou. What are some of the symptoms that maybe it specifically does and does not help?

Dr. Kelvin Chou: Yes, I think the best way to think about deep brain stimulation is that it actually, in most cases, helps the symptoms that are helped by Levodopa or the medications that you would take. When people have Parkinson's disease and go on for a longer period of time and are treated with Levodopa, they might have what we call on and off states, where you take the medication, after about a half an hour, medication kicks in, and then many of your symptoms improve, like the tremor, the stiffness, the slowness, walking problems, et cetera. Then you're considered in an on state. And then maybe before your next dose, medication wears off, and the tremor, stiffness slowness, all those types of symptoms, come back again.

Dr. Kelvin Chou: Well, deep brain stimulation basically makes you feel like you're on your on state throughout the entire day. So symptoms that respond to Levodopa are the symptoms that are responding to deep brain stimulation. If it doesn't respond to Levodopa, then typically, it will not respond to stimulation either. The one exception to that rule is tremor. And so there are many patients who may have a tremor in which you take high doses of these medications, like Levodopa, but it doesn't respond. Then deep brain stimulation will help that. That's the best way to think about how it would help you.

Larry Gifford: Yeah. If you have extreme differences between your ons and offs, and it's impacted by Levodopa, then you probably are a good candidate for this.

Dr. Kelvin Chou: Exactly.

Larry Gifford: Great. Now who should consider DBS, and when is a good time to get DBS? Let's bring in some of our other guests here too. Jim and Donny, what made Jim a good candidate for DBS?

Jim McNasby: Well, I would say I had symptoms that responded to Levodopa first, and second-

Larry Gifford: What were those?

Jim McNasby: What were those? Tremor and stiffness and gait in speed of movement, I would say. Bradykinesias, for sure too. What made me change or get the surgery was I was taking a ton of pills a day, and I was dependent on them. Wherever I went, I carried my Parkinson's medication with me. If I was on a trip or something for work, I would always have medicine with me all the time. I just wanted to break the cycle of continued dependence on medication. My doctor thought my symptomology made me a good candidate, so we went ahead with it.

Donny Moss: Also, you were the right age for it.

Jim McNasby: Yeah, that's true.

Larry Gifford: Well, let's talk about that a little bit more. Dr. Shahed, share some more information about the viable candidates. Is there an age limit?

Dr. Joohi Shahed: Yeah, no, that's a common question that we get. I think that, generally speaking, there's not a specific age limit for getting deep brain stimulation. We know that the main things that we're looking for are whether patients have had, as Dr. Chou described, and as Jim and Donny were describing, the fluctuations that are present and maybe even the refractory tremor. But we do know that as people get older, they can have other medical conditions and potentially other risk factors that might affect their response to the surgery itself. And so there might be different surgical risks associated with patients who are older, and so we do want to make sure that those are all investigated appropriately. But there really isn't a strict age cut off for a DBS.

Larry Gifford: One of the symptoms that is bothersome for a lot of people, especially with YOPD, who are still in the work field, is the decline of the executive functioning. Is that affected at all in a positive way by DBS?

Dr. Joohi Shahed: Well, executive functioning is, unfortunately, a common feature of Parkinson's disease, and it's not necessarily something that we look to be improved necessarily with deep brain stimulation. Oftentimes, maybe there are some features of that executive dysfunctioning that can improve with Levodopa, and to the extent that those happen, perhaps there's also some improvement in that with deep brain stimulation as well. But generally speaking, that's not something we expect to change. When you think about the long-term profile of patients who have undergone deep brain stimulation and what can happen to their cognition over time, there's a small proportion of patients who can have greater difficulties in certain areas in association with the surgery. But generally speaking, over time, we may see Parkinson's advance, but we're not necessarily seeing it advancing as a cause of doing the deep brain stimulation.

Larry Gifford: Okay. As far as access to DBS, like most things that I find with Parkinson's, I'm guessing there's inequities of access to DBS in the United States and around the world.

Dr. Joohi Shahed: Yeah. Deep brain stimulation, first and foremost, I think it's important for everybody to understand that it is approved by insurance. It is a well-recognized treatment. It is something that people who have access to care for their Parkinson's and have insurance and things like that, those things should not be barriers for patients to get it.

Dr. Joohi Shahed: I think what we see are reflective of the care patterns in Parkinson's disease. We know that places that have large hospital systems or have movement disorders clinics, or neurology programs where they see larger numbers of patients with Parkinson's disease, those are places where we're also seeing more deep brain stimulation happening.

Dr. Joohi Shahed: Now it's growing, and it's changing. There are centers or smaller programs around the country, but I think one of the challenges that we've seen is that if there isn't a place close by that the patient can go to to get that DBS care, it becomes harder for them to commit to it. That distance from the center, whether or not they're being managed in a place that has regular and consolidated care for Parkinson's patients, I think those are probably more the factors that we're seeing in terms of patients' access to deep brain stimulation.

Dr. Joohi Shahed: Now, some of the studies do show that patients of certain demographics are less likely to receive that, but I do think that it has a lot to do with how these care patterns for the underlying Parkinson's disease are situated around the country.

Larry Gifford: Great. Dr. Chou, she talked about insurance. What if you don't have insurance? Are there other places you can go to help get finance for this? I imagine brain surgery is not a cheap operation.

Dr. Kelvin Chou: Yeah. That's a really good question. I don't think there are other options out there if insurance doesn't cover it, really. I think some health systems, you might be able to call and talk with them and negotiate that they may have certain assistance programs that may be maybe able to help with it. But yeah, unfortunately, I don't think there's much help if you don't really have insurance.

