



## Living with Parkinson's Meetup

### October 2022: Parkinson's is Hard

Davis Phinney Foundation

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

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

Hello everybody and welcome to our monthly living with Parkinson's meetup. My name is Melanie Dizon. I'm the Director of Education and content at the Davis Phinney Foundation, and I'm here with all of these super fabulous panelists. And we are going to introduce them in just a second. Oh, yay. Street's here too. Excellent. Okay, so first of all, I'm going to start off with a story before we get into everybody's name because I'm so happy about this. Madison, Wisconsin. Yay, Scranton, Pennsylvania. So, we were starting today, and I sent out the note and you know, we do this every, the third Thursday of every month. And a couple of people we thought weren't going to be here today. Kevin was, is supposed to be traveling in a car right now to Michigan and said he wasn't going to be able to be here, because being in a car is not the best you know, internet, it doesn't work out that great.

And then Heather is supposedly on her way to Washington, DC for a conference. And so, we thought none of this was going to happen. Well, these people weren't going to be here, and then they showed up and said they stayed, and they delayed their trips so they could stay here for this event on Thursday. So that makes me so happy. And I think that is a testament to how important this is for the group here. And for all of you who come to show up every month, it is just something that has turned into such a great family, and we are thrilled to be part of it. So, thank you guys for delaying your trip plans so that you could make it today. And let's do a quick real quick round robin for any new people who are on today. Let's just tell everybody your name, where you're dialing in from, and then maybe how long you've been living with Parkinson's. That would be awesome. And then we'll get to know you throughout the time. So, I'm just going to call who's on my wheel in order. Kat?

Kat Hill (Ambassador, Davis Phinney Foundation):

Hey everybody, I'm Kat Hill. I'm calling in today from Petaluma, California, but I'm really from Portland, Oregon. I'm just traveling the US and an Airstream.

Melani Dizon:

Awesome. And how long have you been living with Parkinson's Kat?

Kat Hill:



Oh, sorry. Since 2015.

Melani Dizon:

Awesome. Okay. Kristi.

Kristi Lamonica (Ambassador, Davis Phinney Foundation):

Hi, I'm Kristi Lamonica. Great to see you all. I'm from upstate New York and I've been formally diagnosed since 2020, but we know it's been longer than that, so.

Melani Dizon:

Thank you. Brian?

Brian Reedy (Ambassador, Davis Phinney Foundation):

I'm Brian Reedy. I'm in near Huntington Beach, California. I've been diagnosed since 2010.

Melani Dizon:

Thanks. Kevin?

Kevin Kwok (Panelist, Living with Parkinson's Meetup, Davis Phinney Foundation):

Hi everyone. I'm Kevin Kwok and I'm supposed to be in Michigan, but I'm right here in Boulder. Been living with Parkinson's for about 14 years now.

Melani Dizon:

Thank you. Robynn?

Robynn Moraites (Panelist, Living with Parkinson's Meetup, Davis Phinney Foundation):

Hey, Robynn Moraites from North Carolina. I got diagnosed in 2015 at the age of 46, but when I understood the full panoply of symptoms, I've been living with it since my early thirties.

Melani Dizon:

Thanks, Amber. Welcome to the panel by the way. We're so glad to have you here today.

Amber Hesford (Panelist, Living with Parkinson's Meetup, Davis Phinney Foundation):

Hi, I'm Amber. I am in El Paso, Texas. I was diagnosed in 2018, but I've been living with it for probably eight or nine years.



Melani Dizon:

Thank you. Heather?

Heather Kennedy (Panelist, Living with Parkinson's Meetup, Davis Phinney Foundation):

Heather Kennedy. And sometimes I wonder if I've had this almost 20 years since the first symptoms I now know were Parkinson's or. for what? My daughter was born, my youngest, but I was only diagnosed approximately 13 years ago. I'm just so grateful to be here. Oh, I'm from New York, but I live in Northern California now.

Melani Dizon:

Awesome. Thank you. Doug.

Doug Reid (Ambassador, Davis Phinney Foundation):

Hi everyone. Doug Re9d. I'm zooming in from Lafayette, Colorado, just outside of Boulder. I was diagnosed in 2010 when I was 36, and I had DBS about three years ago.

Melani Dizon:

Awesome. Thank you. Is that the real amber? Yes, that is.

Amber Hesford:

Hi Chris.

Melani Dizon:

Hi. You're muted.

Sree Sripathy (Ambassador, Davis Phinney Foundation):

I'm Sree, I'm from the San Francisco Bay area. I was diagnosed in 2015, so I've had this for maybe seven to eight years now. But my first symptoms showed up in my twenties as non-motor symptoms.

Melani Dizon:

Great. Yeah, so it sounds like everybody here has their official Parkinson's, and then the many, many years that they were like, something's not quite totally right, but certainly not a thing that they diagnosed at that point. I would think that most people on the call have a similar experience. Today we kind of threw out there that we were going to talk about some hard things because this when I asked the group what do you guys want to address today? We had

we threw a few things out and a couple of people mentioned just some of the big challenges they're facing right now, and I think it's important to talk about those when they happen. And so, we're going to, we're going to go for that. I'd love for those of you in the chat if you feel at all comfortable sharing maybe what is a challenge for you. And then we will address these as we go on. But I think I'm going to have Kevin get started because Kevin was one of the people who prompted this discussion. And you definitely have some insight, some thoughts, some experience to share. And, since you, you know, delayed your vacation, we want to absolutely hear from you. So, take it away.

