



Living with Parkinson's Meetup

April 2023

Davis Phinney Foundation

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

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

Welcome everybody to the Monthly Living Well with Parkinson's Care Partner Meetup every third Thursday of every month. We're excited to have you here. My name is Melani Dizon. I'm the Director of Education and Content at the Davis Phinney Foundation, and I am here with eight awesome people that are part of the panel. We have a few that we're not able to make it here today but they'll be here next time. I am sure. So, you're all doing great in the chat. Everybody knows how to do this which is awesome. If you don't, there's a little icon at the bottom of your screen that says Chat, and you can click that and send us a message if you would like. I have enabled close caption. If you like to see the close caption, you can leave it as it is.

If you don't love it, then you can say hide subtitles. We will send out the recording and all the good stuff next week. And I think that's it for housekeeping. So, Samantha is in the background. Samantha Narciso, she's our program associate. She's in the background and she is going to be throwing in links for things that we talk about. I know for a fact that we have quite a few questions that we have sort of answered in one way or another in a webinar or an article. So, we'll share those as well in the chat if they come up. And then we'll also share them in the show notes. So, let's do a quick around the horn. You guys tell everybody your name, who you are, where you're calling in from, and let's see the most surprising thing that you've learned since your diagnosis about Parkinson's. I'm going to start with Kat because she made that face, okay.

Kat Hill (Ambassador, Davis Phinney Foundation):

Oh darn. Hi, I'm Kat Hill. I am currently in North Carolina. And I'm originally though from Portland. I've been diagnosed for almost eight years. What's the most surprising thing? That there's not a cure yet. How's that?

Melani Dizon:

Yeah, that is surprising. Robynn.

Robynn Moraites (Ambassador, Davis Phinney Foundation):

Hey, everybody, I'm Robynn Moraites calling in from North Carolina. I got diagnosed in 2015 at the age of 46, but once I understood the full constellation of symptoms, I had symptoms going



back as early as 2002, 2003. And I think the most surprising thing that I have discovered is that there either is an autoimmune component or one that very much looks like an autoimmune component.

Melani Dizon:

Interesting. Thank you for that, Kevin.

Kevin Kwok (Ambassador, Davis Phinney Foundation):

Hi everyone. Kevin Kwok dialing in from Boulder, Colorado. I've been living with Parkinson's since 48 years old. And so, it's been 14 years now. And what's been surprising for me I think that, like Kat, I'm amazed at the slow progression of research getting us to where we are. That said I'm very excited about the recent news on the biomarker data that just came out. And the new staging, the new staging, I think is even more interesting to me. For those who haven't listened to the Michael J. Fox podcast talking about this, I am now according to this chart, which is really allegedly complicated. I am now officially a stage five Parkinson stage.

Melani Dizon:

All right, Kevin, we have a, we do have a couple of questions about that, so I'm going to pose that and look forward to sharing a little bit on that. Doug.

Doug Reid (Ambassador, Davis Phinney Foundation):

Hi, everyone. Doug Reid from Lafayette, Colorado, about 15 minutes from the Davis Phinney Foundation office. I was diagnosed just over 13 years ago at the age of 36. I'd been experiencing a slight tremor in my left hand for at least a year or two prior to that though. And I had DBS in 2019, so just about three and a half years ago. And I'm doing great. The most surprising thing about Parkinson's I need to listen to my body I was skiing almost three weeks ago and didn't listen to my body when I was, it was trying to tell me it was tiring, and I fell and broke my leg. So, lesson learned.

Melani Dizon:

Lesson learned. That's why Doug is coming from a couch. He's, he's coming from his couch today. Tom,

Tom Palizzi (Ambassador, Davis Phinney Foundation):

Hi everybody. I'm Tom Palizzi. I'm in Ava, Colorado, just a little bit south of the office, and I was diagnosed in 2008 at the age of 48 years old. And let's see. I think the thing that that's most surprising to me is not knowing how many people out there actually do have Parkinson's. There is no real, there's no real data to support that, and that's something that we're working on. But



I guess the most pleasant surprise though that I've had to be the announcement this week of the biomarker discovery. It was, it was, it's been going in the works for a long time, those of you who are kind of tied into the research system, but it's still, it's probably the most epic thing to happen in the 15 years I've been living in this world. I mean, it has at the top of the top running on the ladder right now. So, we're making progress, so, sure.

Melani Dizon:

Yeah. Thanks, Tom. Kristi.

Kristi LaMonica (Ambassador, Davis Phinney Foundation):

Hi, I'm Kristi LaMonica. I'm from Troy, New York, and I've been diagnosed for three years. But as Robynn was saying that as soon as she knew the constellation of different symptoms, I really can go back to about 2014 when I started ignoring all my symptoms. And the prodromal symptoms really started in like 2005 during grad school. I think that I'm most surprised about that we still spend so much money on genetic testing for these mono genes when only 13% of patients are going to have one of those mono genes that are mutations. Why do we spend so much money that can be used for other testing to be done? We need to start focusing on looking at multiple genes and grouping patients into like symptom clusters. And I think that we'll see more and learn more there.

Melani Dizon:

Awesome.

Kristi LaMonica:

I just came from class, obviously, so.

Melani Dizon:

That's great.

Kristi LaMonica:

We should talk about it.

Melani Dizon:

So, Brian, oh, you're unmuted. It doesn't look like you're muted, but we can't hear you. We can't-

Tom Palizzi:



Laugh. Louder.

Melani Dizon:

Is your volume on your computer? Maybe the volume actually on your actual computer is not turned up. I'm going to go; I'm going to move for a second to Sree.

