



Deep Brain Stimulation Series

An Interview with People Living with Deep Brain Stimulation (0-3 Years)

Davis Phinney Foundation

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

Melani Dizon:

Hi everybody. My name is Melanie Dizon. I'm the Director of Education and Content at the Davis Phinney Foundation, and I am here today to talk to people who have been living with deep brain stimulation or DBS. They've gotten it somewhere within the last three years, and we're going to talk about the ins, the outs, the good, the bad, the ugly and everything how they decided on DBS the process of getting DBS and the approval process, the surgery itself, healing programming, all of those different things. I want to thank our primary sponsors for this, Medtronic and Boston Scientific for making this possible and for making this entire DBS series free to our community. Alright, so, so I really would love to get started by just going around. I'll, I'll call you out based on how I see you on my screen, and just introduce yourself by sharing your name, your age, if you're comfortable, years of living with pd. You can either say, I've had symptoms for such and such a time, or my clinical diagnosis was in such and such a date year of or when you got DBS in particular, and then the device that you have. All right, so I'm just going to go around as I see you, Bart.

Bart:

Hi, my name is Bart. I was diagnosed in December of 2011, and I had DBS in January of 2016. And then again in May of 2021, I had it done two times, because the first time it got infected, and we had to take it out kind of immediately. I think I've answered all your questions, but if not, tell me more.

Melani Dizon:

Yes. which device? First time and second time.

Bart:

First time was Medtronic, and the second time was Boston Scientific.

Melani Dizon:

Okay, great. Susan.

Susan:



I've had Parkinson's diagnosis seven years. I have had DBS for four months. I might win the prize for the most recent, I don't know, maybe not, but that's the reason for the extra hair. Let's see. I am almost 72. What am I missing? Oh, Boston Scientific. Sorry. Okay.

Melani Dizon:

Yeah, great.

Susan:

Okay,

Melani Dizon:

Thanks, Amber.

Amber:

I started having symptoms around 32 or 33. I was diagnosed at 35, had the deep brain stimulation at 38. I am now 39, and the device is Medtronic's.

Melani Dizon:

Great. Thank you, Peter.

Peter:

Hi. I'm Peter. I'm 51. I was diagnosed about eight and a half years ago at age 43 which is around the time my symptoms started. And I had DBS six months ago, so one of the new ones also June 2022 and the device is Abbott.

Melani Dizon:

Okay, great. Doug.

Doug:

Hi everyone. I'm Doug Reid. I was diagnosed in 2010. I've been experiencing symptoms for at least a couple years prior to that. I was 36 at the time. I'm 49 now, and I had D DBS just over three years ago. I have Boston Scientific rechargeable blood.

Melani Dizon:

Okay, great. Steve?

Steve:

Hi, my name is Steve Howie. I was diagnosed in 2007 and I also had symptoms a couple years before that. I was 50 when I was diagnosed. I had the Boston Scientific in installed in exactly a year ago. So, I'm 65 now.

Melani Dizon:

Great, thank you. Robynn.

Robynn

I'm Robynn, I'm out of North Carolina. I was diagnosed in 2015, but I was misdiagnosed. My tremors started appearing in 2013, but once I understood the full constellation of symptoms, I was having my earliest symptoms back in like 2003. I'm currently 53, so back in my early to mid-thirties, I was having symptoms. I had DBS in July of 2020, and I got the Boston Scientific device.

Melani Dizon:

Okay, great. All right. Now let's go back to those days around your initial diagnosis. And I'd love to hear from some of you, anyone who wants to chime in about what your first line of treatment was, you know, what happened when you got your diagnosis, and then what did you do? Did you get on medication right away? Did you try and hold off? What happened? Anybody? just let me know. Okay, Susan

Susan:

I completely forgot what you just asked me.

Melani Dizon:

You, what was your first line of treatment?

Susan:

Oh, the first line, I'm sorry, was an immediate diagnosis a prescription for sentiment and AEC and it made, you know, from one day to the next. It just made a tremendous difference. And from then on, my doctor had in the back of her head and then started eventually saying to me, the fact that you responded the way you did and continued to do well with the medication is a good indicator for the surgery. Which seemed quiet, I mean, I understood what she meant, but I felt so good because of the fact that the medication works so well. I couldn't imagine having the surgery. Why would I do?

Melani Dizon:

That? Right, right. Okay. Bart

Bart:

I had stayed off medication a while so I could participate in PPMI, the Parkinson progressions markers initiative by the Fox Foundation because they wanted people who hadn't had drugs yet. And I, once I got on that program, I was given some Premol which is a MAO-B inhibitor, I believe. And that helped enough, and I stayed on that for quite a while, and then only then went to cinema after probably six or months to a year.

Melani Dizon:

Oh, okay. Great. Amber and then Peter.

Amber:

I immediately was put on medication, but during the process of me being diagnosed because it took years, I had already done the research, I was already convinced that I had Parkinson's, and I knew that eventually I was going to want to do DBS anyways. So, when it was brought up, there was no hesitation on doing that.

Melani Dizon:

Okay. So just really quickly, you, what was the time between the clinical diagnosis and DBS?

Amber:

About two, two and a half years.

Melani Dizon:

Okay. And you said you had done a lot of research before, so was it just like, Hey, no problem with brain surgery. I'm just, I'm in like, as soon as I'm allowed, I'm getting it.

Amber:

Basically, I mean, I have young children, so there was risk definitely. But they were also the reason why I had it, if that makes any sense. So,

Melani Dizon:

Okay. Peter and then Steve.

Peter:

Right. So, for me, getting on medication was never a question. Nobody said there was any sort of alternative to medication. I guess my doctor said, here, take these pills, here's a prescription. And I did. My symptoms were pretty mild at the beginning, but I would say the other major part of my treatment at the beginning was that I became athletic. I tried to become the most athletic person I'd ever been. I started commuting by bike and doing, you know, several miles a day. And I was probably in better shape at that point than I had been since my twenties. And I feel like that that was an important contributor to my wellbeing for many years. Even though you know, I did start on Primax also, which I think is called, what is it called? In MI States? Mirapex. Yeah. I started on that. I think people know that that can become problematic after a while, but I did respond well to it. That and the exercise I think we're really important at the, in the early stages.

Melani Dizon:

Great. Steve?

Steve:

Yeah, I just want to echo what Peter said. You know, when I, when I think when you're first diagnosed it's almost like they prescribed the cinema to, to see if there's a reaction to it. For me, there was really hardly any change at all, so I stopped taking it. I tend, I told my doctor that I wasn't going to take it and I probably didn't take Sinemet for five years, and I just, I just exercised like crazy. And I-

Melani Dizon:

What were you, what were your predominant symptoms?

