



Living with Parkinson's Meetup

March 2023: What I Wish I Knew Then

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):

My name is Melani Dizon. I'm the Director of Education and Content at the Davis Phinney Foundation. And this is the Living Well with Parkinson's Meetup. Today we're going to have sort of a q and a, but also, we're going to talk about one of the things that people sort of have written in about was we want to know what people wish they knew then. So, we're going to say I'm going to get everybody a chance to kind of finish the sentence. What I wish I knew then was dot-dot-dot, or, I liked the way Robynn said it. She sometimes says, what would, I think I may have mixed it a little bit. What would today you say to back then? You and we want everybody, oh, hi Heather. I just saw you. We want everybody to participate in the chat too, so definitely share your ideas and comments, and stories in the chat. But to get going as usual, I would love for everybody to just introduce yourselves to the people who are new in the audience. Tell us who you are, maybe how long you've been living with Parkinson's, and how you, let's do, actually, let's do something different this time. Let's do your favorite outdoor activity. And I'm going to just go around my screen and I'm going to start with Robynn.

Robynn Moraites (Ambassador, Davis Phinney Foundation):

Oh. My favorite outdoor activity is biking, for sure. Robynn Moraites out of North Carolina, diagnosed in late 2015, had very visible symptoms starting a couple of years before and was misdiagnosed. But when I understood the full constellation of symptoms, I've been living with Parkinson's since probably 2003 or 2004.

Melani Dizon:

Wow. That was made you how old? Wait, I'm not going to do the math. What was that in two? What were you in 2003?

Robynn Moraites:

Two, probably like 30. 30, 30 maybe 33 years old.

Melani Dizon:

Wow. That's-



Robynn Moraites:

Yeah. And you know, I have, there's a couple of things I suspect may go back earlier, but that's when I can really identify symptoms. I got officially diagnosed when I was 46, about eight years ago. So, I'm a true, you know, sort of young onset diagnosis. And just so the audience knows, I also had DBS in 2020, and that'll be important to our discussion for me.

Melani Dizon:

Awesome. Thank you. Kristi.

Kristi LaMonica (Ambassador, Davis Phinney Foundation):

Hi, I'm Kristi LaMonica. I live in upstate New York and the capital region. I was diagnosed in 2020 in the beginning of the pandemic, but I really have symptoms that I could kind of really trace back to, like actual visual motor symptoms to about like 2014 when I moved out here from Denver in 2000 thousand 14. A lot of my shoes, every pair of shoes I brought with me and the inside and the left shoe, they were all worn out from curling my toes. And then going back to 2005, I had rum sleep disorder. So, I have been trained to do stem cell work. So, my PhD is in cell biology. And so, I've grown stem cells for a long time. And I used to do cell work in my sleep in 2005, starting in my, in 2005. My husband would be like, you were doing cell work again in your sleep. So, I started, I was working in science like 24 hours a day because I was doing my sleep. So, my room sleep disorder goes back that far. Wow. We just thought it was pretty funny, you know, until I started, you know, punching my husband eventually my sleep.

Melani Dizon:

Yeah. Yeah. Never good. Yeah. Doug, what about you?

Doug Reid (Ambassador, Davis Phinney Foundation):

Doug Reid from Lafayette, Colorado. I was diagnosed in 2010 when I was 36. I'd been exhibiting a hand tremor for at least a few years before that. I had DBS just over three years ago, and it's been life-changing for me.

Melani Dizon:

Right. Thank you. Brian?

Doug Reid:

My favorite outdoor activity is hiking.

Melani Dizon:



Hiking. Okay. Brian?

Brian Reedy (Ambassador, Davis Phinney Foundation):

Hi, I'm Brian. I'm in Southern California in Huntington Beach area. I've had Parkinson's for 12 years now. I was a high school teacher teaching photography when it hits on, and it took me four years to realize I couldn't maintain the career anymore. But getting involved in advocacy work, advocacy work is almost like teaching again. Yeah. And my favorite activity is anything outside. But I love doing pool therapy. I do my exercises with a full-face mask underwater so my body can do things that I can't do on land, so, oh,

Melani Dizon:

Get stretches in.

Brian Reedy:

Yeah.

Melani Dizon:

Thank you. Heather?

Heather Kennedy (Panelist, Davis Phinney Foundation):

Heather Kennedy, diagnosed in 2011. Didn't believe it until 2012 when I started taking the meds. And just like Robynn said, now that we understand the consolation, that's a great way to put it. Evolved, but different symptoms. I started experiencing symptoms right before my daughter was born, and she's 20. My favorite after activity was streaking. Of course.

Melani Dizon:

I expect no less.

Heather Kennedy:

Come on.

Kristi LaMonica:

Mine, I'm hiking. Sorry.

Melani Dizon:

Yes. Okay. Hiking with your babies, with your little baby doggies. Yes,



Kristi LaMonica:

Yes.

Melani Dizon:

Yes. Okay. So, some people put in some things in the chat already. So, let's say that they're finishing their sentence. What I wish I knew then I've got, I'd say it's going to be okay. Don't let the pandemic stop your exercise routine. Life is going to get really hard, but you will be okay. I wish to find a more natural way to get some sleep. Maybe we'll talk about that Sweet. Okay. Larry. Hi. Larry says the journey ahead is not for the faint of heart, but you can live well with Parkinson's and not against it. Love it. Remember, don't panic. That's good too. All right. So, I would love to hear from all of you. I think, you know, part of this is going back and saying that that really, really much older self that was, was experiencing those symptoms, but not having any idea of what it was. And then there's that part of you that went and got your diagnosis and spent the next couple of weeks wherever your head was. And if you could talk to that person, let's think about that. What would you want to say to them? And what do you wish you had known? Hi, Kevin. Thanks for joining us. Yeah.

Kevin Kwok (Ambassador, Davis Phinney Foundation):

Hey everyone. Sorry. Hi. I was having trouble dialing in.

