



Living with Parkinson's Meetup

January 2023: Hope and Optimism

Davis Phinney Foundation

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

Polly Dawkins (MBA Executive Director, Davis Phinney Foundation):

Hello everyone, and welcome to the Living Well with Parkinson's meetup for January. I'm Polly Dawkins and I am the executive director of the Davis Phinney Foundation. And we are glad you all are here, and we are glad all of you panelists are here to join us today. We are excited to kick off the year, the year being 2023 with a topic of hope and optimism. And it's great to see all of your faces here on the screen since it's been since December, no November since we saw you all here together for the benefit of our larger community of folks joining us would you start off in the panel introducing yourself and where you are calling in from and maybe in the spirit of the sort of hope, maybe share one thing you're looking forward to in 2023. Does that work? All righty,

Kat Hill (Ambassador, Davis Phinney Foundation):

Sure.

Polly Dawkins:

Who would like to start, or would you like me to call on you? Kat?

Kat Hill:

I'll kick it off. I am so happy and grateful to be here today. I'm Kat Hill. I am currently in Palm Desert, California on the road, and I am looking forward to seeing some of you all in person this year. And it's given me optimism and great joy to think about that. So, hoping you can come out to WPC, or I might come to see you in my Airstream. So,

Polly Dawkins:

Thanks, Kat, and Sarah.

Sarah Zenner (Ambassador, Davis Phinney Foundation):

Sure. So, I'm so glad to be with all of you today and I'm Sarah Zenner calling in from Evergreen, Colorado. I've had Parkinson's that I've known about for a little over four years. And I am really excited because in 2023 I'm getting married. So, I am really excited and so enough said,



Polly Dawkins:

Congratulations.

Sarah Zenner:

Thank you!

Polly Dawkins:

Amber.

Amber Hesford (Content Creator, TikTok):

I am Amber Hesford. I am calling in from El Paso, Texas. I've been living with Parkinson's for I think eight or nine years, and I am looking forward to hopefully attending WPC as well. So, seeing you guys in person too.

Polly Dawkins:

Terrific. Thanks, Amber. Kristi?

Kristi LaMonica (Ambassador, Davis Phinney Foundation):

I'm Kristi LaMonica. I'm in upstate New York. It's currently having some nice weather outside, so I'm in the capital region and I am really excited, like Kat said, to meet all my people in person. So, I'm so excited for WPC to get to see everyone. It's going to be fantastic. It's just going to be great. So

Polly Dawkins:

Wonderful For those who are watching, and they don't know the acronym WPC,

Kristi LaMonica:

World Parkinson's Congress, right?

Polly Dawkins:

World Parkinson's Congress. Exactly. That's happening in Barcelona this year. Exactly

Kristi LaMonica:

In July.



Polly Dawkins:

In July. Kevin hi.

Kevin Kwok (Ambassador, Davis Phinney Foundation):

Hi, everyone. Kevin Kwok dialing in from Boulder, Colorado. What am I excited for this year, well, within, with the addition of Chinese New Year being Sunday, which I'm welcoming with all my family what I'm excited about most is ski season. Skiing is not something that most Parkinson's people do, and I'll talk a little bit more about it, but I've been out this week and loving it.

Polly Dawkins:

That's great. Hi, Heather.

Heather Kennedy (Content Creator, HeatherKennedy.com):

I'm amazed, I'm amazed that you're skiing Kevin.

Kevin Kwok:

So, so well, most people say I'm crazy.

Heather Kennedy:

Yeah, you have to be a little crazy to manage this disease for as long as you have, as we have. And what I'm looking forward to is just seeing all my peeps. I want to see you walking and dancing and singing and at karaoke, whether that's the WPC or just in your own lives, and sending pictures and sharing, staying connected is keeping me, it's keeping me afloat. So, thanks. Yeah,

Kevin Kwok:

Your rap, your rap song keeps us afloat too, Heather.

Heather Kennedy:

Some shaky.

Polly Dawkins:

Yeah.

Kristi LaMonica:



Oh, It's fantastic.

Polly Dawkins:

I can't get it out of my head. slim. Shaky,

Heather Kennedy:

Yes. Slim up. Even when I feel achy.

Polly Dawkins:

Achy.

Brian Reedy (Ambassador, Davis Phinney Foundation):

I love it. I love it.

Polly Dawkins:

Don't get us started. Maybe we could have Heather, if you'd like, as today as we close out, maybe you could just do a little cameo for us if you feel like it

Heather Kennedy:

Was written by a great film producer called Sequoia Lowe, he's phenomenal. So, I can't take any credit, but I'll, I'll be happy to

Polly Dawkins:

Do a little, but maybe you could perform a little bit for us.