Steve:

Well, my arm didn't swing and my, and I had a little bit of a foot drag, and I was also, at the time I was ironically, in the same year I get diagnosed with Parkinson's and had my hip replaced. So, I blamed the foot drag and the, and the lack of arm swing on the fact that my hip was so sore. And once I got the hip replaced, it still was happening. So

Melani Dizon:

That is, that's so crazy. I was just Christie Lamonica, she's on our panel, right. And I just had a conversation with her. It's the exact same thing. She had the surgery, she did all the stuff with her hip, and she's like, this is still didn't, that's not doing anything. This, this can't just be my hip. Right,

Steve:

Right, right, right. You know, and so just, and the end of it is just that the, what, what, what my neurologist told me is that, you know, as the Parkinson progresses, you'll find that the medicine does make a difference. And he was right. I mean, you know. So eventually I did start taking levodopa carbidopa now I'm on Azilect, I mean, not Azilect, Rytary. And it, and it works great. So. Great. That's my story.

Melani Dizon:

Yeah. Doug?

Doug:

Like Bart, after I was diagnosed, I tried to stay off medications for a while to participate in clinical trials. But after about two years post-diagnosis, I felt the need for medication. I went on Mirapex and then Azilect, and then it was probably about three years, maybe four years after diagnosis that I started taking Carbidopa-Levodopa. And after three years on that, I became very disconnected. And so that was one of my goals of DBS was to hopefully get off of Carbidopa-Levodopa which I have been able to do. Prior to having DBS, I wasn't exercising. I was in a very deep depression, and I'm sure that contributed to my dyskinesia. Just the lack of exercise, the lack of physical fitness. But now I exercise almost daily and I'm three years after DBS, I'm still off Carbidopa-Levodopa. I just take two Sinemet a day.

Melani Dizon:

Okay. Yeah. So curious about the volume of medication that people were taking before they ended up going to DBS. I know that, you know, we talk to a lot of people in our, our other panel. They, some of them had 35 pills a day. You know, the volume and the timing and all and the cost. Like all of those things really sort of started adding up and leading them toward looking at DBS. But does anybody want to share their experience with that and Robynn?

Robynn

Sure. I echo what many other people said. Medication and exercise were my primary, primary first, first response. But what had happened for me with the medication is that I had to set a timer. I was so tremor dominant, and my job is so visible, and I do so much public speaking that I had to set a timer so that my medication timing could overlap so that I would not have breakthrough tremor. And I was, it wasn't that my dosage had increased so much, it's just I had, I had this timer and I had to take, I had to be sure to take my medication 30 minutes before the initial dose wore off. And it was like a slave to the medication. And it got to where for me I started getting dyskinetic and even with the same low dose of medicine, and I never knew how long my medicine would be effective.

I give talks that are exactly one hour, and I could not count on my medication to last 60 minutes. I didn't know if it would last 55 or 52 or 48, but, you know, and I started doing all kinds of things like twirling a pen in my hand and trying to disguise it. But it was that, it just got really unmanageable. And I too like Amber, I always knew I was going to be a candidate for DBS because my tremor was so dominant and so disruptive. And so, I'm the one who brought it up with my neurologist. She didn't bring it up with me. I brought it up with her and I thought she would tell me that I was, you know, way, way too young, way too early. And she said, no, you're an ideal candidate.

Melani Dizon:

Oh, sorry, Peter, and then Doug.

Peter:

Right. So, I started out on, you know, very low dose of Mirapex all in. My neurologist would up it like double it every six months or something like that. And eventually the maximum dose of preop xol is I think three milligrams. So, I was on three milligrams extended release. And anybody else who's been there probably knows that you can get some very serious psychological problems from that. I mean, equivalent to mental illness and very destructive. We knew that that was coming eventually. I mean, we knew it was a possibility, but when it actually happens, it kind of sneaks up on you and it can be very scary. And so fortunately, you know, I mean, with the help of my family, my wife, I was able to get off that medication. You know, the neurologist changed me from Primary Pol, and I was also on AEC to levodopa-Carbidopa.

I was very resistant to that because I was afraid of dyskinesia and I was afraid of on off and all that, which eventually dyskinesia didn't become a problem, but on off did. So, I have always had re rigidity dominant Parkinson's, and I do get tremors, but only when I'm nervous or cold, like public speaking us usually wasn't a problem before. Now, you know, sometimes I shake a bit, I get a bit stiffer, and I do shake sometimes less now with the DBS. But with, with the, with the Carbidopa-Levodopa eventually I got up to, the highest dose I ever took was four tablets of 250 milligrams per tablet. So, I was up to a thousand milligrams a day. Eventually, we sort of shaved some of that off by replacing it with a patch, the Nepro patch, the, what is it? Can't remember the ingredient name, but you know, it's a patch, a transdermal patch which is another one of these sort of dopamine agonists.

And we were very wary of that one as well, because when you get up even to the higher dosage of the patch as well, you can have some of these same sorts of symptoms, psychological symptoms at that time. Fortunately, we knew what was going on and we would immediately call the neurologist and say No, you know, lower that dose. But all of that is very, very scary and very, you know, can be very difficult for relationships. So, and then eventually when I did get up into the higher doses of Levodopa Carbidopa, what would happen was, like Robynn, I knew that they were going to be off times. My off times became very severe, so I wasn't ever like, sort of

stuck to the floor. I've heard about that, you know. But I would go for a walk and I knew that I needed to be back at a certain time, you know, because I was taking, I was taking Levodopa Carbidopa every four hours, and if I walk for more than, you know, an hour and a half, I would get stuck somewhere and I'd have to call and get a ride because it just couldn't move my feet.

I mean, I could walk, but it was so hard and so painful that it was just exhausting. And that was eventually when I started thinking about the surgery. Although my doctors had mentioned it from the beginning, you know, you might be a candidate for this later on. And I just never liked the idea of having somebody drill into my head. I don't know about you guys. That was very scary for me. But when, when my symptoms became so severe that I couldn't even walk across the room on the off times without falling over or leaning on something, then, then I just wanted it so badly. Yeah,

Doug:

Yeah. Yeah.

Melani Dizon:

Doug and the neighbor-

Doug:

At the time I had DBS I was heavily medicated. I took one AEC a day and then I took the extended-release Carbidopa-Levodopa Rytary. I think I was on three of every four hours. And I would take one calm 10 with each one of those Rytary doses. If I wouldn't set an alarm to wake up in the middle of the night and take a dose, but if I woke up, I would take a dose. If I was lucky enough to sleep through the night, I would allow myself to sleep through the night. But again, one of my goals of DBS was to try and get off as much medication as I could.

Melani Dizon:

Amber.

Amber:

So, my medication is the same before and after surgery. I am on three doses of Ropinirole a day and three half tablets of Carbidopa-Levodopa have extremely high sensitivity to it. I get very dyskinetic. I'm not on any medication right now because if I was, I am like a jerking mess. So, I don't take it if I have like something where I have to speak because it's just very distracting to me. Okay. So, I'd rather deal with the tremor than the dyskinesia.