Sree Sripathy (Ambassador, Davis Phinney Foundation):

Oh, hey. Okay. So, hey, my name is Sree. I'm from California. I've been diagnosed since 2015, at the age of 40, but I had some symptoms a couple of years before in prodromal symptoms, meaning sleep issues and stuff for years before that. And the thing I find most surprising, a couple of things I find most surprising since diagnosis is number one, is how little information there is out there on some of these non-obvious symptoms we experience, like issues with vision issues with fatigue, and how to manage that, particularly issues with dyskinesia as a result of medication. That's a big problem for me. And the other issue that I've experienced is after I got diagnosed with Parkinson's disease, just in October of last year, I was diagnosed with ADHD officially diagnosed. And I find the interaction of ADHD in Parkinson's to be very interesting. And I've had ADHD symptoms since I was a teen. So, for me, that's very interesting how little research there is on those two-concerning result from a lack of dopamine in the brain at the very least.

Melani Dizon:

Yeah. Interesting. Thank you. Heather,

Heather Kennedy (Panelist, Davis Phinney Foundation):

I come to you from an airport. I'm on my way to do the talk in Grand Rapids, Michigan. And it's a little bit loud. Let me know if you have some trouble hearing, but I don't even know what the question was. It sounds like what.

Melani Dizon:

You're just saying who you are and where you are, which you said. And then what has surprised you the most since you've been living with Parkinson's?

Heather Kennedy:

Oh, that's an easy one. I'm quite surprised by my ability to think that everything is so fateful. Like, oh my gosh, I can't walk today. I'm doomed. I'm going to die, you know, and alone and sad and nobody will love me when in fact, everything's always changing. The dynamic nature, the mercurial nature of this disease is what's most surprising. So, I just want to remind everybody, whether you're new or you consider yourself old school, whatever you are, everything's



temporary. And when someone acts out too, nowadays, I just find it to be like, hey, did you check your meds? Rather than that person's being mean, you know, it's, it's all just flowed all the time. Flowing all the time. Thank you. Thank

Melani Dizon:

You. Thanks, Heather. Brian, let's try again.

Brian Reedy (Ambassador, Davis Phinney Foundation):

Okay. Can you hear me?

Melani Dizon:

Yep. You got you.

Brian Reedy:

Yay. Okay, so yeah, I'm Brian Reedy. I'm in Huntington Beach, California. I was diagnosed in 2010. Actually 2008. They said, oh, if you were older, I'd say you had Parkinson's. So, we won another two years because I was 48 at that time. But I think the thing that I find most surprising, I'm not sure somebody said this in the time I zoned out, but I, when we took over a support group, I was amazed at how helpful the pharmaceutical companies are at education and at listening to patients. I'd never seen that or heard of anything like that before. And I think that's part of why world Parkinson's Congress is so successful because you have so many entities involved in the education and the progression of knowledge. So

Melani Dizon:

Yeah, actually, Brian, I'm going to second that. I don't have Parkinson's obviously, but I will say that I had a very different view of pharma until I came into this Parkinson's world. And I too am just amazed all the time when I'm talking to all the reps from different places and there, they, so many of them are in it because they care so much about what's happening with other people. I, and I think that it was definitely surprising to me. The other thing I find very surprising, which Mary said, which I was surprised no one else said, and I bet all of you would agree, is she says, I find it interesting how little physicians other than movement disorder specialists know about Parkinson's. Oh, I was even misdiagnosed by my first neurologist. Thank God I went for a second opinion. So, I think that's true as well.

You know, you think a neurologist is going to, of course, they're going to know Parkinson's, of course, this is their field right? In some respects, and a lot of them don't, you know, for, they don't have the clients, right? Like, you, you as a doctor, you learn with the clients that you get, right. The clients that walk in the door. And so, but I find that super interesting as well. I love everything that y'all said. I think everything you said bears a question too, like, we're going to

get there. But I'm going to start out with this new biomarker because everyone's writing in about it. Everyone's asking the question. And Kevin, you have been participating in some of the discussions and as a pharma person, and I'll been in this space for a very long time, I would love to get your take on it.

Kevin Kwok:

Sure, yeah. I'm actually being invited to the PPMI investigators meeting in New York in a couple of weeks. So, I'll even have more to say after I return. One of the things that I've spoken to in the past is why does it take so long to develop a drug for Parkinson's? And one of the things we talk about is the complexity without having a biomarker. And what does a biomarker mean? Right? Well, the analogy that I used in the last conference call that I was on with a number of other patient advisors to the Michael J. Fox Foundation is that we really need to put this news and perspective A biomarker is a tool for a diagnosis with the eventual hope for a treatment. And what that means for us, if you have, for instance, if you have prostate cancer, PSA is a biomarker, right?

Cholesterol is a biomarker for cardiovascular disease. And what we now have with these alpha nuclei, which still requires a spinal tap to get a sample, is that we've now shown that we actually can validate early on patients before they have symptoms, they now have a marker to show that. And so, the analogy that I like to use for this is it's like instead of groping in a cave in the dark, which is the way research used to be done for Parkinson's, we now have a flashlight. And that flashlight doesn't mean we'll get out of the cave, but we certainly can see the crevices and the terms of where we need to go. So that part is hugely important in there, but not to take out a context that there's still a lot of work that needs to happen.