Melani Dizon:

No problem. Kevin, Kevin's only got a little bit of time with us. He's got about 20 minutes, so we're going to make sure we get your voice in here, Kevin. So, here's the question. Imagine, you know, it's back when you got diagnosed, when you finally really got that clinical diagnosis and those, you know, few weeks after, months after. Where was your head and what do you wish you knew then that, you know, now?

Robynn Moraites:

I would tell myself, okay, I'll start. So that particular person I was, someone wrote, don't panic. I was panicked. I was hypervigilant about every symptom that appeared. Everything I just felt like was catastrophic, you know? And I had a neurologist, a very kind and wise neurologist. I call him affectionately neurologist number four, who said to me you're hypervigilant about and your body aware in a way that a lot of people with Parkinson's aren't. He said, that's good and it's bad, and it's good because you'll be able to tell me about side effects with the meds, and you'll be able to sort of notice how things are affecting you. And he said, but it's really bad because you're hypervigilant. And I did a lot of, I do a lot of public speaking for my job. And he said, if I flub a, if I'm giving a talk and I flub a word, I just flub a word and I keep going.

If you flub a word, you're going to get, you know, catastrophize and say, oh my God, I'm getting Lewy body dementia. And he's turned out to be right about my, you know, sort of thinking in it. And so, I think if I could go back and tell the me that just got diagnosed, I would say, don't live in the wreckage of an imagined future. Stay in the day with what's really happening. Don't panic. And it's actually going to be that living with the uncertainty is going to be more difficult than the actual day-to-day life with the symptoms. Which a lot of times they're just annoying for me right now. Still. They're just annoying. They're an inconvenience. They're not really debilitating. So that's what I would tell me. That particular version of me.

Melani Dizon:

I like it, Kevin.

Kevin Kwok:

Yeah. I was just influenced by call that I just came off on. And that is, and that call dealt with Parkinson's in developing countries. And what was really interesting for me was to hear what goes on in countries like Africa where they feel like the stigma of Parkinson's is, is witchcraft that you've been possessed. And there's a really interesting thing that just came about on this call was that a producer who worked with David Attenborough was recently I think he was living in India, and he has Parkinson's for 14 years. And he was getting arrested at banks because of what he came across a as a as sort of being really out there possessed. And so, he traveled to Kenya, and they shot a video where he deliberately went off meds and went to villages to meet Africans.

And he said it was so physically hard and emotionally, physically hard because he was off meds to meet with other people who could not get meds. And he said it was in Africa. It is just that civil things like you know, carbidopa-levodopa are just not available. So, I think that the thing that I want to address is stigma and need. And the one thing that I would say, is we're all looking for the cure or the thing that makes us better, but there are people that are much worse places than we are in the, in the western world. So maybe my, as hard as it is living with Parkinson's for all of us today here, there are people that have it worse.

Kristi LaMonica:

You sure are lucky Kevin, aren't we? I know all, I work with Tosh a lot. And so, Tosh was part of the, with the, with the initiative in Africa and knowing that, so if people can only get like 10 days of medication, right? Or most people will only stay on their first dose when they were originally diagnosed. So, they're under diagnosed, they're under medicated for the rest of their lives. There are not enough movement disorder specialist. It's just absolutely heartbreaking, you know, and carbidopa-levodopa, I don't even pay my copay for it. I pay for it out pocket because it's ends up being cheaper than my insurance. It's so cheap. To think that they don't



have it in a lot of these countries is just so upsetting. Right. So, we really are very lucky. Even as much, even as hard as it is, we still are really, really lucky.

Kevin Kwok:

Yeah. That was my point, Kristi. I think you're more eloquent than I

Kristi LaMonica:

I told I you No, you are my friend. I think that you explained it very well. It's just really frustrating and heartbreaking that people can be in the sit the situation. So

Melani Dizon:

Yeah. Michael Fahning Parkinson's could be considered a blessing, not a curse. The most important things in life are faith, family, and friends. Ken says, don't ignore it. Make the Melissa make the rest of your years the best of your years. Joe says you can feel better than you might imagine. Exercise is your friend. Many, many symptoms aren't visible to others. Yes, exercise is so important. Doc says not to procrastinate. Parkinson's made us live for today. We don't say we will do this later on. Yep. Suzanne and I think we'll definitely talk about this say, I wish I knew that DBS might be the only long-term option. Chris, also, how important support groups are you have to find your people. Parkinson's isn't punishment from God. In fact, look for the blessings. Ethan says, not to drown in all of the posts made by everyone. Be smart and selective. But keep aware when I was diagnosed, I thought it had to be me. I caused it somehow and felt so guilty if I wasn't such a party animal when younger, all those dead shows. And to have something to do with it, I was heartbroken and cried to my wife telling her I was sorry. I now know it had nothing to do with that. Heather,

Heather Kennedy:

I wanted to just chime in here about something really important. Can you hear me, okay? I wish that I knew the toll this takes on people around me. I have a lot of pain and shame for how I came into this disease for how this disease affected the people around me that I didn't realize. If you're getting some feedback, I can change my you put on the headset. But I feel as if I hurt a lot of people because I was on a hunt for dopamine. I was relentless in my hunt for dopamine. And I was cocky enough to think that if I just worked out, I could maintain this disease. You might see in the background here, I have a new friend, it's called a walker. This disease is going to take everything eventually and to soften into it and be a little more vulnerable. I now know is the way that I can get through. So, I wish I would've known all that. I went so hard, so big, so fast. I wasn't really paying enough attention to the elders, the wise elders in our community who've done this for years. Like Davis. I just needed to listen more and soften. And so, to all the people who supported me when I wasn't very lovable and when I wasn't very soft or



thoughtful, I just really want to thank them for sticking around. So that's what I want to say about that. Thanks.

Melani Dizon:

The people who stuck around are lucky, Heather.

