



How to Start and Run

A Deep Brain Stimulation (DBS) Support Group for People with Parkinson's

Davis Phinney Foundation

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

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

Hello and welcome everybody. My name is Melani Dizon. I'm the Director of Education and content at the Davis Phinney Foundation, and I am here today with Doug Reed and Kenlynn White. And we are going to be talking about deep brain stimulation and the support group that they run together. Hi, Doug. And Kenlynn.

Kenlynn White (Ambassador, Davis Phinney Foundation):

Hi. Hi.

Melani Dizon:

It's good to see you guys. So, I want to talk a lot about the group, but I'd love to start with both of you telling us about your DBS story and how did you come to DBS? What was your experience and, you know, how has it changed your life? Kenlynn let's start with you.

Kenlynn White:

Okay. I was diagnosed with Parkinson's in 2015, young onset. And basically, my doctor said, I think it's time for you to consider DBS. And I knew some people that didn't qualify for DBS, and so, I kind of, you know, I took, I took the reins, if you will, because I was nervous that I didn't qualify. And then so, when they said, oh, you qualify, I just kind of like jumped right in and didn't, didn't really know what to expect. My mom and my husband did a lot of the research, and so, I just kind of went in, not really expecting the worst, just more or less hoping for the best.

Melani Dizon:

Did you do much research on the system or was that something that they sort of filled you in on? Or did, did your doctor just say, hey, this is what I do, kind of thing? How did it work?

Kenlynn White:

They where I see they gave you choices. And the system that I chose was for very specific reasons that were important to me. You know, size, battery capabilities, and stuff, you know.



those kinds of things. Those are important to me because I'm not a huge individual, so, the different size of the batteries and stuff like that was important to me.

Melani Dizon:

Yeah. And so, how many years had you been living with Parkinson's before you were implanted?

Kenlynn White:

I was diagnosed in 2015, and I got, I've had DBS for a year and a half now. Okay. So, I got it at the end of what, 2021.

Melani Dizon:

Okay. Yeah. Great. Thank you. What about you, Doug?

Doug Reid (Ambassador, Davis Phinney Foundation):

I was diagnosed with Parkinson's at age 36 in 2010. I had DBS in the fall of 2019, so, it was about nine and a half years after diagnosis that I got DBS. And it's been life-changing for me. It's I, those of you who've seen me on here before, probably heard me jokingly call myself the poster child for positive outcomes of DBS, but I was very dyskinetic beforehand. I had dystonia in my neck. And DBS has allowed me to go off of Carbidopa levodopa completely. My dyskinesia has gone away. The dystonia still lingers a little bit, but it's nowhere near as significant as it was prior to the surgeries. And I'm ecstatic with the results I've had. I realize not everybody is the same, but for me, DBS has been a life-changing thing. Yeah. Best.

Melani Dizon:

Yeah. You are the poster child. You are. We need, hey, we need it. We need everything. Right. We need all sides of the table, so, thank you.

Doug Reid:

A DBS advocates?

Melani Dizon:

Yes. So, you both co-lead a DBS support group through Parkinson's Association of the Rockies par. Can you tell me how that even started? How did you, how'd you get involved?

Doug Reid:



Well, for me, par sent out a new newsletter and mentioned they were looking to start a DBS support group for the community. And I volunteered. It was at a point in time when the pandemic was winding down and I was on long-term disability. I wasn't working. I had plenty of time, and so, I immediately responded and said, hey, I'm interested. And this was about a year and a half ago.

Melani Dizon:

Okay. And then Ken, how'd you get involved?

Kenlynn White:

That was the same, the same way. I volunteered as well. I had recently stopped working and I just answered the call to volunteer for this DBS support group that they were putting together and felt like I had something to offer.

Melani Dizon:

And so, you guys didn't know each other before?

Doug Reid:

Oh, we did.

Melani Dizon:

Oh, you did? Okay.

Doug Reid:

We both attend a young onset support group meeting that meets monthly done in Denver.

Melani Dizon:

Oh, okay. That's great. Love that. And you're, do you guys still do that group?

Doug Reid:

Yeah.

Melani Dizon:

Yeah. Oh, I love that. That's great. How many people go to that group?