Melani Dizon:

So exact amount you like went into DBS with the medication that you've normally had and the same now,

Amber:

And granted it is a very low dosage of both medications, but it hasn't increased.

Melani Dizon:

Okay. Okay. Susan?

Susan:

I did get switched to Rotary within a year and a half or so in, so I have not taken very much medication at all. It was every five hours and it; it was a higher dose; it was the 2 45. But since the surgery, that dose has come down. So, it's, I'm still taking some Carbidopa-Levodopa and also the Azilect, but that's it. One of the big surprises to me that no one talked about is I suffer, if you will, a lot from NoH. You know, when you get lightheaded and dizzy and just, you know, going down on the floor to play with my dog when I get back up, I'm, you know, and that's almost gone. And I thought, is that a result of the surgery? And recently learned that in fact as a result of the fact that I have my medication lowered, I don't, I'm not taking quite as much. Because yes, the Parkinson's contributes to it, but the medication does too.

Melani Dizon:

Right, right.

Susan:

And it's a happy story for me. I'm going in the right direction. I too would love to be off of it. It was because of dyskinesia that I finally said yes.

Bart:

I'm sorry, what does NoH stand for?

Susan:

Sorry?

Melani Dizon:

Neurogenic orthostatic hypertension. Okay. Right. Pressure drops. Okay, Bart, so let's, let's go to you first on fig on this whole you got diagnosed and that your initial DBS process, what happened with that? And then tell, tell us like how long, you know, you waited for the next one.

So, was this something that your doctor initially reached out to you about? Or you said, hey, like, I'm interested in this.

Bart:

I considered it inevitable that I would have DBS because I was diagnosed in, in at age 50. And I, you know, I, and they said I'm a great candidate because I'm relatively young and relatively strong and it was all goodness. Until, and there was no choice back then. It was Medtronic or nothing. And so, I went with Medtronic and my neurologist has an MD PhD in pharmacology. So, when he recommends DBS, I know it's having to be good because he believes in drugs since he's pharmacology. So when, when he agreed to it, I just said, okay, let's do it. And I went with a world-famous surgeon Jamie Henderson, who's well known across the western United States and even the world. And he did a great job in terms of nailing the target. Right on which was the sub nucleus. You have bilateral or just bilateral?

Yeah. Okay. And that all happened, the stimulator went in on the 3rd of February of 2016. We turned it on the 12th of February. And on the 19th of February, it was red and puffy all around the stimulator. And I said, it must be in fact it. So, I went to the er hen Dr. Henderson's at Stanford. So I went to Stanford, er, he sent his intern to look after me and I had a white blood cell, kind of 12,000, which is best I can tell is red light at a minimum. And they sent me home with the diagnosis of inflammation of the chest, which I thought was more a description of the symptoms rather than a diagnosis. And they sent me, I'm like in shock, I was like, how could they send me home? And I was with two friends who acted as my second eyes and ears, and they agreed with me.

So, then I called my neurologist and said, look, this is infected. And the surgeon's in denial. And then indeed was the case because they said, come back the next day. And that time my white blood cell count was 17,600, which is flashing red light. And I could tell it was pretty serious by the way, the resident's eyes kind of dilated it when he told me this. They saw the data and they scheduled surgery for the next morning to pull out the stimulator, which was indeed surrounded by puss. And it, they have something, it was just a staph infection, regular staph infection. They said that staph lights, metal, and it loves the follow metal up into the brain, which is where it was bleeding. And let's see, what date was that they took the probes out on? They took the simulator out on the 21st and they took the brain probes out on the 24th when they did a little test. The, in the ear, behind the ear, this little junction box. And that tested positive as well. Wow. They had to pull out the brain probes as well. Wow. Which is kind of scary. But there, there was a happy ending to this. There's something called the micro lesion effect. And what that does is it, the act of inserting and removing the probes causes little lesions in the brain, which help with Parkinson's. And it typically lasts three or four months. It might lasted three or four years. Wow. Why nobody.

Wow. Yeah. I took it and, it was kind of an adventure. I was very angry at the mu the surgeon though, and I years later submitted something to the bud Ombudsman at Stanford. That was, it got their attention. Big time.

Melani Dizon:

So, then you have this scary experience. You get the benefits from the lesions and then you, what prompts you to say, hey, let's do this again.

Bart:

Well, what the little time that it was in, it worked really well.

Melani Dizon:

So, did you have time to actually get programs like, well, like you were dialed in for a couple days?

Bart:

Yeah. I mean, so I've got all these dates here so I can answer your question exactly. Let's see here. So, it went in on, they turned it on the 12th of February. And I had until the 19th of February before I got the ER visit, my first ER visit. So, when they turned it on, it was my neurologist that turned it on and he started programming it and it was working really well, just right out of the, right out of the gate. So, I did enjoy a few blissful days of DBS part one. And how could, and I actually went to the same surgeon for part two just because he's so good at insert. I just made sure my after-surgery care was managed by someone else. And he was especially aware of these issues as well. So, I'm sorry, I'm rambling now. You asked how did I get DBS one to DBS two?

Melani Dizon:

Yeah. Just, you know, what were the symptoms that you were just like, this is not, I can't, well,

Bart:

Again, I still consider it inevitable that I get it stuck in again. And what happened is I was on Tari three times, four times a day at 245 milligrams. And that's not quite the maximum or even, but we were starting to dance around in areas where I could get dyskinesia and I just said, let's do it again. In addition, I considered this kind of like a consumer electronics buy now. I had choices and everybody's lead pro in everybody, and I liked where the Boston Scientific product was because they had this rechargeable battery that I wouldn't have to replace for 15 or 20 years. And given my experience with infections around the battery, I wanted something that he didn't have to open up and replace every two years or three years.



Melani Dizon:

Right.

Bart:

So, that was a winner for me. I came in there ready to go with Boston Scientific and my surgeon, who initially was a big Medtronic's fan also was recommending Boston Scientific. So, we were an immediate agreement and off we went.

Melani Dizon:

Okay. So just by a show of hands I just want to see where everyone was. How many people on the panel actually had a choice of what device to get? Okay, great. So, Amber and Robynn, you pretty much had your neurologist who worked with surgeons that were like, this is what we're u this is what I use, this is what we're using. Yeah. Okay. And so, what were some of the things, for those of you who did have a choice, what were some of the things that you did to research and determine what the best one for you was going to be?

Steve:

My surgeon actually preferred Abbott. And was, that was pretty vocal about that. I mean, not, not that she, she said that she would work with either one, but she just, I think what it came down to is she had a really close working relationship with the Abbott rep. I, like Bart said, I liked what Boston Scientific was, was offering, and I just felt like technology-wise at that moment, they had the lead. So, I went out to lunch with the Boston Scientific rep really got to know him, got to know the product and I was just really comfortable with that. So that's the reason why.