Larry Gifford: Are there other obstacles, beyond financial, that people need to consider?

Dr. Kelvin Chou: To getting deep brain stimulation?

Larry Gifford: Yeah.

Dr. Kelvin Chou: I think it's really more, like Dr. Shahed said, it's the distance from the center, I think, is one of the major obstacles and trying to find a good team that can do it for you, that's more convenient.

Larry Gifford: Yeah. One of the reasons you want to be close is because you still need to get the dial-it-in. After you have the surgery, you still have to see that and get the technician to adjust the DBS. Correct?

Dr. Kelvin Chou: Yeah. That has a lot to do. After the surgery, there are fairly frequent visits where you need to tweak and adjust the stimulation in order to make it better for you. That can take a fair amount of time after the surgery, so frequent visits is important. But also, I think, as Dr. Shahed mentioned, a lot of times, these tertiary academic medical centers, the university centers, tend to have a lot more of the people who are experts in managing Parkinson's disease. So they are going to be the places that tend to have a lot more of the deep brain stimulation-type programs because people have been trained, they see Parkinson's disease. If you don't do this a whole lot, it's hard to maintain a program with good care and quality surgeons and people helping to manage it.

Larry Gifford: Now, if somebody is considering DBS, you have to recommend them for that. Their movement disorder specialist has to recommend them for the surgery. How important is the relationship that you have with the patient and how honest they're being with you weigh into that decision?

Dr. Kelvin Chou: Well, actually, I think if you're a patient, being honest with your neurologist about your symptoms, I think, is very helpful. I guess the example that I can think of is I may have patients who come in, and I think they come in, and they want to try and present their best self. Yeah, I may ask how are they doing? Are they having any problems today? And they say, "No. Things are going really well." And then I look at the spouse, and they're shaking their head no. [crosstalk 00:13:33] not going well. And then they start talking, and then you find out, oh, maybe when the medication wears off, they can't move a whole lot. Or they they're having problems or more problems than maybe a patient is letting on.

Dr. Kelvin Chou: And I think that's actually very important, just for your general care in Parkinson's disease because from a physician's point of view, if you come in saying things are great, I might just say, "Okay, well, things are great. We're not going to change anything." Nothing is actually going to improve for you.

Dr. Kelvin Chou: If you lay out your problems, then we can at least try and come up with a plan to try and make those better. And I think the same thing as with the deep brain stimulation. After you have it, if we're tweaking, and you want certain symptoms to be better, if we can make it better, I can only make a plan if it's brought up. But if you just say, "Things are great", I'm going to say, "Okay, good. We don't need to change anything."

Larry Gifford: Donny, do you ever catch Jim saying he's great when you know he's not?

Donny Moss: I always had to go to the doctor with him because I knew he wouldn't be honest about how bad his symptoms were if I wasn't there. And that affects me too when his symptoms were worse. I wanted him to take better care of himself for him, and also for me. And part of me wonders, looking back, if none of his neurologist recommended deep brain stimulation surgery, precisely because he said, "I'm doing fine. Everything's fine." It was actually other care partners who asked me about why he hadn't gotten DBS already that triggered the discussion between us.

Larry Gifford: And, Jim, looking back, do you wish you would have been more forthright?

Jim McNasby: Well, yeah. There's a piece about Parkinson's that's no fun to manage, which is, yeah, there is no cure. Part of the defense mechanisms I'd bring to that problem is to try to put a positive spin on how I'm feeling or how I'm doing battling the disease. So my optimism wants to carry me across the finish line, but I do think Donny's right that, over time, if you looked at my doctor's appointments, I was saying all the good things and holding back or being quicker about the bad things. That may have led them to think that I was less symptomatic than I might have otherwise really actually been. And that delayed a recommendation about DBS because of it.

Larry Gifford: When Donny came back from talking to the other care partners who had suggested that you should get DBS, what was that conversation like?

Jim McNasby: Well the chorus from that meeting, which came from the care partners, wives, that life gets better and easier. You can actually turn back the clock on your symptoms. And that's where I felt like I needed at the time, because I was having lots of trouble with basic motor skills, like buttoning my shirt, or tying a tie or anything like that. And then now in retrospect, having gone through the surgery, all of those mundane things have become mundane again. I don't need help carrying a tie, tying a tie. I don't need help tying shoes. I don't need help walking. I don't need help with my balance as much. So, I mean, a lot of things have been resolved and return to what's normal, which is great.

Larry Gifford: Yeah. Dr. Chou as soon as that sounds, what's being described here, sounds like a miracle. I think that people are lining up, count me in, but there's some other things to consider and some questions to ask while considering DBS, what are some of the questions people should be asking themselves before they say, "yeah, cut my brain open."

Dr. Kelvin Chou: Well, I think the first thing is, whether or not you would qualify. And so are you having the motor fluctuations that we talked about or are you having a tremor that's interfering with the quality of your life, but it's not being treated adequately with medications. That would be the first question. And then I think when you're looking into deep brain stimulation, I think you want to look for a place that does it fairly often. And so it's not like there's a minimum per se, but I think a place that does one a week is very familiar with it and knows a lot more about it than one that does one a year, right? So probably one a month, a couple of month is a place where you want to at least explore and then talk about the experience of the neurosurgeon and the team, and then make sure that you go to a place where there's at least I think that the best outcomes come from place where there's a multidisciplinary team helping you.