Kevin Kwok:

Thanks, Mel. You know, the struggle that I'm currently having is that we're entering, I personally am entering a new stage of Parkinson's. It's almost like a midlife crisis Parkinson's, right in the beginning. You kind of get by with just moxie and grit and muscle through things. But unfortunately, I'm getting to the stage now where all of those tricks that I used to do aren't working quite as well. You can tell my voice is really, really high, pitched up, because I can talk and the symptoms that I used to just ignore are becoming more and more prevalent. And so, this topic today really hit home for me is how do we enter into this new phase? And so, I'm curious to hear if others in this group have entered into a similar stage of life or just dealing with at their stage of where their diagnosis is.

Heather Kennedy:

Sometimes we feel like we've been dropped off in this unfamiliar place, you know, often like, like our pockets are turned inside out. We don't know where our wallet is, we're in this unfamiliar place. And when I have these off times now, that's how I feel. I'll be walking along through my day, minding my own business, not in a particularly sad mood or anything. All of a sudden I just drop off completely complete paralysis. It's actually kind of terrifying. And I've tried all the things that bump us up to them on time. But as we go through these stages, having had it for so long it's shocking to me still that this is happening. Yet we expected this. Like what did I think was going to happen that I'd become more fluid over time? And so, there are new ways to manage, and I will, I will say one thing, I should have been slowed down. I was moving too fast. I'm not just talking about my lead foot. I really, I really feel like slowing down is not such a bad thing. But when I try to cram too much in, it reminds me I'm pretty advanced in this disease more than I care to admit. So, I really like what Davis said. Davis Phinney said that he can really only do, you know, choose one thing a day or maybe two things a day. Sweet. We, have discernment after all these stages. What do you think, Kevin?

Kevin Kwok:

Yeah, you know, my neurologist used to say that Parkinson's is the curse for you Type a. She, her comment was, even in rest and vacation, you guys are constantly on the moon and this whole aspect of Parkinson's is in some way the curse to slow you down. But rather than taking



it as a curse, if you take it like you have Heather as a maybe a silver line blessing, it, let's be serious. Now, none of us think that Parkinson's is a blessing, but we have to survive. And this is what I'm trying to cope with at the moment.

Brian Reedy:

Yeah, Kat.

Kat Hill:

Yeah. And I think, excuse me, that the part of what seems to happen is that you kind of reach a plateau somewhere where things are working, or you feel like you can manage, or your meds are working well. And then there's the shift. And so, each time there's that shift, there's the new loss of, oh gosh, okay, that's what I got, I've got to accommodate and shift and change again. I remember when I was first diagnosed, I started taking out watercolor classes to try to learn to slow down and, to get my mind off of what I was doing. And then my hands got very dystonic, and I know Kevin can relate to this. And I felt like, oh my gosh, I just learned this new tool that, that was kind of keeping me positive and my mind in the game. And then I was like, Then I had to shift and learn how to do it differently. And so, one of the things I shifted and learned how to do differently, thank you, Heather is that you know, I've, I've learned how to write, I wrote a book, it just came out this week. Thank you, Heather.

Never in a million years did I think I would have a voice that someone would want to listen to. Much less read more about. But I never wish Parkinson's on anybody. But I'm going to quote Kevin now. And learning to pivot becomes an art with chronic illness. It becomes an art and that the symptoms are testing and they're pushing, and we just can't give up. You know, I guess that's all I can say.

Melani Dizon:

Anyone else?

Brian Reedy:

I think I might chime in and say, I think that, as things change as I'm more aware of how awkward I am in conversations when I can't find words that I at least track of the conversation or something, I tend to exile myself more from doing things in public. And that's not a good thing to do, but that's something I'm noticing now that I'm doing and it's not helping much at all. So got to get back on track to something better, but don't want to be overwhelmed.

Kat Hill:

Brian, how do you do that? Like, you're showing up here, but, and that's awesome, but how do people keep jumping in back into their lives? I'm curious, what



Brian Reedy:

Do you mean by jumping back in?

Kat Hill:

Well, it, you know, you, I feel that same way. I can't speak the way as the same way that I used to or engage the same way. So, it gets scarier to go out. How do you make yourself get out and do it?

Brian Reedy:

That's what I haven't been too good at. So, I have friends who call and want to do things and I find excuses. And I'm starting to embarrass myself. So, I'm realizing that's why this conversation is good because it's something I've been thinking about. But hearing you guys talk about it, you know, it's just awkward being different. And I'm in a community where I don't know anybody now because I just moved here six months ago. And so, they don't know much about how Parkinson's is, and I'm just amazed that they keep trying to do things with me. So, they haven't gifted up on me.

Kevin Kwok:

Brian, they always call you.

Brian Reedy:

Yeah.

Kevin Kwok:

And if they don't, we'll call you. There

Brian Reedy:

You go.

Melani Dizon:

Right, Doug, I think you were going to jump in.

Doug Reid:

Yeah, I was empathizing with Brian where he said he sometimes can't find the words. I used to be a very social person and loved telling stories, love making people laugh. And I find that the brain fog and the inability to find words, I talk a lot less. And I also live alone. And so, some days

will go by where I've hardly said a word to anyone and then I'll start talking and I'll notice my voice is kind of raspy and I just need to use my voice more, I think. So, it's good to be on a panel like this and good to speak up.

Melani Dizon:

Yeah, because I mean it Sree, and then go ahead.

Sree Sripathy:

Yeah, I found that I push myself too hard and sometimes I forget that I have Parkinson's, not that I can forget, but I took on a job that actually challenges all the symptoms and side effects. I'm a full-time photojournalist and I just started in June of 2022 after being in tech for 20 years. And my doctor told me, especially my neurologist at the time, told me, well, I don't want to prevent you from doing anything that you want to do, but just be aware that stress is going to exacerbate your symptoms. And yes it did. And so, what I found myself doing was thinking, okay, I'm still 22, I'm still 28. I can compete with my co my colleagues in my co-fellows, most of whom are all in their twenties or late twenties or early thirties without any, you know, neurological, or physical conditions whatsoever. And I realized after a really difficult weekend, working three days that were like 12 to 13-hour days that I could not do that, my body just shut down.