Melani Dizon:

Okay, great. Peter, who's Cat? Cat that?

Peter:

Not mine, mine

Steve:

Edit that out.

Peter:

So, it was important to me to go to a surgeon who didn't really have like a specific brand that they were married to. I wanted to have a choice. And in fact, it's hard to know that ahead of time. It's really hard to get a lot of information about what the surgeons are working with. I found that one to be one of the most difficult parts of the process. But fortunately, the surgeon, I went to Dr. Gordon Baltic at Columbia University. He just, his people just handed me the brochures for all the brands and said, you decide, you know, I ultimately went with Abbott because for me it was important to be able to have remote programming. And it was the only brand that had a remote programming option. I live far from any sort of big city.

And here where I live, there's nobody who does any programming. So remote programming was absolutely essential to me. Okay. I had hoped to have a rechargeable device. Like Bart said, you know, that would last 15 years, and the Abbott device is not a rechargeable device. And I thought that that was a negative at first. But then the surgeon said, well, you know, actually it means that when you get a new device, you're getting an update, you're getting the latest technology. And I thought, okay, I can live with that, you know, as a tradeoff for the remote programming. And the Abbott team has been really great. I didn't meet any reps before my surgery. In fact, the first time I met a rep was actually in the or which is kind of an interesting way to meet someone. But they've been great in terms of follow up and we had a good relationship.

Melani Dizon:

Great. That's great. Doug and then Susan.

Doug:

I had a choice of which manufactured to go with, but my neurosurgeon was recommending the Boston Scientific device. At the time, I think it was the latest and greatest tech again, this was three years ago, but the ability to recharge was also an attractive aspect for me. I also had an old college hall mate who worked for Boston Scientific in the DBS department. And so, I talked with him and or emailed with him, messaged with him, and it, I was sold. So, it was kind of an easy decision when the neurosurgeons recommending the device and it had certain qualifications that appealed to me and met my interests and needs.

Melani Dizon:

Right. Susan?

Susan:

So, my neuro-Parkinson's specialist, my MDs is very involved in, in the surgery. She's present and does everything. So, she's very familiar. She works with all three systems. She brought all three batteries, you know, into the examining room you know, on one of my presurgical visits.

And so, we held them and looked at them and talked about it. I had had a bilateral mastectomy one year before, and so there was a lot of two tissue that wasn't there. And so, there's, I was just really lean and the busted scientific was the smallest. And so that was appealing to me for that reason. It appealed to her for that reason as well. And because it can take two leads. She also only, she, she believes very strongly and only doing one side at a time of, you know, the operation. But that if I need to have a second one, the Boston Scientific has, can, can accommodate two leads in second ones in there waiting to get attached if it, if it ever needs to be. Did I Right. Did I hit all the? Yeah,

Melani Dizon:

You had, you had all the, all the choices. I, you know, it's interesting and I love it when people do have the choices. A lot of people don't have the choice and you just, you know, as long as you trust your MDs and surgeon, that's usually Okay. Right. But it is nice to be able to do some research and have that choice. Bart

Bart:

Yeah. This would be the case of trust, but verify, you know, my neurosurgeon lost a lot of status with me. So, I did a serious amount of research on this. So, I was going to do a research study at Stanford, and that would've led to a technology cul-de-sac because the only people who could get these special units from Medtronic were in research studies. And I didn't want to be stuck with something that was so far out. And Boston Scientific had a lot of good features about it. For example, the multiple endpoints it has many more endpoints than the Medtronic at the time. Again, you can only take, do this and take a snapshot in time because now they're adding features when you have three competitors. Right. and again, when I came to the conclusion the Boston scientist was best and so did my neurosurgeon, we, it was all just a giant love fest.

Melani Dizon:

Yeah. so honest, let's Okay. Raise your hand. Let's, let's do this. Raise your hand if the process between you considering DBS through getting approval was fairly simple, easy process.

Robynn

I mean, it was very involved.

Melani Dizon:

Right, right, right. But it wasn't a lot.

Robynn

I didn't, I didn't hit any roadblocks, but I had to go for neuropsychic testing. I mean, there was a lot that had to happen.

Melani Dizon:

Yeah. Okay. Peter, did you have a different experience?

Peter:

Yeah. For me, finding, choosing a surgeon was a major ordeal. And I don't know if this is true for everyone. I guess I'm in the fortunate situation that my insurance would cover me in many different parts of the country, even the world. So, I was kind of spoiled for choices. But on the other hand, how do you choose a surgeon? I mean, I talked to friends who have a lot of experience as surgeons themselves, and, you know, there's not really sort of clear answer. And I read New York Times articles and I did a lot of research, and they say, ask this question, ask that question. But first of all, if you're just calling or emailing, you can't get answers. And a lot of this information isn't published. So finally, you know, I had to base my choice on okay, who has the most experience? And I ended up finding, again my surgeon, Dr. Gordon Baltic at Columbia, he's done, I think, more, more DBSs than anybody else. And so, for me, that was a good

Melani Dizon:

Story. Do you, do you have an MDs at the time? A specialist?

Peter:

Yes, but I don't live in the us, so my specialist didn't know the surgeons in the US, and I was going to the US for the surgery. Wow.

Peter:

And they agreed to help me sort of vet them, but that didn't really work out. So, I really felt like I was on my own. And ultimately, I think I made a good, I was very happy with my choice. I was super, super happy with Dr. Baltic and how everything went. His, you know, his degree of experience meant that not only, you know, has he done a lot of these, but also, he's developed a different approach. And one of the things I wish I knew you know, at the outset was like that there are so many different approaches to the same, you know, umbrella of DBS surgery, like one surgery, two surgeries, three surgeries, you know, one side, two side which are, which area are they going to target, which, you know, which device you're going to use may affect how, how things go.

Peter:

So, all these things for me were just like a big black box. And I spent a lot of time worrying about it and doing research. And I think, you know, I guess ultimately it paid off. I think ultimately, I was very, very happy with, with where I went. I don't know how much of it was just luck, you know, I mean, you know, there's, they don't have a lot of the hospitals don't publish how many times a given surgeon has done this surgery. And you don't know if they've done it a dozen times or, you know, 500 times or 600 times or more. Like Dr. Baltic. Yes.

Melani Dizon:

Yeah. Yeah.

Robynn

I want to say that I think Peter brings up such an interesting point and for the listening audience. So, I was comfortable with my local team, but I knew what kinds of questions to ask. So, I ask my doctor's the head of the DBS program, she's a movement disorder specialist. She's not the neurosurgeon, but she pairs with a neurosurgeon. And I ask things like how many of these surgeries have you done? What has been your complication rate? Have you had any deaths? You know, things like that. And I was comfortable with their answers. They hadn't done more than anyone in the US but at the time I had my surgery, they had done more than 300 of these surgeries and they had a less than 1% complication rate, which is lower than the national average. And they had had no deaths. So, you know, I knew, I think it's important to, to tell folks what kinds of questions to be asking.