Doug Reid:

When I was first diagnosed, when I was first diagnosed, I put on this air of being positive. And I was so masked, I guess to my inner feelings of such depression and fear and worry. And I didn't speak up, I didn't seek help and I wish I had like doc and the chat, I had thoughts that I somehow caused this on myself. And it, I know now I didn't was the environment pesticides most likely of where I grew up. And later down the road, I wish I'd gotten DBS sooner. I always knew it was going to be some time in my future, but I think, and it doesn't pay at all to live in the past, but I wish I had taken the leap and done it a little sooner.

Melani Dizon:

Yeah. Lori says, I would warn myself to not take dopamine agonists.

Kristi LaMonica:

Yes. Yes. Yes. Yes. I think that's unanimous. Amen. I know. I notice that when there were so many boxes outside my house one day when I did not know what was in any single one of them, I knew that there was a bit of a problem. Shoes. It wasn't even shoes; it was even fun.

Melani Dizon:

It was Stu, who knows. Right? Eric says, I would tell myself I would reach my destiny, but also my family. In this diagnosis, Melissa, Chris and Heather. Oh, Eric. Yes. Kevin and Kristen. You helped to globalize this and put life in perspective. Neda. Hello Neda. We didn't conquer Parkinson's, but we conquered the fear of Parkinson's. Yes. No dopamine agonist does give up memories of the dead, the band. Alman Brothers. No way. Jose. Okay. Suzanne Clark. It takes so much from us, but we can get so much back from it. Marilyn says, don't avoid people whose Parkinson's is more advanced than yours. You can learn a lot from other people with Parkinson's. Tim says every day is different. It's not easy. It's not impossible. Keep reaching out to people till you find someone that will be your friend. I am, oh Chris, I'm here as anyone needs to lean on me. Okay. Any anyone else? Brian did you want to? Yeah.

Brian Reedy:

I was going to say, I would tell myself take things seriously, but not too seriously. Don't let Parkinson's take your joy. Always find something to laugh about. I think that's one of the great



things I've seen in the friends that I've made. And one of the, that's always been my way anyway. But to have it reinforced on such a serious level from some great people, I think that's the gift of how to live with this thing that's constantly challenging us. Just don't let it take your joy. Don't let it take your sense of humor. And then I would also add to my earlier self or to anyone who's newly diagnosed, learn about the non-motor symptoms. Because that's the stuff that's really the makeup that'll challenge us more than anything else in this disease. And trusted national stuff on the internet. Stay away from the squeaky noise. Go to reputable sources at first. But yeah, it's I love what everybody is sharing. It's humbling and remarkable.

Doug Reid:

Yeah.

Melani Dizon:

Someone says I would take meds sooner. And then there's a question, Doug. So, Doug, would you recommend DBS anyone else have reasons I should reconsider?

Doug Reid:

Yeah, I'm actually typing a response to that now. I would recommend DBS do your research though. The dpf.org has a lot of information on it. And I just saw Heather's message that she doesn't recommend it. So, there it's not for everybody.

Melani Dizon:

Yeah. That's such an important thing. Right? It's not for everyone.

Doug Reid:

I'd recommend to anyone who's considering DBS that they try to find a DBS support group so they can talk to other people who have, have received the therapy, people who it's worked for and people who it hasn't.

Melani Dizon:

Yeah. is your, yours isn't virtual, is it, Doug?

Doug Reid:

It is.

Melani Dizon:

Oh, well, perfect. Here's your DBS support group.



Doug Reid:

Yeah. So, if anyone would like to join, I co-lead a Parkinson's support group or DBS support group for Parkinson's Association of the Rockies. And if you want to, what is it? Chat dpf.org or go to my ambassador blog.

Melani Dizon:

Blog@Dpf.Org and we will hook you up. Just let us know. And

Doug Reid:

Or go to my ambassador page and reach out to me and I'll get you anything.

Melani Dizon:

I think Sam will throw that in there. Thank you, Sam.

Brian Reedy:

Well then if I can add something because I just, I just started with the new MDs yesterday. Oh. Because my symptoms have progressed significantly. And for years they've been advocating DBS for me, but because of the struggles Heather has had, and another dear friend of mine in the last year or two, I've been very much, no, don't even start. But this new doctor was saying, okay, wait, you know, there's a lot of changes that have happened and she explained stuff with Medtronic's and Boston Scientific and there's new ways of doing this and that. And I just said, okay, well I'll look at it a little more carefully. So, I'm not keeping a closed mind, but I like what Doug is saying. You don't find a group and get that knowledge and listen to your doctors and see what's really out there and what's changing and where they're at with things. So, I'm trying to be open-minded, but when I, when I see the people who've had their voices softened because of it or stuff like that, and this is what the doctor was saying, that they've addressed that now that there's more to this than we might think. So, it's not an easy response that looks like Kevin has something on that.

Kevin Kwok:

Yeah. I mean, DS changed my life, you know, for the better. And I went on a pedestal to tell everybody how great it was in recommending it, but then I recommended to several friends where the outcome was so positive. And so, I'm much more now about doing the blind. You have to do DBS even though it works so well for me. You know, you hear so much about the successes in there, but you don't always hear about the people that struggle and have problems. So go, go at it with a really open mind. And, but you really need to get really expert advice on this and don't be afraid to get a second opinion.

Robynn Moraites:

Yeah. And I think it's so important. One of the things, I use the word agency all the time. Someone said in the chat, don't ignore it. That they would tell themselves not to ignore it. And Parkinson's is a disease where if you put your, I mean, I'm preaching to the converted because people who are watching this webinar are not ignoring it. They're not head in the sand. But Parkinson's is a disease where the more you're informed, the more you have autonomy over certain choices that you make that will directly impact your quality of life on a day-to-day basis. And it is such an individual progression and an individual disease. You know, I would say I would've gotten DBS sooner. You know, Heather probably might say she wouldn't have gotten it at all. Everybody has such different reactions to different things. But whatever you do, don't ignore it. And get as much information as you can. You might find some really simple little interventional thing that makes your life much easier.

Melani Dizon:

Yeah, Kristi?