And I was out of commission for two to three weeks, missed a lot of my deadlines, and I did manage to get summer again. But I thought, oh my God, I am not the person I used to be. And that was really hard for me. And it happens in stages like, you know, you lose your ability to swallow, you lose your ability to speak. And then I start crying at the most random things. I'll say hi to somebody, they'll say hi back. And I just start crying and I'm thinking, what is going on with my emotions? This is just crazy. And I can't do that when I'm interviewing someone. So, what I've learned, and I'm still trying to put into practice is that I have to slow down to be able to do my job because, and if, if I don't slow down, then I'm definitely not going to be able to do my job. And trying to compete with people who are 20 years younger, not, it's not competing, trying to keep up, be like people who are 20 years younger than me or re-try and be the person I wasn't, 28 is not feasible anymore. And I think many people, whether you have Parkinson's or not, go through this as you age, you just keep forgetting. And I just have to find the little graces now. So, I always make sure to carry water with me because dehydration is a big issue and sometimes I'm talking to somebody and then my face just freezes. My lips don't move properly. It's like I can't get any words out and they're just looking at me. And if I tell them, oh, I have Parkinson's, they don't care. They don't know what that means, it makes no difference to their life. So, I have to really do a lot of, I hate this word, but self-care. I have to do a lot of self-care and I'm just really learning how to do that now.

Melani Dizon:

Yeah. Sree, I think that's, it's really interesting there are, you know, all of you work because I know how much work all of you do. It's incredible, for what you do for what you're going through. And some of you I know are also still sort of full-time in the non-Parkinson's world, right? Like there's just like Amber and Kristi and Robynn and Sree. And can any of you relate to what she said about keeping up and like that feeling of Yeah? All of you? Okay. I want to hear from all of you. Great. Kristi, I think you had your hand up first and then we'll go to Amber and Robynn.

Kristi LaMonica:

Oh gosh. This week has been just for my job. It's a week of advising for students too. So, I have my normal duties advising students. All the other duties that I've just kind of taken on for stuff. I'm also organizing all of the students in our PT and OT programs to do the L S V T big program. So, I've just been at like eight o'clock at night. I fallen asleep like every night on the couch at eight o'clock at night and I just have ignored all texts, all emails, whatever. And it's okay, I'm just, that's what I have to do this week. But can I just really quickly address another, I saw a comment up in the chat about mental health and being on medication. I don't think that anybody should worry about any stigmas for that because think about it, we're our brains aren't functioning correctly anyways. Our neurotransmitters aren't working, right? So how can you expect for your serotonergic system to be working correctly if your dopaminergic system isn't working correctly? There are all these feedback loops that we know little about, so it's okay if your depression and anxiety kind of go hand in hand with Allis, so that's okay. Reach out, feel free to talk about it. Let's chat about it, let's not be afraid to worry about our mental health too, but let's all first say sera tonic and dopaminergic together. because I was so impressed that you those out of there. So

Melani Dizon:

I love those words. We have a chemical, and it's like a storm in our brains of like chemicals that are not balanced correctly. So, it's okay to need a little extra help to get them balanced. That was personally one of my first symptoms was intense anxiety. It's just because my brain doesn't work. Right. And that's okay. Yeah. So

Melani Dizon:

Amber?

Amber Hesford:

I think I relate, but I have not learned how to slow myself down. I think I'm overcommitting myself to a lot of things. Just really wanting to immerse me in the Parkinson's community. But I





do still have a full-time job where I'm a manager at a credit union and I'm a single mother raising two boys. And so, I haven't learned how to pump the brakes on that. And I don't know if I can, I feel like if I do if I slowdown in any sort of way, it'll stop me. And then I'm still also trying, basically working another full-time job doing TikTok. So, I'm my cup runneth over.

Melani Dizon:

Yeah. So curious, do you notice any time when like you're, you are extra overloaded that your symptoms are getting worse or your medication still? Yeah. That's what happens. Oh

Amber Hesford:

Yeah, absolutely.

Kristi LaMonica:

Daily. And-

Melani Dizon:

So how do you, how do you deal with that?

Amber Hesford:

I don't feel like I deal with much of anything. I feel like I just push through. I don't feel like I'm like coping properly with anything. I make a lot of jokes about it and, you know when people are noticing those things, I'm, you know, I know Brian, I think you were talking about slowing down and drawing out of things and I'm like pushing myself in and I'm talking more than I ever have before and I'm like really putting myself out there in a way that I never had prior to Parkinson's. So, it's a completely opposite effect for me. Not necessarily the right thing to do. Sometimes I think I've lost my mind doing it, but I don't know how else I would be managing Kevin. Yeah.

Kevin Kwok:

And can I brag for Amber for a second?

Melani Dizon:

Please do.

Kevin Kwok:

Amber has over 90,000 followers on you are just the master of getting the word out and the tribe is, is spreading the message so much because of what you're doing.



Amber Hesford:

Thank you, Kevin.

Kevin Kwok:

And you're funnier than all get out

Amber Hesford:

Well, you are my competition, so...

Melani Dizon:

Yeah, you're about to have a lot more followers. We just put your TikTok up there. It's all over Now.

