Deep Brain Stimulation Series

A Conversation about Deep Brain Stimulation between a Boston Scientific Therapy Consultant and Person with Parkinson's

Davis Phinney Foundation

Note: This is not a flawless, word-for-word transcript, but it's close.

Melani Dizon (Director of Education & Content, Davis Phinney Foundation):

Welcome, everyone. My name is Melani Dizon. I'm the Director of Education and Content at the Davis Phinney Foundation, and I am here today talking to talking about DBS, Deep Brain Stimulation a lot of the decisions and questions that go into it. And I'm fortunate enough to be here with a therapy consultant from Boston Scientific. Alaine, how are you doing?

Alaine Keebaugh, Ph.D. (Therapist Consultant, Boston Scientific):

Hi. Thanks for having me, Mel. Doing great.

Melani Dizon:

Great to have you. And Scott is a person with Parkinson's. He's been living with Parkinson's for 17 years, and he is considering deep brain stimulation. Thank you so much for joining us, Scott.

Scott Rider (Person Living with Parkinson's):

Good pleasure. Thank you for having me.

Melani Dizon:

Great. So, can you share first Alaine, like who are you and what is your role?

Alaine Keebaugh:

Sure. So, hi everyone. Thanks for having me, Mel. My name is Alaine Keebaugh, and I am a DBS therapy consultant for Boston Scientific. And I live in Jacksonville, Florida.

Melani Dizon:

Thanks. And Scott, what about you? Just a quick little intro, we'll get into the details soon.

Scott Rider:

Sure. My name's Scott Rye. I'm, I'm married to my high school sweetheart, Kelly. We have three wonderful kids. And I live in Before, South Carolina.

Melani Dizon:

Ooh, nice. Two southerners. I like this out. Okay, so let's get into it. Scott, can you tell us a little bit about your Parkinson's story as much as you want to about your diagnosis, symptoms, you know, what you've started, and then in terms of treatment and then how DBS came into the picture?

Scott Rider:

Sure. well, my story's probably not very different than a lot of people's stories that I've Parkinson's. There's the official date of diagnosis, which was 17 years ago. And then looking back, I realized that I started really showing symptoms about five years prior to that. So, it's been part of my life for so long. Honestly, I don't remember life without Parkinson's. Like most people, I started on a low dose of medication, which was relieved my symptoms, which for a slight tremor in my right hand, but mostly I was experiencing toe-curling when I would run. Running has always been a big part of my life. And that kind of led me down a journey that took about three years to discover that I did indeed have Parkinson's disease. And then my, obviously my dosage of medicine has increased over time and that's kind of why I'm, we're talking today because there are concerns associated with that, obviously with an increase of dosage of medication.

Melani Dizon:

Right. Okay. So, can you talk to me about like, how much medication are you taking right now?

Scott Rider:

Oh gosh. I could go get you that strip and show you.

Melani Dizon:

It's okay. So, it's too long. That's what we know. It's too long.

Scott Rider:

Yeah. I mean, I will tell you I take medicine every four hours and it's just a, it's a big burden and a big part of my life and yeah, sometimes I forget it and sometimes I remember it and it's kind of crazy when I look how many pills, I actually take every day.

Melani Dizon:

Right. Okay. So that is great. Thank you for sharing that. Alaine, what is your role at Boston Scientific and how did you get into this work?

Alaine Keebaugh:

Sure. So, I'll actually start by telling everyone how I ended up here. I actually started out my career in academic research. So, I went to Emory University where I got my Ph.D. in genetics and actually studied the role of genes and movement disorders. So those would be things like dystonia, OCD, and even Parkinson's disease. And my goal back then many, many years ago was I wanted to make better animal models of these human diseases so we could find better solutions for patients. And it was during this time that I was actually working with a neurosurgeon to figure out how we could more precisely deliver different agents into the brains of these animal models that he invited me to come to watch a DBS surgery which is a very precise way, right, to deliver a device.