Kristi LaMonica:

That's what I was going to say, that I wish I'd ignore my symptoms. I had ignored my symptoms for a number of years. I remember back in probably 2016, I was working on a lot that time, doing a lot of CrossFit. I remember I was back squatting, and my fingers would go crazy when I was back squatting because I had real weird tremors in my hands. And I remember I was working out with a surgeon at the time, and I would say, Dr. Greg, I think I had Parkinson's. And he's like, you're too young to have Parkinson's. And I said, Dr. Greg, I think I had Parkinson's, so you're too young to have Parkinson's. And I did that for like, years, like two, three years. Why, why didn't I seek help if I thought there was something wrong? Like I knew what my symptoms were from teaching and dealing in science for so many years, but I just ignored everything for so long until then I couldn't because the anxiety was just crippling.

Melani Dizon:

Yeah. And Kristi, that's actually, I mean, that brings up the point that just because they're a doctor doesn't mean.

Robynn Moraites:

that they know what they're talking

Melani Dizon:

About or they just don't know Parkinson's. Right. I mean, if that's,



Kristi LaMonica:

It's just it. Right. Don't know everything. He's a surgeon, you know? Yeah. Non-Parkinson, non-movement specialist.

Melani Dizon:

Right. Do you know the term ultra-creepier?

Heather Kennedy:

Why'd you call us.

Brian Reedy:

?

Robynn Moraites:

Excuse

Melani Dizon:

Me. It's

Brian Reedy:

Sounds like really creepy people.

Melani Dizon:

Yeah, no, it's the thing that like, because you're really amazing at something like a surgeon that you somehow can like transfer that to all other areas and you're not amazing.

Kristi LaMonica:

Not amazing. You don't, we don't expect our nutritionist to know, you know, how, you know, fix their car.

Melani Dizon:

And how to do surgery on the stomach. I mean, so it's, you know, when you have a doctor and like you said, Kristi, you just knew something was not right. Trust that.



Kristi LaMonica:

Ignored it for so long.

Melani Dizon:

Yeah. Trust it.

Kristi LaMonica:

I, you know, it's-

Brian Reedy:

Just my first, my first neurologist said, man, if you were 80, I'd say you have Parkinson's, but you're too young. And I was 45 or 47 or whatever. But yeah, I think the, it's the movement disorder specialist. You really have to find.

Melani Dizon:

Yeah, Heather?

Heather Kennedy:

It's almost as if we have to teach them. But I also want to give special thanks to those doctors and those helpers and everybody involved in medical field who do the research and who understand the complexities and really take their time with us makes a big difference. But to be fair too, it's like someone just mentioned they're just humans and they're all in their own silos, unfortunately. you know, and they also they have their specialties, but they also have areas within their specialties that they're good at. Like, for example, my first doctor was good until I reached about 10 years. Then he kind of fell apart. Like the wheels kind of came off like, what do I do with her now? you know, and then then some doctors are just good at programming or just good at, you know, one certain thing. So, but what I would also add, just as a, just a real quick note, another thing I wish I had paid attention to when I was first diagnosed, don't forget the rest of your body and your other doctors.

Doug Reid:

Yeah.

Heather Kennedy:

What can happen,

Kristi LaMonica:

Which is really difficult. So, being, being a female and being, you know, 43 years old, who do you talk to about what issues? You know, you know, when it comes down to gynecological issues, your oncologist isn't going to know about Parkinson's in most cases, so it ends up being really difficult to find care, appropriate care.

Heather Kennedy:

Yeah.

Doug Reid:

Kirsty had something in the chat about don't take me too seriously anymore. I kind of agree with that. Try not to sweat the small stuff and try to maintain a sense of humor.

Heather Kennedy:

Good advice.

Robynn Moraites:

I'm curious about Heather's comment about having to change doctors at about 10 years. Has anybody else had to change providers over time? Not just sort of the, I've got to find someone who can actually, I mean, I'm, I have four and five or my two neurologists, but they have been now for years. Did anyone finally they had to transition, like Heather was mentioning?

Kevin Kwok:

Yeah. I think it's really a good idea to get someone after about 10 years, to take a different set of eyes to look at you. Because one of the things that happens oftentimes is we become friends with our physicians. And that friendship can sometimes create a little bit of a filter on the way they see you and give you advice. So, I think I, the way I look at it is creating your dream team when you're first diagnosed. That should be your primary care physician, your neurologist, your chiropractor, your physical therapist, everybody. But over time, don't be afraid to swap it and swap out people on that dream team.

Kristi LaMonica:

Do you get those people to all talk to each other, Kevin?

Kevin Kwok:

They don't.

Kristi LaMonica:



Okay. I was going to say, did you figure out something that I wish that everyone knew how to do?

Heather Kennedy:

Imagine the right hand talking to the left.

Kristi LaMonica:

It would be amazing. Right?

Heather Kennedy:

It's like when you call customer service, you have to re-explain the whole problem to each person who answers the phone. Then they hang up and you have to start all over again. Right? It feels like that a lot. Like, like who's on first, you know? Yeah.

Kristi LaMonica:

Right.

Melani Dizon:

It's like just here, I'm going to give a little more voice to some of the people in the chat. Laugh at yourself because you're going to do some wonky stuff. Wonky. Yes. Just started reequipping and it is working beautifully for me. Y'all just scared me with your unanimous vote not to take an agonist. Why? So yes. Except for sometimes it works for people, right? So, this is one thing I am this is just a small snippet of people. So, if it's working for you, pay attention to that. Yeah, we do have some stuff on dopamine agonists. Sam, put some of that in the, in the chat. Let's see. I would've come out sooner. Yeah. I would tell myself pre-diagnosis, even when you suffer some pain, it's going to work out. God is always there. Didn't trust the depressive state and the depressing thoughts don't make any decisions when off and depressed.