Heather Kennedy:

I followed and I mentioned the Y OPN network two that I do the podcast with Mike Q and he's the one who first found Amber and was like, you've got to meet this person. So, we really own Mike. Thanks. And the only reason I'm on that radio show is that Mike Akin lost his voice once he had DBS. So, I actually ended up replacing Mike. But we still talk regularly. And one of the biggest problems that he has is just his brain is going much faster and his processing is going much faster, just like Amber's brain. But you know, then his speech, so the speech isn't caught up. And so, people don't pause and let him speak sometimes it's really frustrating. You know, people like Amber, me, and many people here, we speak at lightning fast. Like, I'm from New York, I want to get it all out of a, you know. But I think it's important to take that pause when we're among our people to know that we all have different speech challenges too. And so, I want to add that back in. And I think you addressed that in one of your videos, Amber, from my recollection. But if you haven't, we'll do it together. It'd be fun.

Amber Hesford:

Yeah. I couldn't even tell you, Heather

Heather Kennedy:

so much work. Thank you

Melani Dizon:

Kat. And then-

Kat Hill:

I also, I can appreciate Amber, that feeling of the going a million miles an hour. I want to go as fast as I can for as long as I can and fit as much in as I can. I feel this sense of urgency with living and life and it's partly why I'm living in an Airstream trailer. You know, we sold everything we owned and our hitting the road because I still feel well enough to do that, you know, minus the last 10 days of Covid. But, you know, other than that I've been feeling great and, but I do, I feel this sense of urgency and I think that that, while Parkinson's again is not the gift, like I don't wish it on anybody. It did give me in some ways permission to put myself out there in ways I might not have otherwise. Like, I hear you, you talk, you know, maybe this, that, that's a little bit of flash curse. Yeah..,

Melani Dizon:

Yeah, Robynn.

Robynn Moraites:

Sure. I'm kind of still in the phase where I can bluff it really good and muscle my way through. I loved when Kevin said that last, last month. But I have to pace myself internally. I know, like she mentioned in a comment between the group when we were emailing, I have a pretty good sense of where my own limits are and where that horizon line is going to be. So, I'm pretty good about pumping the brakes before I hit that horizon line and go over the deep end. I remember one of the surveys was like you know, as your symptoms progressed, you have trouble communicating your thoughts. And I thought, what an odd question. And so, one day I was like, oh, this is what they mean. And for me, it wasn't even about word finding, it was just like neurologically processing, trying to communicate something was really difficult.

Robynn Moraites:

And I find that that happens to me. It is so diet-dependent, and I, you know, and I think I'm a little bit whistling in the dark. I don't know if I am, I kind of hope that I have more control over this through a diet that I maybe actually do long term. But I can tell you this, I know when I eat something that's not good for Parkinson's, because it is like, I am trying to walk and think and speak through molasses, and I'm the phase I'm getting to right now, Kevin is, I'm behind you in the sense. But it is a phase where sometimes I can't hide my symptoms anymore. I can't disguise them, I can't bluff my way through, and things are more visible, and I get really self-conscious. So that's kind of where I am at with it. And it's interesting because I've given myself permission to tell people now, and we were at an event the other night with some friends of friends and everyone said, Go, go around today, and say, what was your greatest thing today? What are you most grateful for? And, without hesitating, I said, I'm most grateful for the fact that I had a really good symptomatic day today because the day before had been a molasses day. And I think everyone at the table, they knew I had Parkinson's, but I think they were a little bit taken aback and it was like, I just want to be transparent because there was so much misunderstanding and non-understanding about it.

Melani Dizon:

Yeah. Robynn, I knew this was going to happen as soon as you said the word food, everyone's going to say what kind of food. So, we definitely, there's not like one diet for anybody, right? Like, this is, it's such a personal thing and people try different things, and they react to foods in different ways. But I do think it would be interesting, Robynn, if you feel like sharing, you said, when I eat something that's not good, for Parkinson's. So, for you specifically, what is it that you eat that gets you in that molasses state?

Robynn Moraites:

Sure. A lot of people have emailed me about this, and it is so individual. There are people who are vegan. A lot of vegan foods affect me badly. I can eat steak. A lot of people with Parkinson's can't eat steak. Some of the foods that are really troubling for me are legumes. Things that are seemingly healthy and innocuous, like hummus. I can have a little bit. But we went to a Mediterranean restaurant, and I had a lot of hummus, and I was nonfunctional the next day. So that happened to be, that happened to be hummus that day.

Melani Dizon:

Yeah. I think it's really good you know, just a reminder to notice, you know notice what's happening in your, in your symptoms and you might look at sleep and work and stress. But hey, you can look at the food too. Yeah. I think you had your hand up.

Sree Sripathy:

I did, but I forgot what I wanted to say. Okay.

Melani Dizon:

Sorry. Not leave it to me to just bring up the problem, right? Like,

Sree Sripathy:

No, that's I think I think I might remember, but it touches just touched upon what Kat said and what Amber was saying a little bit, is that I am also pushing myself because I feel like time is of the essence, right? I do not know how my disease is going to progress. I don't know when the next functionality loss will happen, right? Right now, like the fact that speaking requires more effort, swallowing is a bit of a problem that for me is tough to deal with. But I work at it, I just take smaller bites and I have to really focus on my words, but I want to do as much as I can, you know, which is why I sit on a non-profit board. I'm doing the photojournalism, I'm doing all these things, but I also have to remember, I am not going to be able to do them well if I don't take care of myself.

Sree Sripathy:

And that is something I still really struggle with. And the other thing is, whether it's brain fog or, my belief that I have ADHD, whatever it is, or Parkinson's or executive dysfunction, juggling all these different things is hard for me. So sometimes I have people email me and I'm like, oh, they emailed me. I should email them back two weeks later. I'm like, wasn't I supposed to email that person back? So, I have trouble remembering now more so than I ever did before, all the responsibilities I have. And then I try and write them down and I'm like, Okay, I'm going to write them down. And then my hand gets tired writing them down, my fingers cramp, and then I'm like, maybe I'll type it and then my tremor sets in. So, it's almost every solution possible has a difficulty related to Parkinson's disease. So that's all I wanted to say. Yeah.