Doug Reid:



It can rain from eight to 20, wouldn't you say, Kevin?

Kenlynn White:

Yeah, I'd say that's about right.

Melani Dizon:

Okay. So, for your DBS group, what are you know, a lot of people reach out and want to start a group themselves. Maybe they want to do it in person in their area, or they want to, you know, they've got a lot of people in their area who want to do it virtually, and they just want to set something up. So, what were some of, when you were thinking about putting this together, what were some of the big considerations you had in terms of how are we going to invite people and who do we want to be part of the group?

Kenlynn White:

It was more like we just put it out there, but it was who's in the, like, it was more like timing. what's the optimal time to do this? Because you have different, different types of people. You have older people that aren't working, or younger people that are still working. And so, what's the optimal time to hold this kind of forum? was the biggest challenge?

Melani Dizon:

So, you guys did it like Par, put the call out for people who were interested, you guys said we're interested, and we would lead it. And then did they then give you, gave you a list of people that they were going to send it out to once you organized the whole thing? Or did you have to rely on your own lists of people?

Doug Reid:

No, it was kind of grassroots. They par granted us access to their Zoom account. so, we didn't have to have any expenses. And they also, put us in touch with a Nur, a clinical nurse manager at a movement disorders center. She works out at one of the hospitals in Denver. And so, we have that kind of insight, but it was really building the email distribution list from the ground up. I had the young onset email distribution list from the support group that Kenlynn and I go to. and then it was more or less word of mouth. People would see through the PAR newsletters that there was a DBS support group. So, we would get people through there. Both, Kenlynn, and I attended a University of Colorado Health Symposium on Parkinson's last year. and we picked up a few members there. And I've connected with other people with Parkinson's through the Davis Phinney Foundation. so, we have the majority of our members are Colorado, Rocky Mountain based but we do have two ladies that dial in from New York. We got a gentleman from Mexico who dials in regularly. But I guess getting back to your question, what



Kenly said, yeah. Trying to find a time that worked well for us primarily. So, we selected Thursday the fourth, Thursday of the month, two 30 to three 30.

Melani Dizon:

Okay. And would you, what's, what is the makeup, you know, more old, younger? What's, what do you think? Is it, or is it just average across?

Doug Reid:

They are pretty diverse.

Melani Dizon:

Yeah.

Kenlynn White:

It's across the board. I mean, there are definitely some retired people and then there are young people that are still working. There are people that have DBS and have, we have people attend that have all different, you know, models you know, Abbott, Medtronic, Boston Scientific. And we have people that are still just doing their research and trying to get information.

Melani Dizon:

Yeah. That's, that's good. That's definitely where I'm getting questions is people, they're just stuck and they keep, yes, I'm going to do it. No, I'm not going to do it. Yes, I'm going to do it. No, I'm not going to do it. And so, it's great to have a place to send them where they can meet other people who are in that situation and also, other people who have made the decision, you know, to go for it. for the people who, well, what, how is it structured? You know, so, for, let's say for people who have not done it, do you do breakout rooms? Do you have you know, themes that you talk about each week? Or is it just, whatever happens, happens?

Doug Reid:

Usually, it's pretty impromptu. As Kenlynn said, we have a good mix of people who have had DBS and people that are new to the group or have been to a couple of meetings and are considering DBS, and we typically just let the conversation evolve. Hey, does anyone have any questions? Those who are new to the group, what are you here for? Have you had DBS or are you considering it? However, at this coming meeting in the, our meeting in April, we have our first guest presenter. She is the nurse manager that works with us in the group and said she was more focused and has more experience on the technology side of Parkinson's. But our questions among the group members, a lot of them were focused on medication. So, she connected us with a former coworker, a nurse practitioner who has worked in a movement



disorders clinic, and now works in the pharmaceutical industry. So, she's going to give us a 30-minute presentation on all things Parkinson's medication-related, and then we'll open it up to Q and A.

Melani Dizon:

Okay. That's cool. When people are researching, what is it that they seem to talk about the most? What support do they need or what answers are they looking for? What are, what are they asking in the group?