Melani Dizon:

Absolutely. Yeah.

Peter:

Can I respond to Robynn just really quickly about that? Absolutely. Yeah. That point that she was making. So, I think that the which questions to ask your surgeon are super important. And for me, you know, percentages are kind of difficult to process. So, I wanted to know how often my surgeon does the surgery, and then given how often they do it, like how many of these complications have they had in the past five years, let's say. So, if my surgeon was doing, you know, one DBS every Thursday, you know, every week. So then how often have they had someone stroke out in the past five years? Or how many times they have a bleed, brain bleed in the past five years? And if the answer was none, I was very happy. And also, I think in, in my family, a number of people have had serious surgeries.

Peter:

And we've already come to the conclusion, you know, before my DBS that your local person may not be the best person for a given surgery. I mean, the local person might be the best person for follow up, but you know, we always want to go to somebody who does it more often. And also, I had the good fortune of speaking to one of the neuroscientists to help develop one of the devices. Not the Abbott device was another device. And what he told me was that just as important as the relationship you develop with the surgeon, you know, for the surgery, the long-term relationship you can have been with the neurologist programmer. And you need to make sure that the surgeon works with somebody who has a lot of experience. Yeah. So, you know, again, the neurologist programmer I work with at Columbia has been doing this for more than a dozen years and has a lot of experience. And that that is the person that I'm going to be in contact with for, you know, a really long time.

Melani Dizon:

Right.

Robynn

And it's so imperative, I don't think people realize, won't get into it a little bit more, but the programming is where the rubber hits the road. Yeah. That's where it for sure all, that's all where the money is.

Melani Dizon:

Yeah. We're get, we're going to get there next. Susan, then Amber, and then Steve.

Susan:

So, I'm feeling really lucky here. I told you guys my MD s is in the surgery. She actually gave me all the information that that you, Robynn was asking the questions. You know, she, she recommended the surgeon. They had done 700 of them together, you know, so I got all the statistics about, you know, infection and everything ahead of time. And that's what I would've said. The one big question that my husband and I had was one side versus two, because my MDs simply would not sanction doing two. Mm. She feels that strongly about it. So, I had the occasion, my niece is an MDs as well, so I talked to a surgeon that she works with via Zoom. And so, I had, I interviewed a second surgeon with respect to that question why, and we may, we may get into that. We, we may not. And then the other thing I wanted to tell you is the Boston Scientific people were also in my MD S'S office before the surgery showing me the equipment and stuff. So, I feel really well cared for her listening to everyone else's stories.

Melani Dizon:

Absolutely. Amber,



Amber:

I'm about to make you feel better. Susan. So, I, the process for me happened so quickly from the time that my neurologist told me that I would be a good candidate to, the time I had the surgery was about two months.

Susan:

Wow. Wow. Wow. So, how's your brain processing that?

Amber:

Still processing it now right now and-

Susan:

You're hard.

Amber:

So, I didn't even think to do the research to find a different surgeon. I went with the surgeon that was recommended by my neurologist. We don't have an MDs anywhere locally, so I don't have one. So, I didn't know to a, I asked how many people have died during their surgeries. That was the one question I asked. And since there were no deaths, I was like, okay, I guess we're good to go.

Susan:

Good enough.

Amber:

But until I have gotten more involved in the community and been involved in more panels, do I hear some of the things that I'm like, wow, you know, I really lucked out. I have a very good relationship with the Medtronic's rep. As a matter of fact, she recommended me for ambassador for Medtronic's. So, I do field calls from people that are considering getting DBS surgery. I don't know why, because I'm very honest about my experience, so I baffles me why she would've offered me up for that. But yeah, that hearing some of your experiences is definitely different than mine.

Melani Dizon:

Wow. Yeah. You got lucky. Steve, and then Doug and then Bart.

Steve:



Yeah. The you guys mentioned it, but it's, the programmer is also so important. And I know, I know of at least three people who were not having a really good experience after their DBS found somebody else to, to do the programming, and it's made a world of difference. Yeah. I mean, the one gentleman that I'm in contact with frequently, he, I could hardly understand him speaking. Yeah. And I felt terrible because I was always going, what, what? Why? You know? And then like the next time we met; it was completely different. So, it, it does make a big difference in who does the programming.

Melani Dizon:

Yeah. We'll, we'll def we'll get to programming after Bart. So, go Doug.

Doug:

Just in hindsight, when I look back on the process and how everything flowed, I feel very blessed. And I was very fortunate. Everything just seemed to fall into place. I guess what started the process, I watched a Davis Phinney Foundation webinar with the neurosurgeon presenting on DBS and I live only about 15 minutes from the foundation's office, the neurosurgeon practices in the area. I have a background in healthcare and medical technology. Everything that she said about the way she did the surgeries, the procedures, the technology, it all made sense to me. And it just kind of, everything fell in line. And as a result, I jokingly consider myself the poster child for positive outcomes of DBS.

Bart:

That's great.

Melani Dizon:

Is this Kara?

Doug:

Yeah.

Melani Dizon:

Yeah. Yeah. Kara Beasley, she's our, on our board really great and surgeon in this area. So yeah. I'm glad you had that experience, Doug. Yeah,

Doug:

I, after I watched the webinar, I checked out her CV and it was amazing. And when I went in for the initial consultation with her, she said, DBS is her favorite procedure to pro to perform



because the outcomes are usually so positive. And she said, it can, it can be life changing for you, and it has been.

Melani Dizon:

And so quickly, Bart.

Bart:

Yes, I was also considered myself very lucky because I live in the San Francisco Bay area where there are gobs of surgeons. Lots of research happens about Ron Parkinson's. And my movement disorder specialist actually programs both Medtronic and Boston Scientific. And he is an amazing guy. He will spend an hour with you if that's what he needs to do to get you dialed in. Right.

Melani Dizon:

That's so good.

Bart:

And he is not from the US since you know, the People's Republic of China, and he says, I just don't understand the capitalist medical system because he wants to make me good. He doesn't care how long it takes. Whereas capitalist medical system is all about how many patients can you see per hour.

Melani Dizon:

Yeah. And something of programming that just doesn't work for so many people. Yeah. So, let's do a raise of hands, how many people had a good result that lasted, you know, a pretty long time with their initial programming?

Bart:

Well,

Melani Dizon:

Wow. Okay. Holy moly. We're talking second round, Bart.

Bart:

Okay.