Thank you. Something with coming out with PD happens automatically after a few years, Heather. Yeah. Believe in yourself, especially if your friends decide they can't handle being around you. Find new friends even as you mourn the laws of previously trusted friends. My, oh, Judy, my husband was diagnosed two weeks ago. Let's see, let's, let's help out Judy here and was put immediately on an agonist. Pam Perel. What are the issues with Take It and have been mentioned. Judy, just, first of all, we're sorry, two weeks. That's fresh. That's a lot going on and everybody on this call, they're ambassadors and are very willing to talk to you. So, we have an ambassador page and if you want to talk to somebody specifically, definitely reach out to them. We'll talk a little bit about agonists in just one second. I wish, and Victor.

Kristi LaMonica:



Counts manual for Judy. She needs to request it, can't.

Melani Dizon:

She? Yes, yes, yes, yes. Every victory count manual. We'll we're sending an email soon. This weekend. We got them printed. We're almost ready to ship. Yeah, I wish. I've been given written materials to read about Parkinson's. I was discouraged from reading anything. Told everything written was out of date. So don't even look. That's not true, Joan. Right?

Robynn Moraites:

That's not true.

Melani Dizon:

We update our every virtual account manual, and it is fully updated now. We also have a companion website so that nothing gets out of date, even the medication section. Okay, let's go back and talk a little bit. Let's talk about dopamine agonists. First of all, can somebody tell us, you know, maybe those of you who are put on it, like as the first line of drugs and then what happened to you and what you're doing now?

Brian Reedy:

I can speak to a little bit because I was talking about this with my MDs yesterday because I had written notes of all my previous stuff, and then at the top, I put a little banner, no dopamine agonist. Because when I was taken off the dopamine agonist, I told the doctor, I said, I really don't want to be taken off the dopamine agonist. It's my superpower. And she said, that's exactly why we're taking you off. Because it gave me more energy or more strength, but I was manic about it. I was building stuff all the time. I was not paying attention to my own home and with my wife and all of that. This was before she was sick though, but I was just like, I just had to keep building things and keep busy all the time.

Brian Reedy:

And I was just nonstop focused. And then there were the addictive things that you get that a friend of mine had with the purchasing. And he purchased planes model airplanes. And he said he had an entire room full of model planes in many of the boxes he never even opened. And so, I think a lot of people will talk to hear about the addictiveness of it, but it did amazing things for me. But I would never want to do that again because I lost too much of quality of life because of it. So that's my take. Yeah.

Robynn Moraites:

So, for anyone who's unfamiliar, dopamine agonists can, not always, but they can create the equivalent of like impulse control disorder and kind of neurotic addictive behaviors. It's not that the medicine itself is addictive, it's that it triggers the dopamine system in the brain, which is always active in the addiction cycle. Dopamine is great and it does some stuff for us across all measures. So do alcoholism is a dopamine dysregulation disorder, drug addiction to many drugs. It's a dopamine dysregulation disorder. And so, what happens though is not so much that people become alcoholics and drug addicts, the impulses that they start having trouble with are things like compulsive shopping, compulsive eating. I mean, I've met people who had co like you talked about Brian, like compulsive building. I've met a guy at a support group up in Massachusetts. He's like, I couldn't stop chopping wood.

Robynn Moraites:

I kept going into my backyard and chopping wood and he just couldn't, he couldn't stop. I met, I met someone at the world Parkinson's Congress, who does a kind of an online YouTube video blog with Parkinson's. She's like, I couldn't stop v blogging and blogging into the middle of the night. Also, there's some people who are very outspoken about sharing their own experience because it can create sexual compulsivity and people who, you know, cheated on their husbands or cheated on their wives, and they had never done that before. It destroyed marriages. So, there's a lot of baggage, I guess I would say with dopamine agonist. So, I think what's important is if your doctor has trying you out on one, just be really aware, of what's happening. That's all. Yeah. Really, really aware of what happened. Have

Kristi LaMonica:

Someone else check in to make sure that you're not doing things that are off the wall like

Melani Dizon:

That. Yeah. And it's great that you know, you're there with your husband who's, who's starting this medication and we don't want to scare you off of it because it does work for some people and some people have been on it a long time and they have really great experiences with it. So, it is not a, you know, hard No it's just a nod for many of the people on this panel because they didn't have great experiences with it. And the other really good thing to know about them is that that goes away the minute you go off of it. Right. Like it truly is just a drug induced situation. Right. Kristi and then Heather,

Kristi LaMonica:

I love the idea of the new ropinirole. So, the Rogaine patch, I love the idea that it's fantastic. I can't use it though because I'm really allergic to the adhesive. Mm. So when I was on it, I was just breaking out into, it would, it would itch, it would hurt, it would burn, and I'd get, I'd get

welts from where I had the patch each time, I moved it. So, I just couldn't take that anymore. Mm.

Melani Dizon:

Yeah, Heather,

Heather Kennedy:

And just to be clear, when I was first diagnosed, I was on another drug. And if you look up that drug, the first thing you see is lawsuit, lawsuit, lawsuit. Oh wow. And then when I switched to these other agonists, it worked better for me. And those took a while to adjust too. The deregulation for those is pretty rough. So, when we talk about how, like, no domine agonists, I think what we mean is with discernment, with checking in with your doctor a lot, with a careful deregulation, like go up slowly, go down slowly. We do have some horror stories in our myths. Not in this group per se, but just, I listen a lot to a lot of different parks, and we get all kinds of crazy stories. And you think that it'd be kind of like, you know, the sexy, dark set of Parkinson's. It is not pretty, it's not like the cool stuff, you know, like, oh, I went out and I had this great time, and I was so sexual and it's so wonderful and everybody had a great time. And then the end, oh hell no, it destroys relationship. It brings a lot of shame. We have enough shame; we don't need it. You know, so just make sure that you check in a lot. That's all.

Brian Reedy:

Just check-in. I would echo that. I think that's the big thing, is if you talk to your care partner, you talk with your doctors, you, the more you have that conversation, the less things can get dark or scary on you if, if you're very open about it. That's true with all aspects of Parkinson's, really. Not just the dopamine agonist, but you know, everything with, like, somebody had written in there that their psychiatrist said that anxiety and depression aren't part of Parkinson's. It's like, oh, I want to slap that guy. You know, but they are. Is it somebody?