Dr. Kelvin Chou: So this would include a neurologist who specializes in Parkinson's disease and movement disorders, a neurosurgeon, who they work in concert together. There's usually a coordinator which is like a nurse or a nurse practitioner who also does programming, but also as kind of the glue that holds the program together, that's your contact to everything. So if you have problems, you can call this one person. And whether it's a neurosurgical problem like infection, or it's a neurological problem, like you need an adjustment, your medications, that person can kind of help triage and get you to the right person who can answer the questions. Many of these teams also have other members such as social workers, speech therapists, maybe it's psychiatrist, because as you know, patients of Parkinson's can have mood problems, depression, anxiety. And so having this team I think is very important.

Larry Gifford: Some of the DBS surgeries patients are awake and sometimes they're asleep. What's the difference?

Dr. Kelvin Chou: Well, so it depends on the center. What they opt to do. I can say that at our center, we basically keep patients awake for the surgery. I think there are several advantages to this, one is that when you're awake and you do the surgery, you have a couple of different ways to confirm that you're in the right spot. When they actually put the electrode in, there is something called micro electrode recording, where you kind of hear the signals of the brain as the electrode or the lead kind of goes through the brain. And when you get to the right spot, every single area of the brain has a difference signal to it. I often use the analogy of, I'm in Michigan. So you hop in the car and you're going to drive down to Florida.

Dr. Kelvin Chou: You turn on the radio station and you start out with Motown and you kind of get in the middle of the country and the Tennessee, and you hear country, you kind of go down to Miami, hear some Cuban music while we're looking for the Cuban music. If you get out down into a structure called the [inaudible 00:20:14] it has a specific type of signal and you know you're in the right place. And then because you're awake, usually we will test the stimulator. So we'll turn it on. And if you have tremor, if we can make it go away with the stimulation, we don't have too many side effects. That's another way of just confirming you're in the right spot. The disadvantages of this of course, is that you have to be awake for this whole time. I'm comfortable being awake and you have to stay still for the surgery, you're usually in a frame and you're locked in and can't move and you can be very anxiety provoking.

Dr. Kelvin Chou: So the asleep DBS takes care of all of those problems. Like you're not going to be anxious about it. And you can see the structure where you're going to put it in, but sometimes just putting it in the structure, you may not one know, is it going to be effective because you're not testing it at that time. And if it's slightly off to our fits close to certain fibers, you might get side effects when it gets turned on, where you might get tingling or motor contractions, where it's stimulating fibers, that can kind of control the strength on the side. So those are kind of the potential downsides. It's not like everyone has those types of problems, but those are the kind of pluses and minuses of each. And there's no one right way to do it. So...

MJFF: A landmark study that could change the way Parkinson's disease is diagnosed, managed and treated is recruiting participants now. PPMI or the Parkinson's Progression Markers Initiative needs people with, and without Parkinson's, especially people aged 60 and up who have close relatives living with the disease. Take a short survey today, at michaeljfox.org/ppmi to see if you're eligible, that's michaeljfox.org/ppmi

Larry Gifford: Dr. Shahed, there are a lot of different... There are several different devices out there too that have risks and benefits. Can you talk about some of those?

Dr. Joohi Shahed: Yeah. So actually, I'll just say that the devices themselves, there's three different ones that are available. There's an Abbott device, Medtronic device, Boston Scientific device. I don't think that the side effect profile is necessarily different from any of these, I think is what it is, is just the bells and whistles that are associated with them. So all of these different devices have been extensively studied. They have shown that when you use these devices, patients with Parkinson's disease can get excellent benefits in their clinical symptoms and the degree of symptom control that they can get from it. As long as we are following kind of what we talked about previously, which is appropriate patient selection and appropriate counseling about what the outcomes are likely to be. So from that standpoint, I think you can think of these devices pretty equally in terms of, am I going to get good therapy?

Dr. Joohi Shahed: But I think there are some differences that do allow a little bit more flexibility, but in different ways with each of these devices. And we talked a little bit about programming. Once you get this device in, you have to fine tune it. And the way that we tune it will be different for individual patients, according to what symptoms they have, there isn't a recipe or a cookbook or anything, or just dial it up here. And this is exactly the setting that you'll need for this particular patient. There's a little bit of trial and error that goes on. And so for example, what the AVID Infinity device their system has something that we call a directional lead. A directional lead, if you think about the wire that's in your brain, normally we would just have four spots on there that we could choose from.

Dr. Joohi Shahed: And when the Abbott's directional lead was the first to do was to come out with this way of being able to segment the lead and then to steer the current in different directions. So as Dr. Chou was talking about, if there are side effects in one direction of stimulation, maybe you could steer away from that and then kind of focus the stimulation in an area where you know you can get the clinical benefit. So that was one of the first things that Abbott came out with. Another thing that they have in their platform is a way to help and guide the clinician in terms of choosing the appropriate stimulation parameters. And then I think one of the more exciting things that has come out recently with their devices is the opportunity for something like remote programming. And so we'll hopefully be seeing that coming out in a greater sort of release in the coming months. But that's kind of where the Abbott device sort of has its niche. If you want to put it that way, the Medtronic device...

Larry Gifford: That would really be beneficial for people who live far away from maybe where they had the surgery. Like let's say you live in Alaska and you have DBS, you don't necessarily have to fly to Seattle to get it to me.

Dr. Joohi Shahed: So I think that's a fantastic concept and I think that's what we hope will eventually happen. But we do have to recognize that there are still restrictions on the way that we can practice that kind of remote care and even DBS care in that sense is going to be subject to those same limitations.