I mean, the fact that we have this flashlight, it's, it's like coming out of the caveman ages, right? But we still, if you look at prostate cancer, if you look at other diseases with biomarkers, there's still years of r and d that has to happen to move us into a what is a cure. So, I'll stop on that. But the other part to it that's actually very interesting is that various neuro movement disorder specialists are tying this biomarker to a staging of disease. So that was that piece of paper that I showed you earlier. It's a chart now that shows if you have an alpha nucleus in your blood, in your cerebral spinal fluid, and you have a positive desk, but you have no symptoms, that's called stage two. And there was the term prodromal used before. That's no longer going to be in our lexicon. We will talk about the early disease before symptoms, but with markers to try to get us there. And that's actually very important for the early stage for the later stage. Right now, we have targets to hopefully go after this alpha nucleus, but it's not yet proven that these reductions in alpha nucleon will actually result in the therapeutic benefit. So anyway, I can delve into a lot more on this as we go on, but I don't want to take this very important meeting to chat about that.

Melani Dizon:

Great. Well, thank you. Thank you, Kevin. Does anyone else on the panel have anything they want to share about that? Robynn?

Robynn Moraites:

One of the things that I found interesting when I was first diagnosed is I was reading John Pal's book *brainstorms the Race to Define the Cure for Parkinson's*. And one of the case studies he talked in about in there is there was a researcher who was able to get a bunch of brain tissue sample from people who had participated in some of his Parkinson's medicine study over the years. And every Parkinson's drug study had failed. And what the research showed is that 50% of the people who participated in the research it turned out did not have Parkinson's. And he, the researcher was just so upset. He walked away from research for a couple of years. But the reason I bring up that topic and the whole idea of autoimmune is that I, when I looked at that study, I w I'm a little bit nervous that it's going to turn out I don't have pd that I have some weird constellation of autoimmune disorders that presents the same as pd, but you're my peace You know, now that there's, I mean, I'm not going to be able to afford to get that test done for a while and until insurance covers it, but it could turn out that half of us don't have idiopathic Parkinson's. Because I think Parkinson's sometimes is also with this whole idea of not only doctors not knowing, but I think it's almost a catchall for any kind of a motor symptom. So more will be reviewed.

Melani Dizon:

Yeah. Thanks Robynn. Heather?

Heather Kennedy:

Can we talk too about the people who have shadowy syndromes or syndromes that aren't readily recognized, who don't have a name for what they have, who are constantly apologized, misjudged, projected upon, and people get out their DSN V, four, or three or nine or whatever on now and they, they, they give them an arm share diagnosis. And I think it, I think it's criminal what's happening to people. Criminal. No, we can point to Michael J. Fox and thank you. You know, we can point to Davis Spinney, we can point to all these people who forged ahead, and we can point to Kevin Kwok, who's the smarty pants in here. I'm going to sit here like this for a lecture next time. You know? And thank you so much, Robynn, for posting that. It really brought up a lively discussion here. Thanks.

Melani Dizon:

Great. Okay. all right. I'm going to start asking questions to see. And just for those of you who wrote in questions that were sort of very medical specific, need a doctor, we're not going to go with those. We're just going to go with the questions that people can ask.



Brian Reedy:

But we have Kevin.

Melani Dizon:

Well, but he's not an MDS. So, we're not going to put that pressure on him. But we will, we will talk about them sort of more generally, but we can't tell you like when you should up your meds or,

Brian Reedy:

You know, can I ask one question really quick? Because I think it relates to what Kevin taught. Kevin was talking about, wasn't there something also announced by Fox about being able to see something Parkinson's in the live brain this week?

Kristi LaMonica:

Oh, that was a while. That was, that was a while ago where they did the tr they had a tracer that they could actually, the changes and the, I think was Alpha Newland. I'd have to look back to see what it was. I

Brian Reedy:

Thought, I thought they had a new announcement. It was, I thought it in the last two weeks.

Kristi LaMonica:

We just expanded studies. Okay. So, there's already proof of concept data there from last year.

Brian Reedy:

Yeah, maybe that's, you know, Brian, you get the mail three days later out there in California and then it gets sucked into the earthquakes in a way as we get it two days late here.

Melani Dizon:

Okay. So, here's a question that is sort of a, several people asked a similar question. So, somebody I recently had a minor procedure done, this person said colonoscopy and it seems like my symptoms of Parkinson's got worse. Has anybody else had surgeries Parkinson's related, not Parkinson's related, and then they experienced some, you know, symptom, like more symptoms or complications or anything like that?

Brian Reedy:



Yeah, I had a couple.

Doug Reid:

Go ahead, Brian.

Brian Reedy:

Well, the first one was just coming out of the knockout juice, whatever. I had really bad tremors when I came out. And that's when I was in the first year I was diagnosed. But the last one, when they had to amputate the thumb three years ago, I had a lot of breathing difficulties because of the incubation, and they lasted for months. Mm. And they put me back on my asthma medication, which was the wrong approach, but it confounded the doctors. It just eventually went away. But yeah, it was.

Melani Dizon:

Did they, did anybody talk to you about potential challenges with anesthesia or surgery because you had Parkinson's?

Brian Reedy:

No. And I know that that conversation should have happened, but at that time I was in Reno, in my MDS was in San Francisco, which is why people are telling me I can't leave here because everybody's here. Yeah. Right. The area. So, Doug yeah.

Doug Reid:

Having just broken my leg and having two surgeries within a week's time yeah, my tremors were worse, I think just because of the stress of, and trauma of breaking my leg and having to deal with the hospital and everything associated with the surgery just had my tremor worse than it had been in years. Fortunately, I'm out of the hospital now in a low-stress environment and the tremors have subsided.

Melani Dizon:

Kat?

Kat Hill:

Yeah, I just was going to mention that my husband broke his leg, a similar fracture to Doug's, and my symptoms were much worse when he had his procedures. And I think both physical stress for us and emotional stress will really impact symptoms. So that's, that's been my



experience both as a care partner for somebody who had a fracture, but also as a person with Parkinson's, Kevin.