Melani Dizon:

Yeah, someone says, my psychiatrist tells me my anxiety of repression is not because of PD because I had it 10 years before. My physical symptoms, need to take responsibility and find the right doctor.

Brian Reedy:

Yeah, good answer. But you know, it's what keeps that from being shameful because it shouldn't be period. And it shouldn't be because of Parkinson's. But what keeps it from being that way is by talking about it openly. The more you keep it closeted, the more you keep it away from anybody knowing about it, the darker it gets. Right. so, with all symptoms it's that

way. But yeah, definitely with the agonist, if you have that dialogue, it could work for you guys. You know, as long as you keep it aware and in check and you're working close, I'd say go for it.

Melani Dizon:

Yeah.

Robynn Moraites:

Mel, I want to say something else to the gal whose husband was recently diagnosed, because this was a piece of advice that I got from a social worker who specialized in Parkinson's. And I've said this before on this panel, but it was so helpful to me, and it's proven to be true. She said, when you first get diagnosed, it's like a pot of water on high, on full rolling boil on the front of the stove. As you learn about your symptoms, as you learn about all aspects of the disease, it's sort of like a pot of water boiling over. But eventually, that does go to a back burner, and it goes down on simmer. And for most of your rest of your life, you will have Parkinson's, but it will be on the back burner, on simmer. And there might be times when it comes back to the front burner to a big boil again.

But that will be temporary, and it will go back to the back burner. And I didn't believe her really at the time, but that has indeed proven to be the case. And by boiling over, I don't mean sort of just a bad symptomatic day. I mean, I've really only had a couple times since my diagnosis that everything, you know, post DBS, immediately post DBS while I was, you know, trying to figure out how to get the system programmed and what meds, if any, meds, hives, all that. You know, there was a lot going on. But for the most part, once that in it, but that I was not ignoring it. I was learning about things and taking a lot of responsibility where I could. So, I hope that that helps. And it's just, right now you're in a time when you're learning, learning, learning, it feels very overwhelming. But we're all sharing, you know, about dopamine agonists. But you know, with eight and 10 and 15 years of history behind us of learning, it's all hindsight's all 2020. It's like drinking from a fire hose, I think a little bit.

Melani Dizon:

Yeah. I like Wendy's comment. I want to share it. After I was diagnosed, I only told my immediate family. I didn't want people to know I was scared. Allow yourself time to process it and then when you are ready, tell a trusted friend. It was liberating. Don't be afraid to get involved in the PD community. It was scary to jump in, but the kindness support and information you can gather from others is strengthening and a great blessing in my life.

Heather Kennedy:

Nice.



Brian Reedy:

Beautifully said.

Melani Dizon:

And-

Heather Kennedy:

I just thought of something else that I wish I had known. I entered the support group, so wide-eyed and naive, like everybody's here to support each other. Ha the, that, you know, it wasn't like a normal subsection of like human beings and human behavior. And there were some people in there who were psychopathic. And when they came back around a few years ago in Facebook, I got out of Facebook so fast cause I recognized who they were, like I knew who they were. Then I started having this drug-induced psychosis moment where other people coming in, I thought it was them. And so, I would respond to them. I'm thinking that they were this kid from Oklahoma, he used to give everybody trouble. I won't say his name, I don't even know where he lived actually. Not really sure what he was about. But anyway, he came into the support groups, like, like a wave and just disrupted everything, the disruptor. And he did it for fun. He would, he would get people in arguments, and it was crazy. So, my point is, people are people. We're just here doing the best we can. Our commonality is one disease. We do have a lot of things in common besides that. But that's the initial, that's our only connection if you think about it. So do so. But we do it with discernment. I mean, I really put myself out there and, you know, look what happens on social media. Imagine that it's not always a kind place.

Brian Reedy:

So yeah. But at the same time, you found some great people and made great friendships through it.

Heather Kennedy:

Precisely.

Melani Dizon:

Yeah. I want to address this: Cheryl, she says, you all are scaring me. While I've been diagnosed with mild and early pd, and my neuropsychologist told me symptoms will get worse. One can die with pd, but not because of pd. I was diagnosed in June of 2022. Does anyone want to respond? Respond to her?

Brian Reedy:

It gets, it gets more challenging. I don't like the word worse, but yeah, it does get more challenging. The great thing is if you have a movement disorder specialist, not just a neurologist, but one who specializes in Parkinson's. A neurologist knows like 250 melodies. A movement disorder specialist is a neurologist who went and did a fellowship for two years or three years and is now specialized in seven disorders. So, they really know what they're doing. So, you get that first and it progresses, but so does the medication. Like when my doctor was talking about DBS yesterday, she was saying, you know, Medtronic has done it this way, but now there's others doing it this way and here's the things you're looking at. So, there's always changes. Dopamine agonists might even be changed a little bit more. There's always, always change. So, what we're saying might be scary because we're talking over, you know, 10 or 15 years, some of us.

Brian Reedy:

But there's always new information. But it's good to hear the scary stuff and kind of figure out where you want to go. But I'd also add, like, one of the things I didn't like when I was first diagnosed with, I didn't like being around the older people who were just like barely getting around. But then I went to rock steady with them and there's this guy who could barely lift his legs to get his knees up. And man, he tried so hard, and it just almost made me cry looking at him. And it gave me such fire in my belly to try to match his effort. So, you really can't judge any of this stuff. It's all different and it's really what's in your heart and where you want to feel and let it take you. Just don't let it take you down.

Robynn Moraites:

I want to speak to that. Also. When I was first diagnosed, I'm from a 12-step background, so I'm really believe in support groups and in my area. I went to a support group meeting that was at noon on a Thursday. And it did not occur to me the demographic of who was going to be there at noon on a Thursday. It was people who were 30 years older than me who could no longer work or drive. I ran from that support group vowing to never go again to any support group for Parkinson's because I felt like I was terrified. And a couple of years later, I met someone locally in another town. I was going back and forth between Massachusetts and North Carolina, and I needed to go to the Parkinson's support group to get some information or meet someone or do something. And I was really scared to do it because of my prior experience.