And after the surgery, I told him that it was the coolest thing I'd ever seen. And so, he said, well, then you must come and watch the team turn the device on. And so of course, I did. And when I saw them turn the device on and the immediate results, you know, that the patient got to tremor, it was one of those moments in your life where like the hair on the back of your neck stands up and you know, you're there for a reason. And so fast forward now, you know, 15 years later, and here I am with Boston Scientific, I was a therapy consultant for DBS and it's the coolest job I've ever had, and I plan to have it for the rest of my life.

Melani Dizon:

Oh, I love that.

Alaine Keebaugh:

Yeah. So, sometimes I think that it found me, right? I didn't necessarily find it.

Melani Dizon:

Yeah. And then-

Alaine Keebaugh:

It's really also, it is just a great job. Not only do I get to witness people have an improvement in their quality of life and play my small role in that, but I get to do different parts of that every day. So, for me as a consultant, no day is really the same. And I really try and offer a concierge d v s service experience, so I might, you know, go out of my way to make sure that everyone feels noticed and special and that they know they're not alone in this journey. And so, for some people that might be them attending a community event where they can get more educational resources on what's available to them. For others, it might be helping them know what their

referral options are in their local area. And then it also might be as simple as just connecting them in with resources in their Parkinson's community may not even have anything to do with DBS.

And then for patients who are already implanted, I also work closely with them, and I really just try, try to be there for them and remove hassles that they might experience along the way. So, you know, one example of this might be if they lose their remote control or their charging puck they can call me directly, right? They don't have to call our one 800 number. Or if they move and they need to find a new physician that can manage their DBS they can work with me to help locate someone in their new area. And so really, I tell people you know, once, once they get implanted with Boston Scientific, they're kind of stuck with me for life. So, we're friends and family forever after that.

Melani Dizon:

But it's, that's great. So, you know, I think a lot of times when people are considering DBS, they go into that mode of, okay, you know, I'm really going to start thinking about it and it feels really overwhelming. So, what do people not know about what a therapy consultant from any given DBS company can do? Like how do you get involved with those people early on?

Alaine Keebaugh:

Yeah, so usually it's, you know, it's kind of, sometimes it's kind of luck or basically it's people who are already involved in their Parkinson's community usually can, you know, will interact with a therapy consultant at say a patient education event or a support group meeting. Or at, like we have a big Parkinson's first Coast Parkinson's run coming up on Saturday. So, we might, might meet someone there. But I always say the earlier they meet us, really the better because we can just help, help answer questions that they might have. Even pre–DBS, so like I know all the movement disorder neurologists in the area you know, I know other pharmaceutical reps in the area. We know about a lot of the different support groups that they can go to. So, we really usually get introduced to them as a first touch that way.

In some cases, actually, though they might, people might be interested in DBS and say, go and watch a national webinar right on the Boston Scientific website. And then when, when that happens that if they're in my, my territory, they'll, their information will come back to me and then I'll usually reach out to them because I know that they're interested. Now. it's a fine line we have to walk as therapy consultants because I don't want to come across as, you know, sales and try to sell DBS to someone because that's not helping anyone. Right. But I do want to be there to offer them help at any point in the journey if they want.

Melani Dizon:

Great. Thanks, Scott. How did you then meet Alaine?

Scott Rider:

Well, a couple of ways. You know, like everybody else, Parkinson's is sort of a journey. You start out and things evolve over time. And so, one thing I did was my movement disorder specialist, my neurologist brought up, wanted to know if I'd ever considered DBS because she asked me a question. She said, what symptom bothers you the most? And for me, it's the tremor in my right hand and I kind of get emotional even thinking about it because it's a big decision. And then I had the benefit, I'm working on a documentary called Parkinson's Across America. So, I've traveled across America from Miami to the West Coast. And I've been in, you name the Parkinson's facility, I've been there all the top physicians really in the world. I've had the benefit of the meeting. And I would hear success stories about DBS and my partner in this project has a Boston Scientific device implanted. And I saw how it changed his life. He went from crazy involuntary movement, and dyskinesia to much more stable and less movement than I presented in the present. And so, I've seen firsthand how Boston Scientific's devices changed the lives of people. I did some research and it's just kind of through networking. I ended up meeting Alaine who's been very helpful and incredibly kind, but also incredibly knowledgeable and, which I honestly care about more than kindness. The kindness is great, but the knowledge is powerful.