Dr. Joohi Shahed: So I, as a practitioner in New York state, I have a license in New York unless I have a license in New Jersey, I can't take care of my patients remotely in New Jersey, right? So same thing would apply to somebody in Alaska as you were sort of giving me examples. So there are going to be those types of regulations right now we're in a very fortunate state, which unfortunately occurred as a result of the pandemic. But what it did was to accelerate this kind of remote care. And now that we have the remote care capability with the DBS device with specifically with this device, I think it opens up a lot of opportunities, but it's going to have to follow those regulatory guidelines. So that's TBD as far as how that's going to play out.

Dr. Joohi Shahed: If we talk about the other devices then, the Medtronic device, their latest release was the Percept device. And so this again, fantastic platform, they have a directional lead similar to the one that I described for the Abbott device. But the other advantage in this Percept device is actually the ability to measure brain signals. And so in Parkinson's disease, we're understanding a lot about being able to record in the same places that we're actually stimulating. And so this device enables us to be able to do that. And there are certain brain signals that are associated with the symptoms of Parkinson's. And we can sometimes tell by looking at those brain signals, is the person on or are they off or are they having dyskinesia? And so if you can use those signals to try to guide your programming of that patient, that can become a very powerful tool.

Dr. Joohi Shahed: And I think what this is moving us towards is the ability to be able to really individualize that symptom control for those patients. So if you're experiencing this symptom and we can see this brain signal, then maybe we should be able to do the stimulation this way. And if you're now having this particular symptom, maybe you took your meds, you turned on your having dyskinesia. Maybe we can dial it down or maybe we need to just dial it a different way.

Dr. Joohi Shahed: And so that's what the new kind of Medtronic percept device platform is hopefully going to allow us to do. Okay, so the Boston scientific device, they have a directional lead as well. They also have the ability for the person who's programming the patient to be able to see the lead inside that deep brain structure that is being stimulated. And so you have this sort of visual tool to be able to guide the way that you choose your programming parameters. And so that interface is a little bit different and the opportunity to be able to fine tune that stimulation is also a little bit different as a consequence. And so, as you can see, I mean, each of these companies, they all have great prices, but they all have different kind of ways of enhancing our ability to improve the way that we're delivering the DBS for individuals.

Larry Gifford: Now, is there a general post-op process that you can discuss the tuning? How does that work?

Dr. Joohi Shahed: Yeah, so I think one general thing that's important for people to understand that it is a process, right? So it's not like you have an appendix, infected, you need to get it out, you go get it out and then you're done, right? Problem solved. Getting the DBS device in is the first part of beginning the process of getting the symptom control. And so what we need to do in Parkinson's disease is to first locate where's the best spot to give that stimulation. I talked about some different strategies that you can use from these different manufacturers to try to find the best spot, but then once we do that, then we have to fine tune it and we have to fine tune it in combination with the medication.

Dr. Joohi Shahed: So then there's a little bit of stimulation adjustment, see how that works, maybe an adjustment to the medications. And then you go back to the stimulation and you can adjust that a little bit and then maybe do something with the medications. So there's this kind of back and forth kind of optimization that has to happen. And I think different practitioners might do it differently. I do it on a monthly basis. And so I will advise my patients that it might take up to six months for us to get it just right, but this is the reason why. And so I'll have you come in every month, we'll tweak something, we'll adjust a medication, we'll tweak something, we'll adjust a medication, and eventually, by the end of that time period, we'll get where we need to be.

Dr. Joohi Shahed: And sometimes it's shorter and sometimes it's a little bit longer. It just depends on the individual patient.

Larry Gifford: Can we bring Jim and Donny in here again. Jim, what was the post-op process like for you?

Jim McNasby: Well immediately, well, first of all, I did so after I got my surgery in three parts, right? Lead number one, lead number two, and then the devices, the Abbott device, in my case, actually I have two of them, one for each side. And right when they turned it on, there was immediate relief for me of some of my symptoms. I was tremoring a lot. My voice was very soft and immediately those two things were resolved.

Larry Gifford: Let's retake that, we have this on film. So if we could pull up the video of Jim, that'd be great.

Donny in Video: This is Jim off medication. We can see shuffling and tremoring.

Jim in Video: We just got to the doctor's office that we're going to turn on the DBS so uncomfortable. And I would like to feel better than I do right now.

Doctor in Video: So it's on, on the right side only. Okay. Let me know if there's any pins or needles. We're just going to progress slowly.

Donny in Video: You feel something?

Jim in Video: Yeah. I'm not moving anymore.

Doctor in Video: Does that feel any different?

Jim in Video: More free

Doctor in Video: Yeah. Though speedy, right? Yeah. Rigid good.

Jim in Video: I was shaking a lot. And now I'm not shaking. I don't actually feel like... Even though you haven't turned on yet, my left side is calmed down all of a sudden this [crosstalk 00:31:00].

Donny in Video: Do you feel Parkinson's free right now?

Jim in Video: I feel like the problem, which is always there is not there, like somebody turned my right arm back on. I just had not felt like this in such a long time. So I'm walking around and all the other patients.

Donny in Video: Don't walk into a wall.

Larry Gifford: That's pure glee. I love seeing that.

Jim McNasby: You make sure you don't come back coming down the hall cause I could, it just, honestly, I felt like an exuberance when I felt the stability. And then from that, that was the initial positive result. And then I actually had a little bit of a bad experience after that because I took a Sinemet and the Sinemet made my arms stiffen and my hands they were moving towards.

Jim McNasby: Then, and my hands, they were moving towards my face and this kind of thing, I couldn't control it. And then since then, that was the last Sinemet that I've taken. So, I would say the... You have to get it right and you definitely have, as Dr. Shahed said, you have to work with other medications and tune the whole system. But for me, it was about five visits before we got to meet to be comfortable. And you could see how I was tremoring before. And now as I hold my hand here, I have zero tremor.