Tom Palizzi:

So, if I could add one thing.

Melani Dizon:

Oh yeah.

Tom Palizzi:

I have surgery scheduled for myself on May 31st this year, and I'll have to go under for that. And it's, I'm not happy about that at all, but that's the way it goes. But you can take some precautions to do that kind of thing. And there's a really good package put out by the Parkinson's Foundation called wear and care. And you can get these from, you can call them up and they'll send it to you. But that came from my doctor when she found out what I was doing and what was going to be going on, she goes, you need this, and fold up all the directions. And that was very helpful.

Brian Reedy:

Okay. I just remembered when, when they did my amputation, Lilly told them about the bad effect I had when I came out. And so, they did the nerve block where they push a Volkswagen bug into your arm just really painful, whatever that stuff is. They're like, holy heck. But then it was pretty good as far as weeks later not having the pain. And he did that because of what he had heard Lilly say about how bad anesthesia can be. So that's another option.

Melani Dizon:

Yeah. Great. Kevin, and then Sree.

Kevin Kwok:

Yeah, just a quick note on Cologuard. Saturday Night Live had a great smooth with Woody Harrelson on that than everybody watches that commercial. More importantly, though, the one of the conversations that I had with my neurologist at Sanford was every time I seem to get sick with a flu or anything in there, the symptoms of that disease get worse and so do our Parkinson's symptoms. And so, I think that we are more prone to sensitivity to almost anything that that brings on that stressor in there. And so, I think it's really ca for those of us that have other issues of, in healthcare, we have to be very cautious. And I think my guidance is, is that go to a neurologist that really understands all the other symptoms that can happen to you of DBS

because it's so important for them to coordinate that conversation with your pulmonologist if you have asthma or, or whatever other neurologic disease or disease you might have out there.

Melani Dizon:

Right.

Kevin Kwok:

I don't know. Others feel the same way when they pick up something that they get worse on both counts.

Tom Palizzi:

And it's absolutely huge important to make sure that the doctors that are on your team all know what's going on. So, my regular doctor knows everything that's going on. My neurologist knows, and my urologist knows. I mean, they all, they all talk to each other. I made sure that that happens. They're all in communication and so that, you know, and then, but then you have to be able to protect yourself, you know? Right. You have to know what your medication regime is so that they can provide that for you when you're there. And it's always good to have somebody there with you, of course, if you can, but.

Melani Dizon:

Great. Thanks.

Brian Reedy:

Well, I want to jump really quick on something Kevin said. With the, if you get a cold, you can't take regular cold medicine, you have to see what, there's a list of stuff with Parkinson's. So just said I hit that. Sorry to interrupt you.

Melani Dizon:

No, thanks. Thanks, Brian. Sree.

Sree Sripathy:

Well, I was going to schedule my neck lift for a couple of years, but listening to you guys, you've just saved me thousands of dollars, so thank you very much. Thank you. But I did have a question for everyone. When you go to the dentist and you have to have local anesthesia, so not general anesthesia, local anesthesia. Has anybody had experiences or issues with that? Because It's been a couple of years since I've been, which has been really bad. I know I should need to go, but I'm a little bit nervous about that in terms of is dyskinesia going to get worse. Or

when they inject the local anesthesia, you know, is it going to be problematic if I'm dyskinetic? I'm wondering if you guys on the panel or anyone who's listening has had experiences or insight into that?

Melani Dizon:

Anyone? No. Anyone in the chat? Oh, Kat?

Kat Hill:

Okay. I know that some of, there is some, I'm going to forget the med, Kevin, help me, mixed with lidocaine, the local anesthesia. It will make my heart, there's a little epinephrine in and my heart will get a little racier and I get more jittery. And that's happened for years prior to my diagnosis, which is interesting. So, I know that. And I have just shared that with my dentist when I got it. My dad was my dentist for decades. When my dad retired, I had to go to a different dentist and I said, I have this reaction to local anesthesia, even though it's just minuscule amounts that gets in your system. It really makes me bounce all over the place. Yeah. So, I just shared with them ahead of time and they're very good about making accommodation street. And sometimes I'll even ask for the leaded x-ray blanket to be put on me. That weighted blanket helps with some of those symptoms. They don't let me take it home. because sometimes that would be nice to have it home. But anyway,

Melani Dizon:

You need a weighted blanket. You take a weighted blanket in with you too, right? You can. And so, Karen says, yeah, it's called, well, she says what the name is, but there's an FNF and free version. Just ask your doctor for that version of it. Carbocyanine, they cannot use lidocaine. Okay. Epilepsy free. That's what Karen says. Okay. Okay. Awesome. Let me see. Okay. I think this is something we've talked about in the past, so I bet you'll all have some of something to offer. I'm a bit worried about my brain fog. I find it hard to remember proper nouns even. And I sometimes have to search for a word. What advice would you give to me? I'm super active and try everything I can. What do you do for Brain Fog? Sree.

Sree Sripathy:

Good. I just go with it. I mean, it's great when I don't have to remember things. So, I mean, it's, it's happened more frequently now, and my friends often help me out, but I have a list. So, I write down things in a case like you can't prepare for brain fog, but if I'm going to the grocery store, although I haven't been in quite some time, or if I'm going to do, for example, I'm a photojournalist visual photographer, whatever you want to call it. And recently I talked to one of my editor mentors and I said, I need to start writing down a shot list because when I go out on photo assignments, I am forgetting certain types of shots that I need to photograph, you know, like an up shot or this, and I'm just kind of forgetting certain things. And it's not, I don't



know if it's a brain fog because of Parkinson's, because I'm going to hit 50 in a couple of years because of perimenopause.