Melani Dizon:

Did you, so when you had said that you kind of went through this long period and you were so overdone, and you ended up kind of crashing and not getting some of your deadlines? Have you put anything in place since then to say, hey you know, maybe not as many projects at once, or what have you done? I'm sure,

Sree Sripathy:

Well, the thing is my boss and my, my boss and my employer are fully aware that I have Parkinson's disease. I don't know if they know what that means exactly. I think very few people truly understand what that means, even within the Parkinson's community as well. But they are willing, they're saying take rest. You know you don't push yourself so hard. I'm the one who's pushing myself hard because I'm thinking, I want to prove that I can still do this with Parkinson's. And I, you know, I want them to believe that they made the right decision in hiring me that I won this fellowship, you know, and nobody thinks badly of my work, but it's the own expectation that I have of myself that because of the problem. Other people are willing to give me leeway or make allowances, you know, I'm very blessed in that aspect, but I'm thinking I can still do it. I can still work as fast as I did at 40 or at 28. And it's a constant struggle as the disease progresses to realize that I have to accept what I can no longer do, and I have to change the way I go about doing things. And I'm not sure if anybody else feels that way. I don't know if you ever fully accept it. I still am in shock that I have Parkinson's disease. It's been almost eight years, you know?

Melani Dizon:

Yeah. Thank you. So, we have the hands up, Kevin, your hand was up, and then Kristi, Doug, and then Brian.

Kevin Kwok:

Yeah, I think we're hitting on the theme here that really is central to all of us, and that's the theme of really knowing our limitations and being our own worst competition. You know, any time I'm posed with a question, do you want A or B? And B is more strenuous, I'll always pick the, to my own detriment, right on there. It is just something that's, that's how I'm wired. And maybe that's a Parkinson's wiring some of this sort of craving for domine, craving for the thrill, you know, that's out there. But it's something that I, that, that I think of we all have to come to grips with. And it's that ability to sort of cut things off and recognizing it's not just recognizing, it's recognizing and accepting that there are limitations, and they will be more limitations coming down the road.

Melani Dizon:

Right, Kristi?

Kristi LaMonica:

So as Troy was talking, I was thinking about this and I'm like, I am forgetting stuff left and right. But I have all my students reminding me what to do, so I'm taking advantage of my environment. So, I don't even recognize it until you're talking about it, that I forgot to email people. I forgot to post a homework assignment up. I already have students emailing me. So, I'm using my environment to make sure that I'm getting stuff done, which if I didn't have them, I wouldn't be able to get it done, you know?

Melani Dizon:

No, luckily for you, students rarely keep their mouths shut.

Kristi LaMonica:

Right?

Melani Dizon:

Right. You're just going to say all the things.

Kristi LaMonica:

Right. And Robynn, I was so amazed when you were saying, talking about hiding your symptoms. I never, I don't even think I ever had a chance of trying to hide my symptoms working with health science people. I think they called me out way before I even know what I had. So, I've just had to just, I've just kind of went with it. That's,

Melani Dizon:



That's kind of a blessing.

Kristi LaMonica:

I go and speak to every class. I can teach them everything I can. So again, then now as though saying I'm working on a breakneck speed to make sure that I'm getting as many students signed up to do Ls, b t certification, do this, do that to help all of us that it's like, it's a big circle, so thank you. But right. They'll, they'll remind me what I need to do.

Melani Dizon:

Doug

Doug Reid:

Three mentioned something earlier about learning self-care and I just think that's so important. To me, I have an ongoing relationship with depression. And so, for me, self-care is a lot of doing activities that I enjoy and make me happy and will get my mind off of being depressed or having Parkinson's. If I'm feeling lonely, I'll go to the gym. If I'm feeling depressed, I'll hop on my iPad and play some word escapes. Just healthy activities that I enjoy doing.

Melani Dizon:

Yeah, that's great. Brian?

Brian Reedy:

Oh, I was just going to say, when, when listening to Sree and Amber and talking about the overworking Kristi, I was a high school teacher when I was first diagnosed and was a very passionate high school teacher. I was teaching video production and we were doing national grants and just amazing programs. And I was really kind of in denial, you know, it's like, oh, okay, that's what I got. And my wife was reading up on what Parkinson's since I didn't want to hear a thing, I didn't want anything in my head. I just wanted to go. And I was open with the staff and open with the students and made jokes about it, giving students extra credit if they could come up with a really good joke. And I just plowed through and tried to keep all my passions going, but I found I was coming home and getting more wiped out.

So, I got more student aids. You're allowed one student a semester. I got six a semester by the time I got to my fourth year with Parkinson's and teaching. But I still tried to keep everything going, but it's things got worse and harder. I had facial blindness. I couldn't tell what student I was talking to when they were right in front of me. The tremors were worse. Everything was worse. And one night my wife came home, and she worked at the school library. And so, I got home before her. She got home and I was just in bed, and I was frozen. I couldn't even move to



get up and give her a kiss. I bet she just wasted. And she just broke out in tears. And that's when I knew I'd been pushing too hard and doing too much.

And so, I gave my two weeks' notice the next day. And sometimes it takes us to have others show us how badly we've pushed and how much we've been in denial. And I think it's important to listen to those around you and those who love you when we're, we are dealing with this because there's so much going on in our heads and our bodies and the changes, and you kind of want to blow past it because you still want to be who you've been and have that passion. But there are recognitions and that's what I love about the group because as things got harder, I didn't know how to do things until I found a beneficial exercise was when I went to my first Victory Summit. And since then, I've continually learned from the group. So, I think, you know, for everybody who's on this platform and listening and watching and participating, this is how you get better at it, and this is how you work through the things, and you see you're not so alone and so crazy.