Kenlynn White:

A lot of the times I think they, I mean, we have people also, that have essential tremors that come to our group. Or essential tremors and Parkinson's come to the group. So, they have questions sometimes on why people that have DBS have chosen the model that they've chosen. So, we can give them feedback on that, you know, and the results that we've gotten. Also, they have questions. Some of them have the option of just doing one side or both sides, so, they have questions around, you know, how that would work. You know if anybody else has had similar situations.

Doug Reid:

Yeah. I think one of the questions we frequently get, for those of us that have had DBS is, would you, now that you have DBS, would you go through the process again? if you had to? Right. Or hindsight being 2020, are you glad you went through the process, to begin with?

Kenlynn White:

I think the, also, the other thing we talk about a lot is the surgery.

Doug Reid:

Yeah. People and our-

Kenlynn White:

Experiences with the surgery,

Doug Reid:

And there are so, many different ways to do it. For example, my surgeon did three separate procedures, right? Brain left brain, and then they implanted the generator, and each was a month apart, some sur and I was awake for the two brain surgeries. Some surgeons are doing the entire procedure in one operation and the patient is asleep. So, there's a mix of ways you



can do it. Some guys will, or some people will get one generator placed and one side of the brain and then they'll come back years later and get the other side done. It really just varies. But there's, with the three manufacturers that are out there, there's some variability in terms of how the neurosurgeons implement the technologies. Right.

Melani Dizon:

Are there anybody, is there anybody in the group who is, just has it and wishes they didn't and is just struggling with it and needs help from that standpoint?

Kenlynn White:

I mean-

Doug Reid:

Go ahead, Kenlynn.

Kenlynn White:

Part of one of my reasons for co-leading, co-leading this group is I've had my struggles with it. I don't wish that I didn't do it. but I've had my struggles and I feel like if I can offer support, you know, or empathy to anybody else, then I can learn so, much from other people.

Melani Dizon:

Yeah.

Kenlynn White:

So, not only do I feel like I have something to offer, but I feel like anybody who attends the group has something to offer to me as well.

Melani Dizon:

Right. One thing I,

Doug Reid:

Go ahead. One thing I discovered my programming was pretty straightforward and, and simple, but in being exposed to other people that have had DBS, I found out that programming is oftentimes a challenge and can take a year or more to get the system really dialed in and tuned for the individual.

Melani Dizon:

Yeah. And I think being able to share that with people is super important because of the feeling of it's not working and it's never going to work. Right. That panic of I've been out of this for a couple of months; I went through this whole thing and it's not working and I'm not better. It's nice to hear from other people who've said, well, yeah, it took me a long time too. So

Kenlynn White:

Yeah. I think Doug and I were on a call recently where there was somebody who had just had it in a month and they were already like, this isn't working. And I felt like we could offer that. You know, you have to give it more time than that.

Melani Dizon:

Yeah. Yeah. For sure. Would you be willing to share some of your challenges or what's been, what's been tough for you in adjusting with it?

Kenlynn White:

Sure. I think I was on, you know, probably 30 pills a day before getting DBS, so, that's taken a lot of that away. But it's made me more, more aware of my symptoms that this disease causes. Also, being a female, being early 50 and right about the sweet spot of getting DBS and all the female things that we go through. You know, sometimes it, I'm questioning, is it the DBS? Yeah. Is it the Parkinson's? Is it Right? Other female stuff. Right. So, it makes, it just makes for a lot of challenges sometimes.

Melani Dizon:

Yeah. Do you feel like you have a fair number of women who are experiencing that? Similarly?

Kenlynn White:

I've seen some women have very successful outcomes with DBS or I know some and I would think that I've been pretty successful, but it's just, it's opened doors that maybe the medicine was masking.

Melani Dizon:

Yeah. That's interesting. Well, yeah, I think it's so, important to have your perspective in there as well. What have you learned aside from, you know, the sort of logistical piece of email and making sure everybody's on track and everything, what have you learned about running this group? And I guess you've been doing it for a little over almost a couple of years or a little over a year.

Doug Reid:



Almost a year and a half, I think.

Melani Dizon:

Okay. So, what have you, what have you learned? What has surprised you? What do you love about it?

Doug Reid:

I get nervous before each meeting that no one's going to have anything to say. And thankfully it's, it just happens in a kind of organic way that people will have something to say. And I mean, even if it's just griping about Parkinson's and is not DBS specific, it's a friendly group of hippies of people and not having been very exposed to the Parkinson's community back when I started this, it's been kind of eye-opening that almost everyone with Parkinson's has a sense of humor and. we've all got a story to tell.