It's just whatever the reason is it's happening. So, I am starting to write things down, look at it before I go on an assignment, check on that list during an assignment, and then double check the list after an assignment. So that's what helps me having a list is really helpful. Whether, and I find that the list on the, like a cell phone doesn't always work. So, I do the cell phone list and I'm doing an actual printed list, whether I write it down or I find a printer and a piece of paper that's so archaic. I know. But I find that that's very helpful.

Melani Dizon:

Thanks, Kevin.

Kevin Kwok:

One pharmacologic intervention that I've been using for the last few years is the use of Ritalin or methylphenidate. I find low doses of that actually help me thinking, get greater clarity, and clear out a little bit of the fatigue. I didn't take one today and I'm slurring words a little bit because of that. But the other thing that I was turned onto more recently, which was, it seems, a little bit like voodoo, but cranial psychotherapy really helped my brain fog after covid exposure. And it was, I went to a therapist here in Boulder who just did basically a light touch to the scalp for about an hour. And then I just all of a sudden drove home feeling really almost like I didn't have Parkinson's again. It was kind of an amazing thing. And I'm not sure if that was a placebo or if that was really real, but I'm willing to try it more to see if it really continues.

Kat Hill:

And Kevin, who cares, right?

Melani Dizon:

I know. It doesn't matter. we actually, there's a woman here in Boulders very, very well known for that. I don't know if this is the same one, but she also can fix colic in kids. She does the cranial sac on babies, and it is miraculous. So, I don't care if it was what it was, it was, oh god, life-changing.

Kat Hill:

So, I sent patients with babies with colic to somebody in the Portland area.

Melani Dizon:

It's really nice.

Sree Sripathy:

I have a really quick add-on to what Kevin said. So, I took cranial sacral therapy years ago, and the person who did that gave me this recommendation to buy this kind of foam like thing that you place underneath your neck. It's almost like two tennis balls that are underneath your neck right at the base of where your neck meets your, whatever it meets, like right here. And I find that that might be helpful. So

Melani Dizon:

Yeah, you can get two cross balls and duct tape them together and then put them on your,

Sree Sripathy:

Or, you could spend a bunch of money like I did. And to me-

Melani Dizon:

Robynn, oh wait, really quickly, Sam, Samantha, we have, we do have an article on Ritalin, so you can throw that in the chat too for people who are interested in learning more about that. Robynn, go ahead.

Robynn Moraites:

I'll pre, I said this all time, but I'll preface it. Everybody's different and you need to know your own food triggers. I have very specific food triggers that cause me to get brain fog, which I brain fog, which I'm not going to list on the webinar. But if I get into an episode of brain fog, often if I pay a lot of attention, I can trace it back to something that I ate. So, I get really clean with my food. And I only eat anti-inflammatory things like a lot of kale, spinach, blueberries, and raspberries. And I'll just eat that for a couple of days. So that's, that's what I do. And so far, that has worked.

Tom Palizzi:

I do a lot of meditation, like, especially in the roll. Like, I'll be out and about, and I'll have a freezing moment or something like that if I just stop like myself, you know, just give it a second or two kind of reboot and then go on. I'm, it usually knocks out my brain fog fairly well.

Melani Dizon:

That's awesome. Thanks. Samantha, if you could throw the interview I just did with about meditation and mindfulness in the chat, that would be great. And just, we just posted it the other day. Kat

Kat Hill:

I was just going to say also being gentle with ourselves and lowering, lowering our expectations a little bit. All of us are human and even and putting yourself in a situation where you're nervous. When I get nervous, I tend to lose my words more. But I, but still putting yourself out there and just being gentle with yourself, I'm having a moment, you know, Parkinson's moment or a senior moment, or a mom moment, whatever moment you want to say. I think that's, that's important because the, you spend too much time beating yourself up after the fact for not finding the word. You know, it comes in the middle of the night. There's the word that I want,

Melani Dizon:

Right. Like, when you're in a fight with somebody and your ah, I should have said it right above, I should have.

Kat Hill:

Spoke. Yeah.

Melani Dizon:

Yeah. So, so-

Kat Hill:

Let's be kind to ourselves.

Melani Dizon:

Yeah. so quite really, I had a really interesting conversation with a woman a couple of weeks ago. She's been watching this for a really long time. She loves coming to this. Her name is Elaine, and she was wondering about she is somebody, she's a grandparent and she has Parkinson's, and she is now the sole caregiver of the grandkids. And wanted to know if there's anybody in a similar situation. I think that that's, you know, we brought up, we were talking about how there are so many grandparents in this situation that are raising grandkids. And especially with the, you know, increase in Parkinson's or at least the increase in knowledge about Parkinson's. There might be more people who are in that situation. So, if you're somebody who is in that situation, I just wanted to share this link. She would be super interested to connect with people other grandparents who have Parkinson's are, are doing this. It's just amazing that she's doing this work. Really young kids have been caring for them for a long time. And if anybody in the chat is in the similar situation, would love to know if you have any thoughts on what that is. So how, how do you deal with that?



Tom Palizzi:

We don't have any grandkids. So, I'm immune.

Melani Dizon:

Oh, this is, oh, sorry.

Kat Hill:

I'm ever hopeful. Yeah. Any of the kids are watching.