Larry Gifford: Wow, that's amazing! How long it's been since you've had the surgery?

Jim McNasby: Two and a half years.

Larry Gifford: Okay. Dr. Chou, how long do the effects of the surgery last?

Dr. Kelvin Chou: Actually, before I get into that, can I ask Jim one question? Because you mentioned you haven't taken Sinemet since that day, the first day of your programming, is that right?

Jim McNasby: That's right.

Dr. Kelvin Chou: Okay. That's an amazing result actually. And so I want to at least let people know that this is great, but not everyone can come off medications [inaudible 00:33:06]. Most people actually still need to take some of their medications. And on average, I think, we say that people can reduce medications by about half after surgery compared to before surgery, after everything is optimized. And so coming off medications is wonderful. I probably have a handful of people who are like that, but I just want to let people know that's not the way everyone necessarily is, but you can still be on gray and have smooth motor function without tremor but still be on a little bit of medication. No.

Dr. Kelvin Chou: So Larry, you were asking how long does this last? It's interesting there was an article that just came out in *Neurology*, which is one of our top journals in our field. And it was published by the group in Grenoble, France. And they actually looked at patients who are at least 15, many of them 20 years after having deep brain stimulation in the subthalamic nucleus, which is one of the targets for deep brain stimulation. And at 15, 20 years, the main things that you want to target, which is the fluctuation. So tremor, slowness and stiffness that respond to levodopa were still maintained even that long afterwards. So, around 70 percent improvement compared to before. Dyskinesias were reduced at same amounts as it was a year, six months or a year after surgery.

Dr. Kelvin Chou: So these are symptoms that can be controlled for a long, long period of time after deep brain stimulation. Now there are other symptoms that do actually probably progress in many patients. So it's not a cure for everything. Many patients can get more gait and balance problems over time. They can get more speech problems over time. You can get more cognitive problems, so problems with thinking and memory over time. So those are the things that tend to progress despite the deep brain stimulation. But what we're aiming for, the fluctuations, slowness, stiffness, tremor, those can be maintained for a long time.

Larry Gifford: Dr. Shahed, should people be considering whether or not to do DBS now, based on the fact that all these new versions of DBS are coming out? I'm a candidate for DBS and do I wait a couple of years and see if the technology advances, and so it's even better for me? Or if I get the good year back now, should we be considering that?

Dr. Joohi Shahed: That's such a hard question to answer, because I think it's such an individual decision about deep brain stimulation. And I think, we've talked a little bit about, obviously you've heard a lot about the fantastic benefits that we can see in an appropriately selected patient. So there's still definitely this idea that there is kind of a timing that's right, right? And so I think each person is going to come to that sort of decision a little bit individually. But I do think that it is important for patients to understand that it is an option that is available to them when they are experiencing these kinds of symptoms. I think that waiting for the newest technology is also a little bit of a challenging question to try to navigate, because we know that there's great benefits from DBS now and what probably is going to happen in the future is that it isn't going to be too hard to take advantage of those newer technologies.

Dr. Joohi Shahed: I mean, if it's a new lead design or something obviously that's going to be a little bit more of an ask. You want to get the newest lead design, cause that would take a new lead surgery. But at least from the standpoint of some of the new bells and whistles that might be coming out, there may be ways to be able to get advantage of those even without having to undergo another procedure to doing it. So, I would almost kind of say, if your life is affected right now by your Parkinson's in a way that is making it hard to sort of get through your day and to do what you need to do because of the fluctuations or the refractory tremor, and you've heard about the DBS, I think you should talk to your doctor and really think about whether or not it's something that can give you the relief that you need today, as opposed to waiting for longer to make that decision.

Dr. Joohi Shahed: I think Dr. Chou was sort of referring to this a little bit, which is, when Parkinson's progresses, there are things that can evolve that are harder to respond to surgery. And so we want people to get the benefit of the surgery when they can and not wait to a point where maybe those benefits aren't as maximal. And so I think that needs to be sort of factored into that decision making as well.

Larry Gifford: After you have DBS, are there restrictions to the activities that you can do?

Dr. Joohi Shahed: I think you have to be sort of practical. I've had patients who have done some really fantastic things after doing deep brain stimulation. We've had one patient actually who went skydiving. I'm not going to say that I recommend that to everybody. I mean, you've got a big expensive piece of hardware in there. And so you want to be smart about what you do so that you don't necessarily put yourself at risk of damaging that hardware. But I think most of the patients can get back to their, you heard this already, that patients can get back to their usual things that they were noticing that they had a hard time doing as a consequence of their poorly controlled Parkinson's symptoms.

Dr. Joohi Shahed: And so there are certain restrictions but they're kind of weird things like certain restrictions on diving, for example, like deep sea diving. Or if you're a welder, then you have to be careful about around certain types of welding equipment. And so these are not necessarily things that apply to everybody, but in certain situations that there might be those kinds of restrictions. So for the most part, we just want people to get back to doing what they are used to doing. And there's really no reason that you can't do that in an appropriately selected patient and a well-placed lead and a good programming strategy for the patient.

Larry Gifford: Jim and Donny, have you found any restrictions post-op?

Donny Moss: Well, a couple of things. I feel like because Jim has batteries here and leads here, I feel like he's a little bit fragile. Like I want to bubble wrap him whenever we leave the house, because if he were to fall and fall on his chest, then you know, if something going to happen. So I'm definitely even more aware than I was before the surgery of keeping him intact and standing straight up on the street. We took a jog, this is now a year or so ago, and he tripped and fell and his hands blocked the fall, but it was just, it was just a scary moment. But also just to circle back to the meds issue, Jim said that he came off of the Sinemet after the surgery.