Melani Dizon:

So, everybody, so, okay, let, in fairness, let's speak for the people who that's not the case. Like as you said, Steve we have lots of people in our community who really excited, got T B s, and they are still struggling. They have not, it's not programmed well, I don't, we, you know, is it where the leads, a lot of it is saying, hey, it's the surgeon where they, the precision in, in placing those leads is critical. But there, they're also still just not getting programmed well, and that is absolute devastating for them. But

Bart:

Yeah, I mean, my, I had to go back for three or four rounds before it was totally dial in. Right. Number one thing and the number two thing, I can't remember anymore, but you can edit this out,

Melani Dizon:

Okay. Yeah. So, I mean, that's an important thing for people to know. It's not a one and done. You go a couple of times there, things change and turn this up, turn this part down. I'm getting this now. I don't want that now. And it's really important to have a good programmer who's open to having those conversations and is willing to see you when you need to be seen. But

Bart:

I remembered what it was now. Okay. What, when I searched into the, whether I should go with Medtronic or Boston Scientific, somebody said that the Boston Scientific was harder to program because there are too many ballots, too many dials that you can turn as a programmer, you know, because you can, you have like 32 endpoints or something like that. And to get every endpoint right is hard. Whereas when you only have four endpoints, it's much easier to get it down in as much as you can. I don't know. Okay. Maybe edit this out as well.

Melani Dizon:

Peter, and then Robynn.

Peter:

So, one of the things I didn't understand at the beginning is why is it important that these, these devices have these multiple endpoints? Is often because it's, the surgeon doesn't get the target quite on target. And so, then they have to direct the signals. And I think the first thing is like, maybe a question people can ask your, the patient, the physician, or they can ask the rep separately, privately, is how often does this surgeon get the target? So, after my surgery, when I started having conversations with the Abbott rep, you know, this Abbott rep that I was talking to works with like eight surgeons and says, you know, the surgeon you chose is great because he gets it on target more than anybody else. And that makes a really, really big difference. And

in fact, I don't know, like if we're, if you want to talk about the actual surgery procedure later on, then we can talk about that.

Peter:

But yeah, I think the programming is definitely an ongoing thing and people need to be patient with it. And if you're the kind of person, like my dad is the kind of patient where the doctor says, take this, and the doctor, you know, he takes that, but he doesn't ask questions. And I think you need to be the kind of patient that asks questions and talks a lot and is willing to kind of complain to your doctor and let them know what's going on and communicate well in order to get this to work. Because it's definitely a back and forth.

Melani Dizon:

Robynn and then Susan.

Robynn

Yep. So, with the programming, Mel, I don't think I appreciated Before I had the surgery, I kind of had this idea that it was a magic bullet and that you just turn on the system and it's all magical and everything just vanishes. And I did not understand that there could be really significant alternative manifestations of things. And I know a couple of people who just upon having the wire inserted, not even turning it on, their dyskinesia vanished, just having the wire inserted before anything was even active. So that's what I was expecting. And I showed up the complete reverse. I don't take any medication at all. Now I'm medication free because even the tiniest bit of medication makes me dyskinetic. So, I've been medication free since 2020. But the other thing that happened, and I think it's pretty significant and people should know about this as an option, is that in order to control my tremor, because my tremor was so dominant and so pronounced, we started having to turn the system up too high.

Robynn

And then I was feeling woozy in the head and my speech was getting slurred. And then, you know, my programmer is the head of the DBS system, she's a movement disorder specialist. So, she's pretty good. And she was dialing it in and changing in points. But then finally back in March of this year, I said, look, this isn't working. I mean, it was, but it wasn't. And I said, you know, here's what's going on. And she said, I want to try something with you. It's something that's being talked about in the conferences right now. I was the first patient she ever tried it with. All of these systems operate typically on a negative polarity. And I don't know if all systems can do this, but the Boston Scientific system can switch to a positive polarity. And she switched the put to the positive polarity.

Robynn

And now I'm having 99% total control with no side effects whatsoever. Wow. And this is like a new thing. So, it's just, I was really disappointed when we, I first finished my surgery, and I was so wildly disconnected when we turned the system on. I mean, I had to almost turn the system off and detox from all my meds and then turn it back on so that I could function. So, it's just not a magic bullet for people. And I know several people who've had really dismal outcomes, and they're not on the panel today. They chose not to be part of the panel, but I think people should know that it isn't a magic bullet.

Melani Dizon:

Absolutely. Susan

Susan:

I want to follow up on, I think it was Bart's comment about the 32, you know, like,

Melani Dizon:

And points

Susan:

Of my impression of that, and I'm interested to know if I'm wrong, or mistaken somehow. But my impression is theirs, there are four points and each one has like eight areas of directionality in power that can be emitted and timing pulsing that can be emitted. But my impression is my doctors only used two of those four points to determine which, how much of all those things I needed, the directionality, you know, at my toes, but not my ankle, that kind of thing. So, so do, does anybody know?

Robynn

No. They don't turn them all on, but they have those choices,

Susan:

So

Robynn

They don't, they're not all on at the same time, but they have more choices with that instrument.

Susan:

That's what I thought too. Yeah. Yeah. And my programmer is my MDs and so again, she's a, she's a tough character. I know a lot of people who've quit her practice because she has such a powerful personality. And this is an amazing experience for me. I really felt blessed, but I really feel blessed by comparison with some of the experiences, even with her strong personality,

Melani Dizon:

Doug.

Doug:

In terms of my programming, my system was fully implanted. And then a week later I went in for the initial programming. And I remember after that meeting, I mean, I had a low dose of electricity going for my generator into my brain. And I remember telling my friends and family the energy, the electricity that the generator produces, it's almost like medicine. If I dial it up too high, I get dyskinetic, like I'm on too much Carbidopa-Levodopa. If I dial it down too low, I'll start tremoring. And it took a while through various programming sessions to, for my body to get used to the energy, if that makes sense. And so, I would go in for a programming session and they would up the threshold of availability of electricity for me to control with my, with my remote-control unit. And over time, it probably took about a year or so to get to the level I'm at now.

Doug:

And now I go in for programming sessions every six months. And it seems like they're trying to fine tune things that may or may not work. I don't swing my arms a lot when I walk, so they've tried to adjust the electricity, adjust the pulse width from the energy to control things. But I found that I recently went in just two weeks ago for a programming session and I told my movement disorder specialist, he does the programming for me. I told him that I was jerking almost like I've had people ask me if I have Tourette's and no, it's Parkinson's. And he tried to create a program to stop me from twitching, but I found that I was tremoring more. And so, I switched back. And long story short, I'm at the same level of energy for both right and left sides of my brain as I've been at for about two years now. So, all things considered my programming is pretty stable, but it took about a year to get things very fine tuned to where, but again, after that initial programming session, I walked out of my neurosurgeon's office and just felt like I was on cloud nine, like my life had been changed.