Melani Dizon:

Yes, exactly. This one is really fascinating, and I have to say, like, I bet you all have, I bet you all have experienced this before, but here's the question. How do you respond to people who are very happy to tell you about all the people they know who have died from Parkinson's? Oh. Or people that say, oh, that's, you know, this is terrible, and my uncle had this and it was awful. Like, what do you, what do you do when people say stuff like that to you? Sweet. I think it's a bigger conversation of like, what do you do when people say's the absolute wrong thing to you? Well, I mean,

Sree Sripathy:

I might cheekily say, well, you know what, when I die you can add me to that list. <Laugh>

Melani Dizon:

Sorry. And you,

Brian Reedy:

I think I, because I had it with my uncle older and my cousins all thought that I was going to go down that same road. And, and he lived with it for 10 years. And I've had it 12 now, or 13. But I just tell people things have changed so much in our knowledge of how to handle it and manage it and that the exercise is really helping a lot of us maintain better life than, than they had 10 years ago.

Melani Dizon:

Yeah.

Brian Reedy:



Really. I mean, because it was 12 years ago when I had had diagnosed and the doctor said, that's it. Your wife's going to be your caregiver for the rest of your life for that only did you 10 ago. That's, that's horrible.

Melani Dizon:

Yeah.

Brian Reedy:

So, it's changed a lot.

Tom Palizzi:

I don't know that anybody's ever really said anything like that to me. I haven't got you know, people ask me, are you sorry? Are you getting better? Do the medications make you better? Like, well, you know,

Brian Reedy:

Kind of, that's awesome.

Tom Palizzi:

You know,

Brian Reedy:

When are you going to get over your Parkinson's?

Tom Palizzi:

Right. Yeah, that's a good one.

Kat Hill:

Wasn't there a cure for that? I heard in the news that he's too young to have that.

Tom Palizzi:

Well, yeah, it was a Grey's Anatomy and an episode on that they were going to cure Parkinson's. I got all excited, tell everybody I knew that, you know, you.

Sree Sripathy:

Know, that's just, I, astonishing to me that people say things like that. I'd have to say I'm very lucky in that no one has said anything like that to me in the almost 10 years, eight or nine years I've, I got diagnosed with the same year as Kat. So however long that is since I've had this, I mean the one thing people will do is only in the past three to four years have they come to me and said, oh, I know someone has Parkinson's or my grandmother has it. So, more people are coming to me, letting me know. They know someone who has Parkinson's, which did not happen before. And other people will send me links or articles and I appreciate that. Sometimes it's a little overwhelming. So, I have to tell them sometimes, hey, I'm covered. I'm good. And sometimes I feel bad because I'm thinking maybe they'll send me something I don't know. But I just don't have the mental capacity or bandwidth to read through everything people send me. I really wish I did, but I don't. Yeah,

Kat Hill:

Kat, I think there's this tendency, people want to connect with you about it. And so, I will usually say, well, we're all going to die of something, you know, because it's a fact. And then, and then the SY symptoms that we're talking about, you know, there's this group of people that I like to call the fixers, and Nancy and I talked about this in our book, people want to help you. And they think that by sending everything that they see on Parkinson's or recommending, you know, the latest thing, whether it's from literally witchcraft to diet to this and that, they mean well by it. But I think, are you laughing Robynn? Am I cracking you up? <Laugh>? You know, I'm a midwife, so that's what they think people, you know, midwives do anyway. But anyway, but you know, people want to help us. And so, I think we have to learn a way to say, thank you so much for thinking about me, but I've got a really solid pa plan that I feel good about.

Kat Hill:

I try to just have those standard answers that I come back with because it gets frustrating. And I've had a kiddo with a chronic illness for a long time and everybody would say, well, you know, this type one diabetes, truly, somebody sent me an article about wrapping his feet and cinnamon. Now I had an eight-year-old kiddo that I was trying to give shots to all day long. And they meant well, yeah. But I was thinking, how on earth am I going to wrap up this kid's feet and cinnamon after negotiating all day over injections in his abdomen? So anyway, yeah, it's a common thing. People mean well.

Tom Palizzi:

Yeah. I got a side too. I'm sorry, Tom, go ahead. I had conversation with a guy I met and on vacation with him, he found out I have Parkinson's later on, he approached me when we were, we were separated from the crowd, and he talked to me about how he could get me into a stem cell research center in Mexico. And I'm like, oh yeah, yeah, they serve tequila too. But I didn't go obviously, but man, I was, I was, was just so stunned that the guy was that brazen about it. And he was so surprised that I was so ignorant of that. But also, so against that, you

know, I thought that that's not my, that's not my realm buddy. I don't think that I'd considered that. But anyway. Yeah, that was kind of strange. Yeah. Means

Brian Reedy:

That was going to say on the other end of the spectrum, sometimes we have people who will see us really off or really dyskinetic and, and then like an hour later we're fine. And then they start to question, you know, are you faking it? Because they don't know about the varying times when I was teaching that had happened. Because I'd be very Ming when I'm down the hall and there's all that stress of everybody and I'm walking down the hall just kind of really tight and just trying to get down there. And then they'd see me in the store a few hours later and they said, he looks fine. So, I think he's faking it. It's like, wow. They have no idea.

Melani Dizon:

Yeah.

Brian Reedy:

That's true. So that's the different realms of it. They're either trying to help or they're trying to be critical sometimes. So yeah. And I just let it go. What can you do?

Melani Dizon:

Has anybody and anybody on this panel had trouble with speech talking and then has actually gone to speech therapy. Somebody's asking and saying that like, they've tried it's not working. Do they just give up? So would love to hear some different stories on, on that, Kevin. And then,

Kevin Kwok:

Yeah, my speech is one of the biggest frustrations in my life as someone who used to speak for a living, right? It's taken away my ability to either get words out or even in general just to formulate the words. So, I feel like I'm always talking like I'm drunk and I promise you I didn't have tequila yet. Yeah. But the speech thing really is a problem for me. I think DBS can actually make it worse for some people. I'd heard that one-third of ds patients to pick up some kind of untoward speech effect. But there is something interesting that I recently participated in and that was an AI initiative between a number of different technology companies. This was Meta, Google, you name them, apple. They were all on a call to try to find tools like voice recognition and change in patterns to see if we could both diagnose patients earlier but also find ways maybe to actually provide tools for them. So maybe chat box will one day be replacing on the screen here.