Donny Moss: He still does take a couple of other medications a couple of times a day, just not completely off of medications. But then there's some days he forgets to take it altogether and isn't having symptoms.

Larry Gifford: So is he on agonists?

Jim McNasby: I try to take amantadine and trihexyphenidyl (Artane). I take one of each in the morning, that's my usual, but I forget at least once a week. I knew exactly where the Sinemet was, because for me that was the big reliever, right. The other ones were helpful[inaudible 00:08:16]. I've weaned myself off of the medication in the last two years, every six months or so[inaudible 00:08:22]. I've removed another pill, so it's about time to do that again for me, in some ways, try to do that, in the summer of this year. But I mean as electives considered neuroprotective anyway, right? That's one that I might add back in which I had gone off because I could.

Donny Moss: Circling back to your question about activities, I mean, I said that he's more fragile, but I kind of, didn't complete my thought, which is that he could do a lot more now than he was able to do before, because of this surgery. I mean, simple things that most of us take for granted, like taking a long walk. He really couldn't do that before. Now we could walk for six miles and he's okay. He's just overall, his fine motor skills are back. He can live pretty much a normal life. And I, as a care partner, don't have to factor his sort of schedule and where he's going to be into my decision making process because I know he's okay. And he can function on his own.

Jim McNasby: Right, except for the bubble wrap, I need help with that.

Larry Gifford: Jim, before the surgery, were you like me where you have stashes of the levodopa everywhere[inaudible 00:09:38] every room?

Jim McNasby: I did. I used to, I wore a suit jacket, and so I would always have, to work, I would always have my medication in every suit, just in case. I would squirrel it away. Some people used to say I used to hide it in my cheeks.

Larry Gifford: That's great. That's great. Okay. We're going to take a little bit of a break here. I want to tell you about the PPMI. It's a landmark study. They're recruiting again for PPMI too. Parkinson's progression markers initiative is a study that could change everything about Parkinson's, how it's diagnosed, how it's managed, how it's treated. And right now the study needs people. They need parents, brothers, sisters, adult children, of people with Parkinson's. You can take a short survey to get started. You get started to take action box on your screen. The study is also recruiting people diagnosed with Parkinson's in the last two years who are not yet on PD medications. So you can learn more about PPMI by clicking the link on the resource list. It helps spread the word about PPMI. The link to share is michaeljfox.org/ppmi, michaeljfox.org/ppmi.

Larry Gifford: It's an amazing study. And if you can be a part of it, you'll be a part of history. I also want to tell you about the deep brain stimulation guide that just came out. I just printed it off this morning. It's fresh, hot off the presses in the last two days. And it looks like this and you can download it on your computer. If you're signed up for the emails, I know Rachel sent out an email earlier this week and so did the Fox Foundation, but you can go to The Michael J. Fox Foundation website and find it there as well. And it's a really great guide, it answers a lot of questions about the DBS. But we're going to continue our discussion and get your questions answered too. So don't forget to go into the chat and ask your questions there and we'll get to as many as we can. What I would like to do is talk to Dr. Chou about the innovative new technologies and advancements in DBS. Where are we going with DBS into the future?

Dr. Kelvin Chou: Well, actually I think Dr. Shahed alluded to this in some of the different features that the different companies have in their devices. One of the things that she mentioned about the Medtronic device, the Percept, is this ability to be able to text signals in the brain. And so there are signals that kind of lead to, if you have dyskinesias, is that there's a certain signal that kind of popped up to, or if you're having Parkinson's symptoms, they may disappear with medication or with stimulation. So it's detecting that and then being able to stimulate that particular area or in a way that kind of helps decrease the signal. That I think is a part of where we see things going. And it's more like two things, actually.

Dr. Kelvin Chou: One is being able to stimulate maybe more as needed as opposed to the way it is right now, where it's just constant. You set it and it just kind of goes. If there's a way where if you can detect certain signals and you can stimulate at that point to make the signals go away, you can potentially maintain function without having the stimulator go on all the time.

Dr. Kelvin Chou: And then there's also just to make it more of a, what we call a closed loop system, where it just automatically detects these, you send a signal and then so there's not as much need for the tweaking for a clinician to really adjust it. It kind of adjusts by itself. This kind of smart DBS or adaptive DBS technology, I think is one of the things that potentially we may be able to have soon. So I think that those are the ways that the companies are improving things to be able to help DBS.

Larry Gifford: So self-regulation is [inaudible 00:45:40] automatic regulation in your body where it just sort of responding to how you're doing.

Dr. Kelvin Chou: Yeah (affirmation). That's the dream right now, to be able to have to do that without us having to just manually go in and adjust and tweak and can make things just much, much easier, much quicker, and you can get relief more quickly than the waiting for the three, six months to kind of get things right.

Larry Gifford: And Jim and Donny, do you feel like that kind of advancement would help you?

Jim McNasby: Sure. I mean... It's... If something was able to... I went through maybe five or six office visits after the completion of the surgery to get the current settings right. They've been the same for about a year now, more or less. And so... But if there comes a point where my disease changes or progresses, to have something that in real time could respond would mean a lot to me, for sure.

Larry Gifford: That's great. Yeah. I mean, I would think so, rather than having to wait. Dr. Shahed, can you explain, we mentioned it earlier, R-A-D dash P-D, what is that? And how could it help guide care directions in the future, decisions in the future?