Melani Dizon:

Yeah. Thank you, Brian, Heather, and then Robynn.

Heather Kennedy:

And-

Melani Dizon:

Reason hand, just because there are so many of us. Just raise your hand so that I can remember. I'm sorry. Okay. Thanks, Heather.

Heather Kennedy:

Cool. I wanted to jump in a bit about what Brian was saying and add to it. Many of us are holding tremendous grief outside of Parkinson's, including the daily losses that we struggle with. There's a lot of shame involved. There's a lot of, someone mentioned mental health issues as Kat gently reminded me, she helped me through a time when I was absolutely psychotic. I was being bullied online, some things were happening, and my drugs were not the right ones. There were two major medications that were causing me to sort of go off the deep end. Many of you remember it. I mean, I really had to get off social media because the real world became odd to me. And then I would get on social media and it became a little too real and my mind would take off with these stories. Then when I changed my meds and talked about it to a therapist, I realized what was going on. So, I just want to put in a plug here for self-compassion. We're just human beings. We didn't study for this test. I don't know how to do any of this. It's unfolding in public before eyes when we're advocates and activists. So, I want you to get a





picture of yourself as a baby. Maybe you're not flipping the bird in your picture, but I'm giving everybody the middle finger when I was born.

Melani Dizon:

Oh my God, that is-

Heather Kennedy:

I want you to know-

Melani Dizon:

Was that Photoshopped or is that real?

Heather Kennedy:

No, it's a real picture. This is the real look. This is right under my mom's album.

Melani Dizon:

Oh my God, Heather,

Heather Kennedy:

I asked her for a baby picture, and she sent me this. She's like, you were always a little bit of a rabble-rouser. So, but, have some compassion. Think of the baby with the people that you're having trouble with too. They don't know about Parkinson's if they don't have it, you know? Aw, I love that one. Oh my. Excellent. That is great. Yeah, so just, you know, and Kat talks about this lot too. Thank you. Everyone has mentioned this.

Melani Dizon:

Thank you so much. That's awesome, for having. Robynn, you're going to, I just want to mention one comment that I have to read. Somebody Cindy says, my husband has his Parkinson's. I appreciate these forms because it helps me understand what he's experiencing. And for all of you care partners on here, I'm seriously going to start crying. You are amazing for being on here. I cannot thank you enough for listening and being open to listening to everybody with Parkinson's to learn about them. That is the best. So, thank you so much for being here. Awesome.

Brian Reedy:

Can I interject one quick comment about Care Partners that I love?

Melani Dizon:

Sure.

Brian Reedy:

I learned this as being a care partner and also that you're like Fred Astaire and Ginger Rogers. The person with the melody is Fred, the care partner is Ginger Rogers. You're doing everything. The other person is doing backward in high heels and a dress.

Melani Dizon:

Oh yes. So good. So good. Thank you, Brian. Robynn.

Robynn Moraites:

Sure. I was going to say that the other thing, the other strategy is that I'm really willing to ask for help more and more and more. And I came on a series of deadlines. I used to be able to multitask like a ninja, I mean like a ninja. And sometimes I'm like, Heather, how are you doing this like ninja chat while we're talking? I mean, I can barely read the comments. She's like, you know, knocking them out. But I hit a bottleneck with deadlines, and I was completely neuro-cognitively overwhelmed. And Kevin, that was the day I reached out to you, and you weren't available. And I reached out to Amy, who's a former member of this group because I just felt like I needed to talk to someone who had Parkinson's who would understand what it was I was talking about that this wasn't just, you had a busy day.

This was like, I'm at a bottleneck. I'm so overwhelmed, I can't, I know everything. I have my list of lists of things I need to do and I'm staring at the wall because I can't get any of it done. And just talking to her for a few minutes really helped. And we made a game plan, and I went on a run the next morning and I started functioning better. It's always exercise, right? It's what I always have to do is exercise, but just, you know, being willing to ask for help. And in that whole process too, I reached out to a couple of my staff members and said, hey, I've gotten this far with this, can you please kind of take it the extra 20%? I've got 80% done. Can you take it over the finish line? And they were willing to do that. And I still have like lots of deadlines, but I just had them all converging at once

Melani Dizon:

And it was too much for me for the first time in my life. Wow. Well, that's so great for asking for help and something good came of it, right? Not usually the bad thing that we think's going to happen when we raise our hand and ask for help. Amber, you had your hand up a little while ago.

Amber Hesford:



Yeah, I think I had a bunch of things on every, so I know diet was talked about. I also find that, sorry guys, but when I'm menstruating my symptoms are so much worse. And I think that's something that is very, very under-talked about and it impacts me the most. And I know because a lot of people that have Parkinson's are not still menstruating, but there are some of us out here that do post-its, which have taken over my life. That is how I try to remember all the things. I find that I can't put it on my phone. I can't put it in anything electronic because that's put away. And so, unless it's in my face constantly, I'm not going to remember it. And as far as Care Partners, I want to give a shout-out to Kevin's. I got the opportunity to meet both of them in person during the relay for the Brian Grant Foundation. And Kevin has the most amazing care partner in all of the land.

Kevin Kwok:

I'm a lucky guy. Yeah.

Melani Dizon:

You're a lucky guy. Thank you, Amber. Kevin, you had your hand up, and then, and then Heather.