Melani Dizon:

Yeah. Peter, then we'll

Peter:

Start well while we're on the topic, topic of programming, it's just I wanted to mention that my, one of my goals was getting off the medication or at least as much medication as possible. And I, you know, it's not instant. I'm six months out now and we've been going very, very gradually. So, we've reduced one of my medications by about two thirds and we'll probably eliminate that one over time. But I kind of thought it would just be like, you know, we switch it on and okay, you don't need that much medication after like a month or something, you know, but no, no, no, no. It's, this is going to go on for at least a year or so, maybe more before we get to the point where my medication reaches the low that it can be, which my surgeons told me from the beginning, you know, like might not be zero 40 to 50% reduction was their target, their sort of average target for the typical patient. And I'm okay with that. I just you know, like at least the ONs and OFFs have become much more stable.

Melani Dizon:

Yeah.

Doug:

The programming.

Melani Dizon:

Yeah. Bart?

Bart:

Two things about what Peter said. One is that you only get tons of me medicine reduction if you go for the S STN target. There are two targets, S STN and GBI I and advantages and disadvantages of both and the advantage of the GBIs is an easier target to hit. And the advantage of the STN, it enables you to cut your meds a lot more.

Melani Dizon:

Yeah. So, we don't have time for everybody to answer, but I would love to hear from two people about anything you think is important for people to know regarding the surgery itself. What is something that surprised you didn't know going in and you just really want people to know Doug?

Doug:

I had the impression that I would be knocked out cold for the start of the procedure. They'd drill into my skull and then wake me up to go through the Parkinson's tests and to, for them to get feedback from me if I was feeling facial pulling and tension. And it was kind of a shock when I was conscious throughout the entire procedure I was sedated, but hearing the sound of the

boar going, drilling through my skull was a shocking sound and something that after the first side of my brain was done, I thought, well, I can go through it again, but I hope I never have to hear that a third time. Yeah.

Melani Dizon:

Really quick, I forgot to ask, did anybody do it asleep. You did Steve. Oh, oh. And Peter. Okay. So.

Steve:

Well, they, but they woke me up to, to test me, you know? Okay. Yeah, yeah, yeah. But thankfully I slept through the drilling part.

Melani Dizon:

Oh, okay. Okay. Yeah. Yeah. because sometimes they do full asleep at this point. And is that what you had full asleep, Peter? Okay. Talk. Yes, I did talk a little bit about that.

Peter:

Well, I was trying to mentally steal myself for, you know, having to be awake and hear the boring drill sound going through my skull and all that. But Dr. Baltic said, look you know, I've been doing more and more of these fully asleep. He does an MRI before the surgery and a CT scan, you know, in the orb, and I believe he can, you know, combines the two images into a very high-resolution scan and he said, statistically, I'm not seeing any better results from people being awake. And I said, look, I'm willing to be awake, you know, if that'll be better. And he said, okay, thanks for letting me know. But my experience was, okay, we're going to give you some medicine so you can sleep now. Okay. Take a deep breath, wake up. And that was it.

Melani Dizon:

Wow. Yeah. Okay. So, he was just a doc. He was convinced this was the best route for you. Did anybody have a choice? Did anybody's doctor say, hey, do you want to do the sleep or awake? Is that the same thing? Sleep Bart?

Bart:

Well, no, but what I had is the first time I had awake, but I was knocked out for the drilling bit, so I didn't hear any of that. He woke me up to do the test the second time I was totally asleep because he already nailed the target in his system. And plus, he didn't want to hear me say things like, make sure you wash your hands before you do this.

Melani Dizon:

Bart:

So, my second time was totally knocked out and my first.

Melani Dizon:

Okay, Robynn,

Bart:

Both. Wonderful.

Robynn

Yep. I was mine was a two-part series where I got the fiduciary drilled into my head in an outpatient procedure where I was fully awake. And I ended up throwing up from, from that procedure because of the sound of the drilling not on the doctor's shoes, but in the garbage can. I said, this must happen a lot. He said, no, actually it doesn't. So that was nice. But my surgery took an extra-long time. They woke me up and the, I was out when they did whatever they did to get me locked into the system. And then they woke me up. And when they woke me up, I said to my neurologist, I said, everybody said, you're so brave, you're so courageous. And I didn't feel like that until right now. Most of these surgeries lasted about an hour an hour and a half to two and a half hours.

Robynn

Mine lasted four hours and 45 minutes because they couldn't get it on one of the sides. I did bilateral under the same procedure because I never want to do this again. And so, my doctor, even though I was having no symptoms on my left-hand side, and I knew that one day I would, and I didn't ever want to do this again. So, they were having trouble getting the reading on one of the sides, and we had to do go up and down a second time to do it. But I remember being awake and when they hit this certain millimeter measurement at a certain wattage, and my tremor just vanished, and I just got this huge smile on my face. I do want to say one other thing. That unexpected thing that happened, I had an immunological, not an infection, but an immunological response to the battery implant there is, which, which means it looked like I had hives for four to six weeks after the chest implant surgery. And my doctors were like, no, no. It's the anesthesia working its way of your body. Anyway, they didn't know. They didn't have a clue. They never experienced it before. And it's listed as the number one side effect on the stimulator packaging Wow. An immunological response. And so just things can happen that you're just not expecting that. You know, I've never come across anybody else who had that

response, but I did. So, I just want people to know there's all kinds of crazy things that can happen.

Melani Dizon:

Yeah. That's great. That's a great point. All right, we're going to start wrapping up, but I would love to know if you have something to share, number one the thing that you are able to do after your DBS that you're so grateful for, and the second thing is, any, anything that you wish you knew before or just want to make sure people know about the entire experience? Anybody is free to answer that, Amber.

Amber:

I was not prepared for equipment in my body. So, the first time that I lay down flat after the surgery, because initially they have you sleep sitting up. So what? So, blood doesn't pull, and you don't get black eyes. The first time I lay down when I woke up, it felt like the wires got bunched up in my neck and I couldn't extend my neck. And it freaked me out. I was like, oh my God, I broke it already, like first week out. I don't know what they're going to do, you just have to rub it out. But I was not prepared for what it was going to feel like to have equipment, like the wires in my head. So, I still feel pressure when I lay down on that side. Sometimes more pressure than others. But that was something that I had not even thought about obviously, because it went by so fast. So, I didn't have time to think about all those things. So that's definitely one of them. Okay,

Melani Dizon:

Peter. And then,

Peter:

So just in terms of how the surgery has changed my life, I mean, when I first went in to see the neurosurgeon, I was using a walker because I couldn't really just, you know, I couldn't walk on my own anymore without falling over. I had originally started using some, like walking sticks, you know, these kind of alpine walking sticks, but I couldn't even ha I couldn't even move them properly. And you know, I didn't even know how I was going to, when I was flying across the country, whether I could do it alone or not. And now I just, I don't need a walker. I don't need sticks. I'm just walking, and I can walk as long as I want, as much as I want. Sometimes I have, most of the time I have not off at all. And so, for me, it just really fulfilled my goals.