Robynn Moraites:

However, this was on a Thursday night at eight o'clock, and I walked in there and it was a totally different demographic. It was people like me and there was someone there who was kind of ended up being my DBS mentor. She came in and she said, look, everybody, it's been one year not a single tremor in my hands since she had DBS. And I realized all these people were still working, they were still driving themselves. They were mostly young onset. And so, you'll find your people, you know, those of us on this panel, we've been doing, this isn't our first rodeo.



We've been doing this for a while, but you'll find your people and you have plenty of time. I like your rodeo thing, Heather.

Brian Reedy:

.

Heather Kennedy:

I should have brought my hats.

Brian Reedy:

Well, and that's a good point about finding your people. I'm sorry to keep jumping in, but the conferences are really where I found my people. You know, I went to the Davis Phinney victory Summits when they had them. I went to world Parkinson's Congress and other groups that had these things. And that's where you get the better information and you also get more calmness because you can talk to the professionals, you can talk to people, and you'll find the community warms up. I think that's the one great thing about Parkinson's is we don't have any we're not trying to be somebody. We can only be who we are. And so, we quickly, there's no mask. We're all genuine and we make friends. Oh,

Heather Kennedy:

There's a mask.

Brian Reedy:

, there's the masked face. But

Melani Dizon:

Heather's giving us a tour of her. You can always paint painting. Yeah. Yes. You can always paint. Yeah.

Heather Kennedy:

I started painting with, with different materials and it's really fun and I made some neat stuff. So

Kristi LaMonica:

Always paint.

Melani Dizon:



Doug and then Kristi

Doug Reid:

I just sorry, I lost my train of thought. Come back to me. Okay,

Melani Dizon:

I'll come back. Kristi. Sorry, I didn't.

Kristi LaMonica:

Mean to distract. So, to go with the support group thing, so I just started a support group for women in my area and I by far am the youngest by like, at least probably 10, 15, maybe 20 years. And it's, I think that everyone has something to bring to the table. So, it's really fun so far. So, I first thought that I wouldn't really enjoy support groups with people that were much older than me since everyone tends to be older than me in, in local support groups. But now it's, I'm learning a lot. I'm enjoying hanging out with other women and learning what they have to bring to the PD party. I,

Doug Reid:

I seek out a, I seek out a variety of different support groups. I mean, this is one of many different formats, but I go to in-person meetings, I go to young onset meetings. I have the DBS meetings and I've joined DBS Zoom meetings from other parts of the country as well. And another thing I was going to say, I think it's very important to keep my finger on the pulse of my own effect and to really be mindful of how I'm feeling mentally and talk to someone when I'm feeling down.

Melani Dizon:

Yeah, somebody mentioned in the chat that it's really important for them to have a counselor on their care team and I think it's really great. I wish we, you know, I wish there were many, many more counselors, therapists, and social workers who specialized in people with chronic illness illnesses such as Parkinson's. But it is, I wouldn't say that if you can't find that to not work with a counselor, because, you know, therapists don't have to have that special knowledge in order to build a relationship with you. And sometimes that's the most important thing. So, for those of you who don't have a counselor or therapist, but have some, you know, issues related to mood disorders or just not even anything clinical, but just needing to talk to somebody that you want a sort of objective third party. It's a great person to have on your team, Brian.

Brian Reedy:

And along those lines, I met a gentleman on an airplane recently and he was talking about therapist, and he says, yeah, I thought I needed one, but I went to one and it was just such a horrible experience. And so, I thought I'd never do that again. I said finding a therapist or a counselor, it's like dating, you know, you don't have to settle with the first one. Find the one that works with you, works for you know, that meets your needs, so don't give up.

Melani Dizon:

Yeah, that's true. I mean, there, I mean, it's a pretty big role. It's a pretty big person to trust and it's actually more likely it's not going to work the first couple times. Just like dating isn't going to work. The first dates you go on with the screen could possibly go along. I have to say that I did get a couple of we did get a couple of emails about last, was it last month? We talked about singles dating sites with people of Parkinson's like match.com, Parkinson's. We did, I did get a couple of those. The dating just reminded me of that. Nelson, the PD party, so that's what this is. I don't on Sunday taught me their solution to skipping as I lost my skip a while ago. Welcome to the party. Yes. okay, Anne, I'm not sure how to message you. So, Sam, can you throw up the ambassador page, and then people, you can all go to that link and then you want to reach out to somebody, you can contact them there. Also, does anybody else have anything on this topic? And I thought, and then I thought it would be fun to ask a question to see.

Brian Reedy:

I wanted to just jump in on one thing that I don't think we've said enough of today that we said at the beginning, but we didn't really push. When I was diagnosed with Parkinson's, it first five years I went downhill, and I was on a cane. We were looking at getting a walker. My wife wanted to get a chair to help lift me up. I was just physically declining quickly. Then I went to the first Victory Summit with the Davis Phinney Foundation in Las Vegas. And my life changed because they talked about exercise, they talked about forced intensive exercise. And we came back home, and we found a physical therapist who actually knew more than just big and loud, but she knew how to work physical therapy and Parkinson's together. I went from a guy who could do one sit to stand in, in maybe three minutes to a guy who could do 25 of them in a minute and a half.

It's a matter of finding that physicality and working with it. Don't say I can't do it. Get the cans out of your head. Physical, physical, physical. Start with walking if it's just around the block or just down the driveway. John Ball, who has run marathons for 32 years with Parkinson's says he got a gentleman who was in their support group that found, kind of gave up and he was just sitting on a chair, and he couldn't even get to the other end of the house. They got him going up and down the driveway, then around the block and within a year he did half a marathon. So, trust me, physical is the best and the more you exercise, the better you are. And Davis Phinney's website has the best stuff on exercising and doing it with groups of people with Parkinson's in, you will rock your world.