Kristi LaMonica:



There's also, yeah.

Melani Dizon:

That's the speech accessibility project. Sam will put the link in their cause. I'm, yeah, exactly, participating in that. We're part of that with the

Kristi LaMonica:

I did that, I finished already. It was awesome.

Melani Dizon:

Oh good.

Kristi LaMonica:

So, I'm waiting for the day that my phone understands me and actually sends like real text instead of garbled things would make me sound like I'm crazy.

Melani Dizon:

Right, Ryan?

Sree Sripathy:

Yeah. So, I have speech issues and I did sign up for that Google study as well. But apparently, my speech isn't bad enough for them to have accepted me, which is frustrating because it's right on the border. So, it depends on when they're my message. They've

Kristi LaMonica:

I'm never going out to karaoke with you, Sree. Sorry.

Sree Sripathy:

Well, I mean, most people think my speech is fine, but if you knew me before I was diagnosed, then you will notice a, you would've noticed a difference. And so, I have speech issues and swallowing issues and unfortunately, these issues pop up at the worst moment, particularly when I'm interviewing someone or when I'm presenting or now that I'm doing all these webinars is when the speech issues of course show up. And I've actually been to speech therapy, which is why I have a very expensive medical bill that I have to pay off. And it, I, they make you go through all of these things, swallow tests and exercises and I've been to three to four different speech therapists and the protocol for getting through some of this stuff is quite

disciplined. So, if you're finding that there's not an improvement, I don't know what that person is doing or what they're working on, but for me, you have to do the work every single day.

Speech exercises as if you're like a singer every single morning, every single evening you're supposed to do, depending on what, you know, you get from the speech therapist exercises and then they give you stuff that you're supposed to do when you're actually talking all sorts of things. And for me, I find it quite embarrassing sometimes that I'm like, if I'm in a hotel room or in the morning or with friends, I'm like, I have to be like, yeah, I don't know how I feel about that. And then I think, okay, this is so stupid. If I was a singer or musician and this is my career, I wouldn't feel embarrassed in considering this is my life. Why am I embarrassed? So, I should just do the work. But I find that when I do the exercises consistently and regularly and when I'm calm and I'm taking deep breaths, my speech does get better. It's never going to be what it used to be, but it does get better.

Melani Dizon:

Yeah.

Brian Reedy:

Yeah. I had it right after getting diagnosed because I was still teaching, and it was really bad. And you know, there was a lot of stress trying. I taught for four years after being diagnosed still. But I remember the first one we got was a student, the first speech therapist we had was a student. She was so diligent; she was so caring and so hardworking. And it's kind of like what we've talked about or what I talked about recently with psychologists. It's like sometimes you have to go to a few different ones. So, I've had four different speech therapists. I had one who was just basically going through the speak loud book and she was wrote and she had no personality, and she wasn't encouraging. And, and that was horrible. The other three were great. And they really get you to Karen.

Brian Reedy:

And what you're saying I think is, you know, because you do the work, it's just like physical therapy. If you just do it there but you don't follow up, it doesn't work. And you know, the key is practicing it at home and stuff for practicing Lilly would make me practice it. But I remember being, I told her it's the most difficult thing I had to do. It was harder than any physical thing because it's, it's mentally torturing sometimes. I remember they flashed up a card and I knew the word, but I couldn't find the word. I mean, I knew I should know it and I; tears just came down my eyes and it was a pair of pants. Yeah. So, it's very frustrating, but you have to keep at it. And I got better. But then I had to do it again and then, you know.

Melani Dizon:



Yeah.

Tom Palizzi:

I point out something. Most major universities teach peach speech pathology and speech therapy. And the students are, they're graduate students usually. And they are always looking for people to help them learn so they can become better. Therapists, they have a lot of programs where you can just go down there into the university and they kind, they kind of use you as a test case. And, and they, you know, you get basically free speech therapy or at least it gets you some insight into that to help.

Brian Reedy:

Well,

Tom Palizzi:

I want to check it in.

Brian Reedy:

I was going to say they had me come and talk to the future students about what we need for speech pathology.

Melani Dizon:

Reno. Okay, great. We are, we have a couple more questions. First one, any suggestions about how to get out of a freezing episode, or as you know, being frozen? What are some trip tips and tricks that you guys use if you issue Kat?

Kat Hill:

I sidestep instead of trying to go forward, I just try to think to the side, you know, to the left, to the left, to the right, to the right. Do you know? Yeah.

Melani Dizon:

You like that song, right?

Tom Palizzi:

I work that works really well. Works really well. Yeah.

Robynn Moraites:

I've never had it happen, but I have a really good friend that when she would freeze, she would do a kickboxing move like a front kick. And by doing the kickboxing move she would be able to start walking again.

Melani Dizon:

Nice.

Kat Hill:

I love that. I'm going to try that next.