Kevin Kwok:

Yeah, you know what, at this stage that I'm in, you know, I I'm an athlete who wants to be, you know, in my mind I still think I can do stuff that I can't do. And that's been sort of hitting this wall now were the one thing that I did that used to get me feeling good was exercise. And I'm feeling like I can't get on my bike on the road because it's not safe and I can't run anymore, and I can't do these certain things. And it was really kind of getting me down, you know? But it was, it was interesting the other day I was invited by a DPF to go visit the Wahoo Science Center here in Boulder. And we did a virtual ride together where we got to raise each other in DPF uniforms. Right. And I have to say that that was so much fun being in a peloton in a pack and just being able to feel like I was part of it again.

So, shout out to Wahoo and the people who use technology and did allow us to get back in the game. Because that just reinvents me more than I can tell you. The second thing that reinvents derates me, and that's the reason why I changed my trip, is this conversation. This conversation is the best. I can't think of a better therapy than getting together with fellow Parkinson's friends and brothers and sisters just to share our frustrations and our ideas and knowing that you all know what we're going through. I don't have to explain it because I get the nod of the heads just by saying stuff. So, thank you all. It means a lot to me.

Melani Dizon:

Thank you, Kevin, Heather, and then Kristi.



Heather Kennedy:

I just wanted to mention someone who was asking about the adaptive housing that I mentioned. We're hoping to talk to someone in DC even during the All-in Summit about how it's massively affordable for everyone in our country to do this because it would be huge tax breaks and also huge take some of the weight off the healthcare system and the loneliness that we have when we live alone. So, when I talk about adaptive housing communities, I mean like a building that's all on a single floor or those old but empty businesses that are gutted. We could really work on this. And I don't mean to change the subject here, I want to go back to the mental health portion, which is what this is all about. We don't need to be isolated. We don't need to be put away in some home, a nursing home. We need to work with each other, support each other and realize that we're still valuable. We have a purpose, meaning like, you know, there's a reason we're here and I think these could, these could really thrive, and people are living longer. So not just for Parkinson's, but we could of course choose that. That's kind of what I wanted to share. Thank you.

Melani Dizon:

I love it. I hope that that is the reality in the future for sure. We would change the way we treat older people, and sick people, and everybody would be happier and better served. Kristi,

Kristi LaMonica:

Even if that's not reality, Heather, I hope that we take advantage and make sure that we are part of our community and that we come together like this in lots of different forms and lots of different places because it's so very valuable to be together. Like at the leadership forum. Can I just hook up just to do some work on one of our other committees and it was just fantastic to be together even if though we were just working, we were doing work and it was awesome to be in the same room at the same time and just fantastic. But I just wanted to mention, so how we were talking about hormones a few moments ago, that there's an awesome survey out through the PD Avengers that's in through the Fox Institute on our Fox Insight, sorry. That is for women. It's just I highly recommend everyone go and do the survey. If you haven't and you have Parkinson's, it's going to be very insightful once we get all the portions out. And it's, part one is out, it's female health and home life. The next one's going to be about menopause, perimenopause, and post-menopause. So, we want everyone's viewpoints on that. And then ending with pregnancy and stuff like that. So.

Melani Dizon:

Great. Thanks, Kristi. And Sam, if you happen to find it before we go off, you can click the link. Otherwise, we'll share it in the show notes for sure.

Kristi LaMonica:



Thank you.

Kat Hill:

You can find it on the Fox website. Kristi and I, Kristi's been really, really instrumental in writing a lot of that, so thank you. Kudos.

Melani Dizon:

Yeah, good job. Does anybody else have something that I didn't call you, you had an Okay, great. Brian and Robynn.

Brian Reedy:

So, we've kind of hit a bit of on depression and Parkinson's. And that's something that really when I about three years ago I had started having suicidal ideations and that blew me away because I lost three students to suicide during my first three years of teaching and then spent the next 17 years teaching about positivity in the face of adversity. So why was I having these thoughts? Why was I beating myself up that I'm no good and all of that? It just, it was mind-blowing. And this was before my wife died from cancer two years ago, so it was just three years ago. And I found that the moment I talked about it because I woke her up at three o'clock in the morning because I was making plans and just sharing it with her took the weight off.

But the more that I talked about it with my MDs with people on the Davis Phinney Foundation group and reached out, the more that became understandable. And then hearing Dr. Hamilton talk about this in a recent webinar that we've had here, that's the first time I've heard somebody talk about suicidal ideations. And I'm struggling back now with that. And the thing I'm finding is I need to just keep telling people, so it doesn't get the power because I fear feel I'm hardwired not to. But why do I keep going to those thoughts? Why do they keep getting into my head? And you know, it's kind of what I think Kristi was alluding to earlier about, you know, the lack of dopamine and stuff like that. You know that there are things that can take over when we don't have that feel-good.

Whatever that the dopamine anymore. Yeah. So, it's important to acknowledge that this is part of the disease, but it's not uncontrollable. It's something you need to talk about. It's something you need to reach out to or help with. I'm having them again. So, I just talked to my psychiatrist the other day and I did not want to do this, but he's upping my medication because I can't get to a counselor yet because I'm in a new place. But talking about it helps. So, I just wanted to broach that and see if anybody else wanted to talk more about that. because it's really important.

Kristi LaMonica:



If you need anything, Brian, I'm happy to talk anytime. Thank you for sharing. I think that's, it's nothing, it's our brains. Yeah, it's our brains and it's all, it's, it's okay.

Brian Reedy:

Yeah. No, I honestly don't think I'll do it, but just why do I keep thinking about it? You know, why does this keep reoccurring?

Kristi LaMonica:

It's just like yesterday I was just in a really dark place for a little bit and in the afternoon then it was just, then it was okay. I think our brains, the circuitry that just, nobody fully understands it. Exactly. So, I think that there's still so much to know and so much to learn that. Sree?