Dr. Joohi Shahed: Yeah (affirmation). Thanks for the opportunity to talk about that. So, RAD-PD is that registry that you mentioned earlier. And so RAD-PD is something that we started a few years ago with the support of The Michael J. Fox Foundation, which we're very grateful for. And this is a registry of patients with Parkinson's, who are undergoing deep brain stimulation. And Dr. Chou is a member of our number group of sites that are participating in this registry and we're very thankful for that.

Dr. Joohi Shahed: But basically, the goal of this registry is to be able to very comprehensively characterize what's happening with deep brain stimulation in patients with Parkinson's disease. So believe it or not, I mean, you've heard a lot of great stories about DBS and all the results that it can give you, but even though we know that a lot of patients can do very well, we do see differences in how individual patients respond. And we also know that there are a number of different decisions that can be made about how to do that DBS. So which part of the brain to put it in? Maybe which device or which device feature to use? Should we change this particular parameter? Should we test this particular symptom? And so we also know that different places that do DBS follow different things in patients. And so, we don't really have this sort of very comprehensive way of assessing patients the same way over time. And so that makes it harder to kind of make generalizations about what are some of the best treatment practices, what are some of the most common side effects or some of the ways to manage those side effects, things like that. And so what we're hoping to do with RAD-PD is to take patients from the beginning of that decision-making process about DBS and to systematically track what's happening with them over time.

Dr. Joohi Shahed: And hopefully, over time then, gathering that same information on every patient really allows us to draw some more firm conclusions about how to do the DBS, which patients to select, which parameters, which features, how to assess it and really kind of get a handle on, on some of these issues and to understand then why certain patients may respond differently to the surgery or have different problems associated with it. And I think it can be a very powerful tool to have that kind of big dataset, which currently doesn't exist in Parkinson's patients with DBS. And so we're hopeful that, as we accumulate this data, that we can start making those connections and start creating those guidelines and those best practices for DBS.

Larry Gifford: No. Is this something that the doctors are signed up for? Or are you looking for patients to sign up for it as well?

Dr. Joohi Shahed: Yes. So right now, the way that this project is being administered is at the site level. So we have a group of sites. We have about 20 sites right now across the country that are participating in this effort, and so patients that are being managed at those sites will be eligible to participate. And so [crosstalk 00:49:31]

Larry Gifford: That's cool. And part of the problem is there's no objective measurement of Parkinson's, so we're all just squirted like, hey, well, we could measure UPDRS. We could measure happiness. We could measure like whatever [inaudible 00:49:43] all sorts of things that can measure. But finding a number of things to follow, I think, would be really interesting. So when do you think you'll begin to get results on that, that are viable?

Dr. Joohi Shahed: Yeah. So right now, we have about 170 subjects that are actually enrolled into the registry. And so there are various levels of data collection. This project has been going on now for a couple of years, and we've had patients kind of at various stages and we're continuing to enroll. And so we're accumulating. We had a very kind of solid set of data, baseline data on a small group of patients from kind of the initial a couple of years of the study that we were able to present at the American Academy of Neurology meeting earlier this year. And so what we were able to show in that information was that this is like a real-world assessment, like deep brain stimulation. And what we're seeing is that there's patients from all backgrounds and with all different experiences with their Parkinson's disease that are getting deep brain stimulation. It's really important to be able to understand how these factors contribute to their experience with DBS.

Dr. Joohi Shahed: So that's what we were able to show initially. Right now, we're working on collecting surgical information on a good number of patients so we can start talking about surgical decision-making and some of the things that the surgeons have to do in order to get that electrode in the right place and to have a good surgical experience for the patients. And so I think little by little, as we get more of that data, we can add to that dataset and start making more sort of comments on what seems to be happening and what seems to be.

Larry Gifford: Yeah. It's interesting this whole process of trying to make that decision. I've got a 12-year-old son. And me and my wife and I've been married for 22 years, and we're at that point now where like it's getting close to where we know we it's probably what needs to happen. But then how do you talk to your 12-year-old about getting brain surgery? Have you had that opportunity to chat with kids about it? [inaudible 00:51:44] Dr. Shahed and Dr. Chou.

Dr. Joohi Shahed: Kids, yeah. I mean, I think a lot of times patients when they come in to make a decision... We're talking about decision-making about DBS. It's like a family decision. So yeah, I mean, I think we have had older children, sometimes younger children who get involved in that discussion or at least are kind of aware of what's going on. I think, again, it's a very individual thing and I think family dynamics are also individual, but it is a family decision. And so I think patients such as yourself do have to go back and kind of have those conversations with their family, this is why I want to do it or this is why I'm worried about it.

Dr. Joohi Shahed: And I'm hoping that the evidence that we'll get from this registry will provide some more sort of really not so much of how much did your UPDRS score, but really what were the improvements in life that patients were able to experience. I mean, did it help their mood and how did it help their moods? Did it help their ability to work and how did it affect their ability to work? And so maybe some of these other questions are by being able to answer some of those additional questions that helps patients like yourselves in making those decisions and having those conversations with your family.

Larry Gifford: Well, I mean, you saw the impact of patient referral that the impact that it had on Jim and Donny. We know from a patient perspective, hey, you get five years back, you get 10 years back, whatever. What's the success from a doctor's perspective with DBS? What would you tell a patient about like, oh, you should do this because why?