Melani Dizon:

Yeah. So do you have any questions for her about the DBS device from Proton Scientific or

Scott Rider:

I do, I have several that I've thought of. I guess just the layout out on the table, I think I know, but I would like to hear it from the expert. I'd really like to understand, Alaine, what you would tell me. The differences are between the Boston Scientific device and really there are just three in the world that I could figure out at least, and the other two companies that make the device.

Alaine Keebaugh:

Sure. Yeah, that's a great question, Scott. So, there are three companies on the market and they each offer a lot of the is a lot of similarities, but they're also very different and unique in their own ways. And so, I want to preface, preface this by saying that all three companies work, right? So doesn't matter which device you get implanted with, or if you have been implanted with one, they all work well and deliver good therapy. But what makes them different is let's start with Abbott. So, Abbott is probably the most limited in the programming options that it offers, but it does offer remote programming. And so, for patients who might have difficulty traveling to a physician's office, this could be a good solution for them. The other company, Medtronic they offer what they have termed brain sensing.

And so, while this doesn't today offer really any clinical benefits or values and not every patient is going to have the biomarker that they're sensing for, it does offer the opportunity to be useful in the future. And so, if you're someone who wants to contribute to research that could be a really good option for you. And then with Boston Scientific, what makes us specific is that we have that is unique is that we have what's called image-guided programming. And so, this actually allows the physician to visualize where the lead is placed in the patient's anatomy. And it also allows the physician to see the electrical field that they're creating in the brain. They can further shape it; they can steer it and can basically move it around in any 360-degree rotation that they want to. They actually can also see structures that are called side effects. And so, they can steer away from those and no other device on the market can offer this type of advanced programming. So that's really what makes us unique. Yeah, so Great. Does that answer your question, Scott?

Scott Rider:

Yeah. May I ask you one other question? Thanks. I asked this because I've seen some of this firsthand with have, once you're in the Parkinson's world, if you get involved, you meet lots of people that have gone lots of different ways as far as treatment, different devices, and I'm, I'm convinced that recharging, you know, it takes energy to run that device that may ultimately be implanted inside my head right down by my, in my brain. And so how the recharging works is really important to me because I want to have the best quality of life I can. What's kind of the least interruption once I make this decision?

Alaine Keebaugh:

Yep. Okay. So that's a really good question. And one thing I want to remind everyone is that DBS doesn't cure Parkinson's disease, right? It basically just sets the timeline of disease progression back in most cases many years. And so, as the Parkinson's evolves you know, you're going to want a system that evolves with it. And Boston Scientific offers different lifestyle choices for you that that might fit with you, whatever lifestyle you're in. So, we have a non-rechargeable battery which has to be replaced every three to five years. And then as Scott mentioned, we also have a rechargeable battery. And again, this might be different for different people, just like, you know, choosing the different device company that you want. You know, some people may not want to have to bother with recharging, whereas other people may not want to have to look for surgery in the near future.

So, the rechargeable devices fit with your lifestyle. So, Scott, if you were to choose that, you could recharge it daily you could recharge it weekly or you could even recharge it monthly. And the amount of time that it's going to take you to charge is going to depend on your charging cycle. So, for example, we usually tell most people if you charge weekly, and that's what most people do, you can expect to charge about an hour a week. I actually have a model of the recharging collar here, so I'm going to show you that. So, it's like a charging collar. It has two pockets on each side, and you just put it around your neck like this. So on this side, I actually

have a counterweight and see that in there. And then on the side where your battery is implanted, you would take a charging puck, turn it on beeping, you put it in the pocket, and then when it starts charging, it stops beeping. And then you just wear it like this. So, it's pretty cool. You can see it's like wireless. I could move around; I could go cook dinner or make coffee if I wanted to. And then when it's done charging it will beep at you just like it did before. But, the beep sounds different. It's kind of like a beep. So, it's like two beats really quick together.