Robynn Moraites:

I would say that in Europe it's the first thing they do is they immediately, as soon as someone is diagnosed, they immediately prescribe intensive physical therapy. And it's like in this country, it's like crickets. And because insurance dominates the market, you maybe get approved for 10, 10 physical therapy sessions a year after you're showing disability or something. So, you know, to the extent you can exercise due, a lot of us became really athletic after our diagnosis.

Brian Reedy:

Yeah.

Kristi LaMonica:

I had to pay a full specialist copay for every time I went for physical therapy for L S V T. Big a specialist copay for each time I went, which is ridiculous also to exercising. So, if you can't do something one day, that's okay. Don't beat yourself up. Do what you can. So, if you're not feeling it one day, try to do yoga or stretch or something. Or even just laying down on the floor and like corpse pose and yoga pose. That's totally okay. Just be kind to yourself. Be gentle for yourself and do something else the next day. Exactly. Move more the next day. You know, and,

Brian Reedy:

And even doing stuff in the pool, if you can't do it on land like I do, do it in the pool. Kind of warm saltwater pool in your community if you can.

Kristi LaMonica:

Right.

Heather Kennedy:

Heather? I was just thinking about this though. What if we would, we didn't go so hard at first, you know, what if we re for the long haul, you're in this for a little while. Look at us, just look at us. We've all had this for like, what, 10, 20 years? Some of us. Come on, you can do this if I can do it. Anybody can, right? Yeah, you don't have to. I love what Chrissy just said. Do yoga, do stretching if you can't do the workout. Yep. Yeah,

Kristi LaMonica:

You can't go. What if you're going harder? Looks different in like five years just because you've gained strength. Like Brian just said, his going harder look different after five years. Jimmy

Heather Kennedy:



Joy, Jimmy, Joy.

Robynn Moraites:

I also found a lot of, I also found a lot of support. If you can find a Parkinson's spin class or the Rock Steady Boxing or Parkinson's yoga class, those are my peeps. And that's like my primary support group now is people who are kind of, you know, being proactive where they can.

Brian Reedy:

And you're with people, you're socializing and that's helping your brain.

Kristi LaMonica:

So, I put that in the chat for Brian that the older gentleman in my rock study class on Sunday, I lost my skip a long time ago and I was watching them, and I learned what their solution was to skip, and it was awesome. It's almost like doing the polka.

Brian Reedy:

Oh, I loved it. I loved everybody in the group. Once I got over my thing, my fear of older people, because I was worried about looking like that picture that we always see, right? And it's like, no, the older people are so freaking amazing. They're so beautiful. They sing so happy

Kristi LaMonica:

They taught me, you know?

Brian Reedy:

Yeah.

Kristi LaMonica:

They have so much to give. Everyone has something to bring to the table. Exactly. You just have to listen, and we just don't listen enough.

Brian Reedy:

You have to get out of your head. That's the best thing you can do with Parkinson's is get out of your own head.

Robynn Moraites:



I loved Rock Steady when I was up in the South Shore. I'm going to just do a shout-out to Brett Miller. He's an ambassador with Davis Phinney. But when I was up there, when Brett first started the Rock Steady, we were all together. And I'll never forget this guy, Fred, the first time that he flipped like a heavy bag, the entire room stopped, and everybody started screaming. Yeah.

Brian Reedy:

Fred.

Robynn Moraites:

Yeah. Fred.

Kristi LaMonica:

It's like Parkinson's, CrossFit, you know.

Robynn Moraites:

Exactly.

Kristi LaMonica:

You do something awesome in CrossFit. Everyone stopped in Cheers, right?

Melani Dizon:

Oh, yep. You can do CrossFit too if you have Parkinson's. Yes, you can. I won't get on that one, so. Okay. Question for everybody in the chat. What are some topics you would love for this group to talk about in the next few months? Let's hear it. Wendy d p f has made a huge difference in my PD journey. I have people contact me all the time looking for information about pd. The first place I send them is to the D P F website. Thank you so much. It is Gold PD runs in my family tree. I want to show my children that you can live well and be happy with pd. Thank you to Davis Phinney and all of you who've used this.

Brian Reedy:

To. Thank you, Wendy.

Melani Dizon:

Okay. Cheryl says new treatment options. I know, I know. People have more ideas. Throw them in there. I love this group.

Brian Reedy:

I think there's, there's new treatments coming out in June. I don't know what they are, but there's supposed to be a plethora.

Melani Dizon:

Topic. Sleep ideas, foods vibrating gloves. Yeah, treatments. That's all-treatment stuff. That might be a good topic for us to, there.

Heather Kennedy:

You go. Can't keep it straight face with the vibrating gloves.

Brian Reedy:

I know. That's, I thought you would go there, Heather. I'm just like, oh, what's she going to say there? Heather,

Robynn Moraites:

Are you back on your agonist?

Melani Dizon:

Oh, lordy, lordy.

Heather Kennedy:

I'm talking about science fiction now. Never mind. You

Melani Dizon:

Know those, oh, this is a good one. Dealing with work when you can't afford to retire red light. Great. And so, and also if, you know, if you think of something later, just email me@blogdpf.org and we will evidence-based to PT approaches. Yep. Kristi has a whole lot to say about that. Let's yeah, we'll talk about a lot of treatment things in the next few months. Okay. And thank you all for being here as usual. Thanks, Doug and Kristi and Robynn and Heather and Brian and Kevin for your ability to come in for a little bit. And we will look forward to seeing you all. Next up. Oh my gosh, April, right? I think it's the 23rd, or maybe it's the week before that. We will let you know. And again, blog@dpf.org. I'm sorry, third Thursday. Yes. I think that's the 23rd, but it could be the one before that. Patty will be here. We'll be here. I think that's right. I think it's the 23rd. Thanks, everybody. Love you all. Bye. Thank you, guys. You're amazing. Bye.

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