Melani Dizon:

Yeah. Yeah. What about you, Kevin?

Kenlynn White:

Yeah, nobody seems, you know, unhappy and complaining about Parkinson's, if you will. It's just life. But DBS, it adds another layer.

Melani Dizon:

Yeah.

Kenlynn White:

You know, I mean there's Parkinson's people and then there's Parkinson's and DBS, I think.

Melani Dizon:

Interesting. Have you guys ever met in person, or have you always been virtual?

Doug Reid:

The support group, it's always been virtual.

Melani Dizon:

Okay. Do you record your sessions and then making them available to people? If they have to miss-



Doug Reid:

We have yet to do that. I think probably because I don't know Zoom as well as I do. But after this, if we can, if you can give us a quick tutorial and not record things, we may start to do that in the future. I'm not sure how it would be involved with Par since it's their account and

Melani Dizon:

Right.

Doug Reid:

Yada, yada yada. But we have had requests to record the meetings and I've just been delinquent in my response.

Melani Dizon:

Anyone can join your group. Right? Doesn't matter where they are.

Doug Reid:

Yeah, for the most part, we get anywhere from eight to 15, 16 people per meeting, and very some, there are some regulars that attend almost every meeting.

Melani Dizon:

And what's the, where can people find out about it?

Doug Reid:

Through parkinsonsrockies.org.

Melani Dizon:

Okay, great. I'll put that up for sure.

Doug Reid:

Or they can email blog@dpf.org and you can get them in touch with me. But don't

Melani Dizon:

Do that. What advice do you have? I'm sorry, what'd you say again?

Kenlynn White:



I said we also, have an email address. It's Rocky Mountain DBS or DBS@gmail.com.

Melani Dizon:

Okay.

Kenlynn White:

So, it's like rockymountain-DBS@gmail.com.

Melani Dizon:

Okay. We'll share that. Anything you want to offer people Advice for people who are, considering going to a virtual DBS group and they're kind of nervous, they don't know anybody and they're just going to show up or be for people who are interested in hosting their own support group for their community.

Doug Reid:

One of the things that we did to try and promote the group was the nurse manager who's on the DBS council, I guess you could say with Kenlynn, and developed a flyer that has been posted in a number of movement disorder specialists' offices in neurosurgeons offices as well to try and get the word out there and grow the group. So, for people looking to start a group, I'd recommend that they advertise in their local community general support group. If there's a young onset group, try to promote it there and then of course try and promote it at the doctor's offices as well.

Melani Dizon:

What about you Ken?

Kenlynn White:

I agree with all that. And then just as far as attending, you know, an online support group, I mean, I think what a better way. I mean it's a safe zone because you're not there in person, you don't have to drive.

Melani Dizon:

Yep.

Kenlynn White:

So



Melani Dizon:

Yep.

Doug Reid:

We try and make it convenient. Just as an aside, one thing that I've been thinking about is offering another monthly session in the evenings to make it available for people who don't have, or who are still working and don't have the flexibility to get to an afternoon session. Right. So, for those looking to start a group, maybe find two optimal times that work for you and your co-facilitators, and your cohort.

Melani Dizon:

Yeah. In terms of managing the email, are you just managing them like through Gmail or using a different system or what are you doing to sort of handle the roster that continues to grow?

Doug Reid:

I am a dinosaur and that I still have a Hotmail account.

Melani Dizon:

I know.

Doug Reid:

And so, I just give my Hotmail address to anyone who's interested, and I add them to my distribution list within Microsoft Outlook, Hotmail.

Melani Dizon:

. Okay. Great. Works

Doug Reid:

For us.

Melani Dizon:

Low tech, high touch. It's good. It's great. Well, thank you so, much for talking to me about this today. I know people are interested in it and I've gotten a lot of emails about how they can join or how they can start one. So, I'm glad to share this with them.

Doug Reid:



Sure.

Melani Dizon:

Thank you, Kenlynn.

Kenlynn White:

Thank you.

Melani Dizon:

Bye, everybody. I will see you again soon.

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