Melani Dizon:

Great. And so, my two questions for everybody listening: is the DBS still working while it's charging? Yes, everything's great. Everything's working great. And then you said you could do it every day or every week or every month. So, who is, is it, are you having to do it every day because you're using so much stimulation, it's just turned up so much? Why would you do it? Even if they have to do it every day.

Alaine Keebaugh:

No, no. So, most people who do it daily do it five minutes a day. Okay. So now they're speaking anecdotally from the patients that I work with. So, for some people, for them it's easy. So, I always tell everyone what, after they have it implanted, they need to get on some type of schedule because as humans, right, we're more likely to do something of our own schedule and you don't want your device running out of energy and then turning off. So, some people, they might get up every morning and they make their coffee every day. They spend five minutes doing that so they can charge the five minutes. They're doing it every day and it's done. That makes them feel comfortable with charging. Other people may watch a TV show every Sunday afternoon and that's, that's when they want to do it. So, it's really just kind of like what fits into their lifestyle.

And I even can tell them early on, you can try multiple different ways. Like do you want to do it five minutes a day, do you want to do it one hour a week or would you rather do it once a month? And of course, it's going to be longer and those times I've given you our averages for like the average person. So, it could vary, you know, more or less. So yeah, but no, it stays on. That's a good question. I didn't think of that. It definitely stays on while you're recharging. And if you do use more power it takes a little bit longer. But we've never had anyone that had to do it once a day. Like that would be a whole lot of power. Yeah.

Melani Dizon:

Scott, do you have more battery questions?

Scott Rider:

Well, I was just going to make an observation. It must be pretty forgiving. Because I have several friends that have that exact charging device that Boston Scientific and one of them in particulars not as diligent as he maybe should be,

Alaine Keebaugh:

Right?

Scott Rider:

He doesn't, like once a month while he is watching football or something on tv, it's, and he says it's no big deal, it works easy, but my point is he'd probably be better off doing a little bit each day, but he kind of forgets and everything keeps on working, tick him like a clock. So, it's pretty cool from what I can tell.

Alaine Keebaugh:

Yeah, and you know, it's like if he's comfortable with that and that, you know, that doesn't stress him out, and more power to him.

Melani Dizon:

Yeah. Yeah.

Scott Rider:

It works.

Melani Dizon:

Who are the candidates who tend to want a non-rechargeable, you know, like what's, what are those people usually looking for, and then what's the procedure to have to get it replaced every few years?

Alaine Keebaugh:

Yeah, so it's funny you asked that, Mel, because I've actually had this, I call it an argument with my husband. So, he would want the non-rechargeable because he says he kind of wants to forget about it. He doesn't think he'd want to be reminded that he had that every day. Right. I however would want the non-rechargeable I think, right? I can't say for sure because I'm not there, but I wouldn't want to have to know it's going to have to go back and have another surgery, you know, in a couple of years. And so, I really just think it just depends on where everyone's headspace is. So, from my experience, and I also think it, the physician that, you know, the patient's working with, I think they play a big role too. So, most of the physicians that

I work with here in Jacksonville really like the rechargeable battery. So, I would say 90% of the people we've even planted here have rechargeable other places. That's definitely not the case, right? So, it might be the non-rechargeable and the few people that have kind of gone against what their physician said and really said, I want the non-rechargeable they were younger, and they said exactly what my husband said. They just didn't want to have to think about it.

Melani Dizon:

Yeah. Right. Any other questions? Battery or not, Scott?

Scott Rider:

No, I think that those are kind of my two big outstanding questions.

Melani Dizon:

Okay. What are, what, you know, when you think about it, what are your biggest concerns? I mean obviously, you want symptom relief, and you want that, you know, 17 years ago. So, what are the things that you're weighing right now?

Scott Rider:

Well, a couple of things that you know, you start researching this and you learn a lot. I don't want to get to what I call the point of no return. And that's different for everybody. But what I mean by that person to Parkinson's, I've learned, I can get to a certain point where maybe they would say, sorry Scott, you're not a candidate for this surgery. I mean, I think that's unusual, but especially I think from, if I would get into cognitive issues that would become, you know, kind of overwhelming so that I'm 63 years old, I'll just tell you that. And that's why I'm looking into it now because I really want to get all my ducks in an order before I do it. And I'm, I'm in the process of getting ready to do the evaluation to see if I'm a candidate for it.