Sree Sripathy:

Yeah. I have thoughts like that often. I'm not sure if it's a prodromal, prodromal, I can't pronounce these PRs anymore. They're a little bit tricky. But thoughts like that. And the other day I was driving, and I thought, what if I just drove right off this edge, what would happen? And I thought, Oh, that's a dangerous thought. Be really careful with that. And so, I reach out to friends a lot. I have a WhatsApp group, I have an iMessage group, I have a, on Twitter, there's an amazing Parkinson's community worldwide on Twitter. I mean, you don't have to have a public account, you can have a private account, but people in Europe, in New Zealand all over the world. And so, at any time of the day or any time of the night, if I'm feeling lower depressed, I can reach out to somebody on Twitter or even on certain Facebook groups and talk to somebody.

Interesting. So, I have, I have to reach out to people because I am also single and I don't have, and while I do have a family with me, it's being single is tough, but at the same time, time, even if you are with a partner, that partner cannot beat everything to you. Right? That is a lot to ask. So, you really do need to build out your system and your network. So, I did that as soon as I got diagnosed. So, there are many communities out there, many people out there. Find your people and if you need help, you know, the Davis Phinney Foundation can absolutely put you in touch, and talk to an ambassador. There are many resources, but the most important thing I found is to let people know where I'm at mentally and to say, hey, keep a watch out. Keep a lookout for this. You know, check-in.

Brian Reedy:

Yeah. That is pretty cool.

Kat Hill:

I think it's really brave. Brian. Thank you. Thank you for bringing it up.

Robynn Moraites:

And I want to comment on something between both what Brian said and what Kevin said about this inner critic dialogue that we have going on in our minds all the time. And whether it's we think we should be doing more or whatever, we need to give ourselves a break and be nurturing to ourselves and to recognize that voice when it's barking at our heels. And I know that when I, before I got diagnosed, I used to run this event, and Heather talks about this a lot, but I did the event and I was like, what the heck is wrong with me? Because to say that I was exhausted or stressed after the event doesn't even capture it. And I would take a three-day weekend and think, okay, I've had the weekend to relax and recuperate and by Tuesday, you know, I was as wrecked as I was Friday. And I have had to learn this kind of internal mindfulness, energy management modulation kind of situation. And whenever I'm having a bad day, it doesn't help anything for me to say, you piece of blah, why can't you? I go, oh, okay, this is Parkinson's. I'm having a bad Parkinson's day and that's it. I don't beat myself up. I don't self-flag. And I think it's really important that we learn those mindfulness techniques to comfort ourselves. That's the only way I can explain it.

Brian Reedy:

And breathe.

Kat Hill:

And breathe. Keep breathing. Yeah.

Brian Reedy:

Well, and even I was talking with my physical therapist yesterday and they were talking about just the importance of breathing and all these new focuses on with mindfulness or whatnot, but that there's so much within just breathing exercises that are mentally positive or nurturing to us. So, it's interesting.

Melani Dizon:

Yeah. Heather, and then Kat.

Heather Kennedy:

Also, just really quick, I wanted to mention Linda K. Olson, she's a triple amputee who then got Parkinson's. She spoke in Kyoto at the World Parkinson's Congress. The reason that I bring her up is because when she had this accident, she didn't think that her partner would come back. When he came back into the room she's like, I know you're just going to leave. He's like, no, no. I was designing a backpack. That's what I was doing. And then he said, you know, I would marry you. I didn't marry your arms or your legs. If you can do it, I'm with you. I can do it. So, I just



want to say, we are not in the bargain bin. We are not people who are not worthy of love and full rich life. We all seek wholeness. And so, let's keep going in that direction. We can do this together. We can't do it alone. Do it together. So here we are. Thank you.

Melani Dizon:

Thank you. We have a, we also have a talk from Linda Olson she did. We'll put that in the show notes. It was so good. So good. Kat, oh, Kat, going to have to get going.

Kat Hill:

Yeah, I can't follow that. That's hard to follow. I just wanted to say, I used to have fantasies that, that I'm not a smoker, but that, that I would learn to smoke so I could have a smoking break. So, what I started doing when I was working was giving myself a breathing break. And so, it worked. It's like I went outside, and I took, not at the smoking section, but a bunch of deep breaths and that really held me in good stead. So, when I start thinking about like, wanting to take up that kind of habit again, I think, oh, it's time for more breathing. It's time for more breathing. So, what a great group thing that is you all feed me. You all feed me.

Melani Dizon:

That's a pretty perfect note to end on. I think. When in doubt, breathe, it's just going back to breathing, right?

Kat Hill:

Yeah.

Melani Dizon:

Oh, thank you all so much for today. The hour went by fast as always. But we're going to be back again next month for sure. So please and please reach out to us at the blog. I'm going to put that in here. I have trouble, I can't even do it at the same time as I talk. So, reach out to me at [blog@dpf.org](mailto:blog@dpf.org). And we will be here Thursday, November, I think it's like the third. And we'll send the show notes to the recordings and everything. Thank you so much. Thank you, Amber, for joining us today. Thank you, Brian, for joining us, The New People. And we hope that you'll come back because this is a super fund group.

Kat Hill:

Thank you, Sam.

Melani Dizon:





And I hope you can all make it back. And everybody's safe travels. DC Michigan, the bobblehead, everybody. Yeah. Oh, everyone's got to wait.

Kat Hill:

Everybody's Got a dog.

Melani Dizon:

I'm going to show my dog. This is them. All right, everybody, thanks.

Kat Hill:

Thanks, friends. Much love to you all.

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