Dr. Joohi Shahed: Yeah. I mean, again, we've talked a little bit about those sort of selection criteria. I think that when patients are taking their medications multiple times per day, they're aware that the medicines are kicking in and wearing off. There's sort of this fluctuation going on. Maybe when they take the meds, it's causing the excess involuntary movements. They're having trouble sort of regulating it. It's really this idea of being able to get that stability back, which probably was something that patients experienced previously.

Dr. Joohi Shahed: And so I do believe that this feeling that patients frequently describe about being taken back in terms of their level of symptom control, and it's really to kind of regain that level of control over symptoms that I think is so much the advantage of doing something like deep brain stimulation where otherwise you're just sort of stuck with taking the meds and waiting for them to work and maybe they work well or maybe they don't work so well or maybe they cause other problems. And this is really kind of one of the most important ways that we have of getting that control back. And I think Dr. Chou mentioned this as well, whatever that on-time is, to be able to feel that more consistently during the day, like who wouldn't want that, right? I mean, I think that's a very powerful thing to be able to obtain for patients. And I think those are the things that I kind of try to highlight for patients who I think are really headed in that direction.

Larry Gifford: That's great. And so afterwards, how do you determine if it's success? Is that patient satisfaction?

Dr. Joohi Shahed: I think that, that plays a large part into it. And I'll tell you a little bit about what we're doing at Mount Sinai, which is to try to have a more comprehensive assessment of patients because, again, it's very easy to sort of say, oh, well, I got your tremor under control or I got your on-time and your off-time, and you can talk about these numbers. But there's this whole qualitative thing about, is the DBS really helping me that we haven't necessarily explored to the full extent? And so at Mount Sinai, we're really kind of taking look at not just the motor profiles of patients, but also the non-motor profiles. So things like the mood or things like the cognitive stuff or other just sort of less tangible features of the Parkinson's disease and trying to understand how that really plays into satisfaction. Okay, so we fixed your tremor. We fixed your fluctuations. We fixed your dyskinesias. What are some things that are still bothering you? And we're finding that there's additional opportunities, even with deep brain stimulation to address some of those other things as well.

Larry Gifford: Cool. Hey, Dr. Chou, are there other side effects that people should be concerned about? Like I know a lot of people who had DBS now have a softer voice or scratchier voice or leave a muscle projection. Is that standard? Or is that just one of the many possible side effects that can happen?

Dr. Kelvin Chou: Yeah. So speech problems can be one of the more common side effects that you see with deep brain stimulation. And so you can talk about side effects in a couple of different ways. One is because of the surgery itself. So placing the deep brain stimulation electrode in. It's possible that you could have bleeding from that stroke infection of the device. It's probably on the order of 1% to 3%, somewhere around there for most surgeons. But once you kind of get past that, then you can talk about side effects from stimulation itself. And like we said, the stimulation kind of spreads in the brain. And so if you're delivering electrical current, it spreads to a structure in the brain that controls something else. For example, speech. You're stimulating that area. You can get slurred speech, softer speech or less clear speech from that.

Dr. Kelvin Chou: Some people get a tingling, numbness sensations. Oftentimes that's temporary. But if you turn it high enough, it can be more sustained. People can get where they feel like their hands are turning in or they have contractions on their face at higher settings. You can get more dyskinesias like Jim experienced, too. And so that tends to peak over the first few days and then kind of stabilizes, but there's some people, every time you turn it up, they get a lot more of dyskinesias. And some people, over time, can get some more gait problems as well, too, due to stimulation. So I think these are a lot of the more common ones. But again, it's individualized, it depends on where you are in the brain and where it's stimulating. And we try and get [crosstalk 00:57:34]

Larry Gifford: Yeah. We have a little bit of time here, but a lot of people are asking questions about the cost and the coverage. Is there a general cost for this price tag, let's say, without coverage and then with coverage? What are we talking about here?

Dr. Kelvin Chou: Well, actually, I don't know the exact cost. I think the problem with our health system is that there's no kind of generalized costs and hospitals list prices that may not be what the actual cost is. But insurance, for sure, will cover it. It's been FDA approved since 2002. So it's a well-known procedure. It's not experimental, and insurances cover it for sure.

Larry Gifford: Great. [crosstalk 00:58:21] Hey Jim, real quick. Oh, go ahead. Go ahead.

Dr. Joohi Shahed: I was just going to say, as a frame of reference, I think at least once previously when I investigated, it's sort of similar to maybe like a knee replacement surgery or something like that. There are hardware costs and then there's hospitals. And those are going to vary from region to region, from insurance to insurance, from hospital to hospital. But most surgery offices are going to be able to give a breakdown to a patient about what their out-of-pocket costs are going to be based on their particular insurance coverage. And so I think the important part is that it is covered. And then there might be these individual variances and what the individual out-of-pocket costs are going to be.

Larry Gifford: Jim, we're going to do some rapid fire with you real quick. Were you awake or asleep during the surgery?

Jim McNasby: Well, both, actually. I was in twilight for most of it. Oops, sorry. And then I woke up in the middle of the surgery to count backwards by seven and do some things to show there wasn't any cognitive impairment and looking for my eyes to make sure that the electrical stimulation wasn't too close to my optic nerve. So they're looking for nystagmus and other things like that. Yeah.

Larry Gifford: And has it affected your ability? Would you be able to swim or anything?

Jim McNasby: No, it hasn't.

Larry Gifford: Okay. Great. Hey, listen. We're out of time. It could go on for hours. Thank you again all of you for being a part of the community and for joining us today. Don't forget to download the Foundation's new guide on DBS. It's right there in the resource list, you can just go straight there. And thanks to our panelists for sharing their time and their expertise. We hope you found it helpful. We wish you all the best. Have a great day and be kind to yourself.

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