So, I feel more in control by getting everything kind of organized ahead of time and not having to make a rush, rush decision. But if you ask why I would consider not having the surgery, probably the only reason, which is not a good reason, is it's, its brain surgery, you know just to be straight up, that's sort of scary. But I know so many people that have had success with it, and that removes a lot of the fear. And I also realize, Mel, that I need therapy, a solution. You know, I need a system that can support me. I hope to live a long life and I see DBS as a way to kind of increase my quality of life versus a disease that we know is a progressive disease. Right.

Melani Dizon:

Right.

Scott Rider:

So, kind of some rational thoughts and some irrational thoughts all wrapped together to be.

Melani Dizon:

Yeah. Alaine, do you have any comments on what Scott said?

Alaine Keebaugh:

Yeah, I just, you know, I really like Scott's approach to learning as much as he can before he's right up against making that decision. Because there is a window of opportunity, right? Where you're eligible you have to be a few years into the diagnosis, but you also don't want to be so far along that the medication doesn't work. So, there is a window of opportunity and I've, I've often found just working with different people that the more you can educate yourself on it, the more empowered you feel, right? And it's a decision that you make, and it can also take a long time. So, there I've seen some people where they decide they want DBS and they start the journey, right? But then it takes them two years to get there, whereas other people started the education journey way before they were ready. And then by the time they were like, okay, I'm ready for DBS, all those other pieces were already in place so they could go ahead and kind of start, you know, just three to six months out. So yeah.

Scott Rider:

Yeah. And Mel, I think what hit me one day is I thought about my dosage of medication when I was first diagnosed and I kind of honestly lost track of the increase in that dosage over time. And I know enough about it that the side effects, yeah. You know, they could kick in tomorrow. And what I'm really referring to is I do not want to have all that involuntary movement that I think that most people recognize that's oftentimes associated with Parkinson's disease. So, I want to be empowered and make the best decision, I can when I'm not under a lot of stress or pressure. And I think the best way to do that is to start learning about it early and get evaluated and research all the devices. So, it's been really, it's been very educational and valuable.

Melani Dizon:

Yeah. Like you said, you're young, you have a long way to go, like thank you. Yeah. Right. Actually, when I think about it, so is there something that you are looking forward to if you get DBS that will improve your quality of life? Aside from, you know, not having to take so many pills, hopefully.

Scott Rider:

Sure. obviously, a decrease in medication, it's just a big hassle. And I mean, who would take medication if you didn't have to take medication for anything? I think not having a tremor and my right hand and I can kind of tell my involuntary movements kind of crossing over to the left

side of my body too. I sense that. And I also know that while this isn't clinical and I probably couldn't prove it, but I just observed through friends that I see other benefits that nobody could prove and say that they are a result of DBS, but I just see an overall increase in quality of life from just their positive outlook. They just feel so much better because they've decreased their medication and their symptoms have changed. And that's exciting. There's not a whole lot to get excited about related to Parkinson's. Right.

Melani Dizon:

Except for making it better, right?

Scott Rider:

That's right. Yep.

Melani Dizon:

Yeah. Thanks. Is there anything I didn't ask that I should have?

Alaine Keebaugh:

Only, no, I think you've asked some really great questions and I think being able to, you know, hear it from Scott's perspective like how, how the patient thinks about it when they're exploring it. Scott, are there any other questions that I could answer for

Scott Rider:

You? You know what I do have I'm a person with Parkinson's, so you know, I don't seriously, and I don't always remember what I should remember, and I did think of a couple of things that I wanted to ask you. One is looking forward like if I'd get this tomorrow is this still going to work in five years or is it going to disappear? The impact of it? I mean, I believe I know the answer, but I want to hear it from the expert.