Tom Palizzi:

There's the imagine a line on the ground. You step over the line. And I know that's really difficult for me. Like when, if I'm walking along across a tile floor and the tile floor is diagonal instead of straight or perpendicular to my path. If it's diagonal, it doesn't work as well. So, in other words, if they look like big diamonds on the floor instead of big squares, I can't do that as well as if they're big squares. So that's when you step from square to square. Yeah. I don't know my brain. No, my brain doesn't do diamond. Very good. So

Sree Sripathy:

I had; I had a question I don't freeze yet. Knock on wood, but who knows when that'll happen. But I read somewhere that some people have a pointer, like, you know, like how when you're in school and the college professor has that pointer with a red beam of light, that there's a pointer that you can get that you turn on and then it'll just put a red beam of light right in front of you and you can step over that red beam of light. So, I'm not sure where you can buy that or, but I've heard that works. Yeah,

Tom Palizzi:

That does. That's the line, that's the step over the line part. It puts the line on the ground for you and it does work pretty well.

Melani Dizon:

Ka

Kat Hill:

I just want to say, I learned a lot going to the World Parkinson Congress and going to some of their sessions about the music too, listening to certain music and certain cadence as we move. And I just want to say, hey, the WPC is happening this year. I'm going to be a commercial some,



it's been life tr changing for so many of us that have gone to the W P C, and I wouldn't have met all of all y'all since I'm in the south sort of. And I just, you know, if you have an opportunity to go, go it's in Barcelona this year. It, we'll be meeting again in a few years. It just staying informed and checking out what people are doing. It's just, its life altering. So,

Sree Sripathy:

And you get to meet a lot of famous people like Kat Hill, Oh,

Brian Reedy:

Yes.

Melani Dizon:

Yes.

Brian Reedy:

Or Kevin

Kat Hill:

Or Kevin Clark. Yeah,

Sree Sripathy:

Kevin Clark. The man that missed the legend.

Brian Reedy:

I haven't, I haven't told you guys yet, but I'm doing the renewal room for le for yoga. Ah, it was a very competitive process. They said they'd tell us in a month, and it took him about three months to figure it out. So, I'm very excited because I learned it 10 years ago at the Montreal W P C 2013. And the gentleman, Peter Davidson who taught it, can't do it now because of voice changes. So, I wrote him as soon as I got approval to start telling people and I said, Peter, I'm carrying on your legacy. 10 years later I'll be doing it just like you did. So

Melani Dizon:

Awesome.

Brian Reedy:



That's also the beautiful and the power of that thing, you know, that we meet and see things and people and you can talk to doctors that have just given lectures and you can ask them questions or there's no conference like it in the world. I'm told that you can get patients that can talk to doctors and talk to physical therapists. I'm really disconnected, so I'm having a hard time today. I can't get You're

Melani Dizon:

Doing great Brian. You're doing great.

Brian Reedy:

I'm in a lot of pain.

Melani Dizon:

Oh, I'm sorry.

Brian Reedy:

Sorry. No, it's okay. But yeah, so I'm super excited we missed Kio, but I've been to the other ones.

Melani Dizon:

Exciting. Kevin, you look like you're about to say something. Am I right?

Kevin Kwok:

No, I was just going to say that I mean W P C changed my life. It really just allowed me to meet people like all of you on the panel and realized that I wasn't alone there. So, if you can go figure a way to get there, I'm still trying to work on travel because it's not cheap. But it's worth going. If you could make it'll be life changing will guarantee it.

Sree Sripathy:

Because of WPC. I met Kat and I would not be at Davis Phinney if it wasn't for WPC. So, I can pretty much with the surety say that.

Melani Dizon:

Go to p go to WPC, everybody. Go. Go. all right, well, I don't want to get into another question at this moment. Does anybody have any sort of final thoughts I'd like to share with the group? I appreciate everyone who did write in. We, we got to a lot we didn't get to all, but I'll also keep



them for, you know, days in the future. But does anybody have any final words they'd like to share?

Sree Sripathy:

The only thing I would say is like, if there's anyone out there looking for a connection and they're struggling, reach out to one of the Davis Finny ambassadors. They're all there for you. And, you know if they're not responding quickly enough, send them another email. Call Polly

Melani Dizon:

Yeah, yeah. Email me

Sree Sripathy:

And say, my ambassadors not getting me touch.

Melani Dizon:

Org,

Sree Sripathy:

But the Davis Finn ambassadors are all there to help and interconnect and, you know, make sure you reach out to yours.

Melani Dizon:

Mm-Hmm.

Tom Palizzi:

and the shameless plug for the Tour to Victory coming up May 20th.

Brian Reedy:

I'm

Tom Palizzi:

Going and Boulder, Colorado. Brian's going to be there. Yeah. Hey, Kevin. Kevin, you going to be there?

Melani Dizon:



Super fun ride.

Tom Palizzi:

Yeah. It's a lot of fun. We've got a lot of people coming from all over the country this year. Real exciting.

Brian Reedy:

It was so incredible last year. Just, just the people, the excitement and just, it doesn't matter where, what you're doing, it just being around everybody. Period. That's the best.

Tom Palizzi:

And Brian, turn it up on that Davis Phinney Foundation, trike the cat, trike.

Melani Dizon:

The outfit. It was all, the whole thing. It was a whole thing. And we look forward to doing that again. So yes, we will share all the links and everything that we talked about. You don't have to worry about any of that. The recording, the transcript, the audio, you can listen, watch here and in whatever way you want. And how can we touch base with ambassadors? It has let me, it's davisphinneyfoundation.org. And then if you go to that, I'm sure Sam will probably throw it up there, but it's Connect. There's like an I think there it's Yeah. Slash ambassadors. Yep. Everyone's there. You can search by topic; you can search by location. But you can reach out to any of them. So, thanks everybody for being here. Thank you. Kevin, Robynn, Kat, Doug, Tom, Kristi, Brian, Sree, and Heather for when you were able to be here. And we look forward to seeing everyone again on May 18th, the third Thursday in May. Thanks, everybody. Thanks.

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