Peter:

Now there were things I experienced, you know, like everybody had problems. I'm sure I had some problem. I was vomiting like crazy for the first 24 hours after the surgery. I mean, and I

said, does this happen a lot? And they say, no, I was vomiting a bile. It was just awful. And it might be because the surgery was a long one, it was like an eight plus hour surgery because they do both sides and the generator all at the same time. Mm-Hmm. And one of the things I wish I had known at the beginning was that that was an option because I mean, I would've chosen to do it all at once. I didn't want to have multiple surgeries and multiple exposures in the hospital, especially during covid and everything. But, you know, even, even just being exposed in that way. So, I'm glad that I, that ended up being a potential option for me. And yeah, it's just been so life changing. I always describe it as life changing.

Melani Dizon:

Wow. That's great. Thank you, Steve. And then Robynn.

Steve:

Yeah. yeah, it's like my, and my wife has to remind me of, of what it was like a year ago. I would wake up in the morning and I would need a cane to go downstairs, and I would freeze. There were times that I would shuffle, freeze. I would, I fell a couple times and you know, and I, you kind of forget the bad stuff. And I'm reminded of that now that never happens. And I do take my medicine is, is like a fraction of what it was before. I, sometimes I wonder if I even needed it all. But I do take a little bit of it. No more shuffling, no more rigidity. The thing that really, that means so much to me is I'm a I'm an active person. I love to cycle.

Steve:

I love to work out, I love to hike. And I'm able to do that again, I la last, before the surgery, I would get off my bike and I would shuffle. I would ha I was like a mummy just walking from the driveway to the garage to put the bike away. And all that's gone. So now that's the good part and it hurts. There's, you know, so at least it hurt me. The other part of it too is the surgery itself. I'm talking about there are some, some unintentional side effects that that you may not be aware of. And I'm sure it can be different for everybody, but and maybe this is a programming thing that I need to, to talk about, but my voice gets very hoarse and very weak. I have to be careful when I eat. I'm choking more than before surgery. And my handwriting is gone from poor to just you can't even read it. So, I've had to work on that. But on the other hand, I'm sleeping too, so, and that wasn't that was not anticipated that it would really have an effect on. Yeah. So, but overall, it has been a home. It's been a grand slam. It's been wonderful. So, thanks Steve. Robynn.

Robynn

Like Steve, I want to say that there can be some unintended consequences. First of all, I live a totally normal life. I followed more the European route, which is get surgery early and have the best quality of life for as long as possible. There's been a reversal in the thinking about how to

treat Parkinson's over the last 10 to 15 years. They used to say, put off medication as long as possible till the last possible moment, then take medication and put off surgery as long as possible. That's completely flipped. They say, now do everything early, have the best quality of life. So that's the path that I followed, but I was doing triathlons and after I got DBS, another side effect that can happen is you lose your ability to swim. And there have been drownings in Australia, there's research, you can Google it. There have been drownings of people who were swimmers who jumped into the deep end of a pool, and they drowned because they couldn't swim. I was training for a triathlon, and I was like, what is going on? And I haven't tried to swim left. I mean, I don't drown, but I cannot do a coordinated freestyle stroke. If I get a good stroke going with my arms, I can't kick with my legs. If I get a good kick going with my legs, I can't go with my arms. And so, Wow.

Melani Dizon:

That is not something I've ever heard that.

Robynn

Yeah. My doctors were like, we've never heard of this. I'm like, Google, it's there. You can even watch; you can even watch the YouTube videos. What, Steve?

Steve:

It happens to me. I, and I never knew that, I never knew. I mean, I, the lower part of my body just sinks, and I love to swim, and I know I, when I jump in the lake, I've had to have a life jacket with me.

Robynn

Well, and so I haven't tried swimming laps since I've had this positive polarity programming. I've been to the beach, and I told my partner, I'm like, I think I'm swimming. Like I used to swim. I mean, I'm from Miami, Florida, so I'm a swimmer and I need to try and like discipline swim laps and see if this positive polarity has restored my ability to swim. Hmm.

Melani Dizon:

Wow. So interesting. Susan. And then Doug.

Susan:

I think your question initially was what are we the happiest about that's changed? And I would say no more dyskinesia, no more. I mean, this is not there, and it is just the best. And the NoH, as I said before, the lightheadedness was a powerful, it affected all my exercise, everything. And the fact that that's diminished some is, is significant. In terms of the surprise part of the

question I think I heard a couple of people say that there are some tiny little new things that they didn't have before. And I have experienced that, and I hope that this, I'm making the right decision. And I think when I was talking listening to Doug, he made me think, yeah, you probably have on the whole I'm, you know, I never had my shoulder, you know, kind of pulled back like that. It's, but it's so quick and brief and liner that I almost feel like I don't want to have her adjust it because it's gone. It's new and different so

Melani Dizon:

You don't have to mess with something else that's going well.

Susan:

Yes, that, you know, on the whole, I forget I have Parkinson's. Most people don't know I have Parkinson's. That's an absolute blessing. And then I just wanted to say what my friends who had had the surgery said to me, you're going to get your life back. And that was such a powerful thing to hear, and I just wanted to share that.

Melani Dizon:

Yeah. Thanks Doug.

Doug:

For me, prior to getting DBS, when I would speak in public or just speak around my friends and family, I would get dis more dyskinetic and I worked in sales, I would have to make sales presentations, and I would be very dyskinetic and then I would start to sweat, and I just felt out of control. And so, I feel like I can talk once again. Whereas before, I would keep my mouth shut oftentimes. And the ability to fall asleep is greatly better than it had been before. So just those two things have been life changing in, in and of themselves. I mean, not wiggling all the time. I can work out I can sleep. Yeah. And I can sleep. I feel better.

Melani Dizon:

Those two things alone. Right. Yep. Pretty great. Well, thank you all so much for being on this panel. I think it's going to be really helpful for our community. So many people are asking us, what is it like, what happens when you get DBS? And we wanted to give a lot of different perspectives and a lot of different stories. So, I really appreciate you being here. I want to thank our sponsors, Medtronic and Boston Scientific for helping us put this together. And we will be sharing more resources about DBS soon. If you have any questions about DBS, you can reach out to me at blog@dpf.org and we will see you online. Thank you so much, everybody.

WANT MORE PRACTICAL ARTICLES LIKE THIS?



You can learn much more about living well with Parkinson's today through our *Every Victory Counts®* suite of resources. Each manual is packed with up-to-date information about everything Parkinson's. Click the link below to reserve your manual(s).

[Reserve Your Manual\(s\) Now](#)

Thank you to our 2023 Peak Partners, **Amneal**, **Kyowa Kirin**, and **Sunovion**, and our Every Victory Counts Gold Sponsor, **AbbVie Grants**, for their ongoing support of these must-have manuals. Additionally, we'd like to thank *Barbara and Dale Ankenman, Abby and Ken Dawkins, Bonnie Gibbons, Gail Gitin in loving memory of Gene Gitin, Irwin Narter, and Lorraine and J Wilson for their generous donations that allow us to make these resources available and free to all.*