Alaine Keebaugh:

Yeah. That's the million-dollar question, right? So, the device will continue to work, you know, indefinitely. We actually did just finish doing a five-year study looking out at data from patients who were implanted. We did the one year and now we just finished the five-year evaluation. And at five years they all were still getting therapy from the DBS device with the same quality of life improvement. So yes, we expect the device to continue working, no one's looked out at 10 years we're going to be doing that so that data will, will come out in the future. You know, and the other comment I have to that is, you know, Parkinson's does, does continue to evolve, right? So, we mentioned earlier that DBS doesn't cure the disease, but it can set the timeline back. And so, I think it's really important when you're choosing which device you have and you

know, too, to know that the Parkinson's is still there, right? It's still evolving and you're going to want to choose a device that can evolve with the disease and to continue to keep up with the Parkinson's as it changes.

Scott Rider:

And the other thing I would ask you is if I could just ask one other question, you know, I think there's so much misunderstanding about Parkinson's. I often tell people that; I think most people just think of Parkinson's as a tremor, but there's so much that goes on. But what, oh, symptoms I guess would be the best choice of words I could use. What symptoms can you tell me? Nothing's guaranteed in life that, can you tell me that you typically see patients get relief from after DBS?

Alaine Keebaugh:

Okay, so DBS is approved to help with motor symptoms, right? So, these are going to be things like f rigidity, and bradykinesia, it's also going to reduce fluctuations in you on time. And as you said, it could also reduce the amount of medication that you take. We don't tell people that it helps with their non-motor symptoms. So, these will be things like sleep, gait you know, and other things that impact your quality of life just as much. But you know, you did mention that sometimes you see, you know, your friends who have other things improve, right? And so, I think it's worth mentioning that sometimes it's hard for us to distinguish or positions to distinguish between the medication-induced side effects and the PD symptoms, right? And so, a lot of medications, let's say, can interfere with sleep or they can lead to brain fog.

Or the motor symptoms can cause you to move slowly or not be able to exercise or not have the energy to exercise. And so D V S comes in and it can reduce the number of medications that you have. It can, you know, decrease your slowness, your rigidity, these are all things that can improve other things secondarily, right? So, you have less rigidity, less trauma, or you're now able to exercise more. And we know that exercise has positive benefits on DBS. So, I think when we talk about that DBS has specific things that it can influence, but improving those things secondarily might, might improve other things like what you saw or see with your friend's answer makes sense.

Scott Rider:

It does. And I guess one comment I have, I've never shared with you in the past, but I think it's worth mentioning, you know, when I was traveling across America and got to interview all these top neurologists, the people that are on the frontline and implanting the devices and everything else, I don't remember who it was, but one of the neurologists used on sort of like the Richter scale, the difference between six and seven is more than the difference between two and three. And what I learned is that DBS has come so far in the past few years. I mean, the difference between DBS today and three years ago or 10 years ago is light years difference. I

mean, I'm probably exaggerating a little bit. There's a huge difference between DBS today and the DBS five years ago, and that really gave me a sense of comfort to hear it from these people that are considered the best in the world.

Alaine Keebaugh:

Yeah. And, you know, towards that end it's an exciting time to be in this field, right? So yeah, there are three companies on the market, right? And we're all competing. But what that means for patients is that the pace of how much further this technology is going to be pushed and how fast that's going to happen is exciting. And I think you're exactly right in saying that the DBS of today is worlds better than the DBS of five or 10 years ago. And there are even so many other things that, from a physics standpoint that we can do programming-wise that we couldn't do before. That plays into this, that we can't really talk about yet. But no, you're exactly right Scott. It's an exciting place to be for both people on my end of it and your end of it. And mouth.

Melani Dizon:

Yeah. Well, thank you both so much, Scott. I really hope you keep us updated on what your plans are and what you do, and you know, whatever that outcome is, we look forward to hearing about it. Thank you so much, Alaine, for your expertise and for sharing with this, with everybody. I think the important thing that I want to get across to are the people watching is that you can reach out to a therapy consultant. They can be a huge ally for you as you start considering this and have questions and want to know more, they're there for you and definitely take advantage of that. So, thank you so much and we will talk about DBS soon.

Alaine Keebaugh:

Thanks for having me. Thank you, Scott. Thanks. Thank you.