Heather Kennedy:

Sure, sure.

Polly Dawkins:

Awesome. Hi, Brian.

Brian Reedy:

Hi. Well, I got my teacher laughter-Yoga certification last week, so I'm looking forward to now teaching classes and doing stuff online, I guess, but more so in person. And I'm, I have a proposal I haven't heard yet if it accepted to do a renewal room at the world, Parkinson's



Congress, so I'm really hoping that comes through. Okay. But yeah, I'm really looking forward to just getting out and traveling more too.

Polly Dawkins:

Wonderful. Sree. Hi, Sree!

Sree Sripathy (Ambassador, Davis Phinney Foundation):

Hi. So, I'm Sree. I've had Parkinson's, this is going into my eighth year, but symptoms for 10 years that I know of. And I'm from the San Francisco Bay area. And what I'm looking forward to is meeting friends that I've already met and new friends that I have yet to meet at the World Parkinson Congress, but also getting in more exercise. Definitely getting in more exercise. Yes.

Polly Dawkins:

And finally, our moderator for today. I'm going to turn over the mic too. Doug.

Doug Reid (Ambassador, Davis Phinney Foundation):

Hi, everyone. Doug Reed. Zooming in from Lafayette, Colorado. I was diagnosed with Parkinson's in 2010 but had been exhibiting symptoms for a couple years, two to three years at least prior to that. I'm looking forward to the world Parkinson's Congress I've never attended before, and I'm 99% committed to going this year. So, I'm looking forward to meeting those of you that I haven't met before.

Polly Dawkins:

Yay. Yay.

Doug Reid:

And to get us started talking about hope and optimism, I have some quotes from people in the greater Parkinson's community. The first one is from none other than our friend and mentor Davis Phinney from chapter 19 of his book, the Happiness of Pursuit. Davis writes, "A chronic illness is not an excuse to stop living one's life, but rather a call to start living it and embracing it more fully." The next couple of quotes are from couple of columnists on Parkinson's News Today. The first two are from Jamie Askari, or Scary, I'm not sure how you pronounce her last name. She is a care partner and wife of a young onset Parkinson's gentleman. Jamie writes in her column of "The Bright Side," "The journey ahead may not be easy and why, while I may make mistakes, I will learn all that I can along the way."

And she ended that column, towards the end of it, she wrote, "I will remain realistically optimistic as I search for the bright side of everything." There's a gentleman with Parkinson's,

Dr. C who also writes for Parkinson's News today, and he wrote, "We are not entitled to a good life without suffering. Instead, we must create that for ourselves." And then lastly, Michael J. Fox. In his book, *No Time Like the Future*, he was quoting his late father-in-law, Steven Poland with gratitude, optimism becomes sustainable. And I forgot to mention this past Monday night, I was carrying a load of laundry up my stairs and fell forward. Fortunately, I did not fall backwards, but I got a nice rug burn on my forehead, so I'm fine. I'm okay but hurt my pride more than my body. So, without further ado with gratitude, optimism becomes sustainable. Again. That was Michael J. Fox. And for me, remembering what I'm grateful for just daily affirmation in the first thing in the morning helps me to get my mind straight and to try and remain happy and optimistic.

Kat Hill:

I think that's really powerful, Doug. I think when I was going through the diagnosis process and kind of laying on my couch, trying to figure out what was going on, I really felt a lot of despair and depression and didn't know if I was going to go back to work. And I needed something really simple to kind of snap me out of things. And it was that gratitude practice of writing three things down every day. Just three things. That's all I had to do. You know, at the time I wasn't big into exercise yet. I wasn't, you know, I wasn't looking at all the things that was all overwhelming, but somehow just hanging on each day to three things that I could be grateful for. And the panel has heard me say this time and time again, but I am still grateful for garbage pickup.

Maybe even more so now that I'm traveling in an RV because it's, you know, everything's smaller and. So, I'm glad the garbage gets picked up by somebody other than me having to take it to the dump. So, I think if anybody's out there thinking about just is really low if you can start with just a simple task of looking for that, I think it can lead you to optimism. Even if you don't feel like you can find it sometimes just little gratitude's can help. For what it's worth.

Doug Reid:

Kevin, go ahead.

Kevin Kwok:

Yeah, I think it's important to say that we have a disease which is with us for the rest of our life. And it's okay to feel low at times, you know, I mean, it wouldn't be normal. And you, we would look at you strange if you didn't say that at times. You've felt the blues. But, but the trick is, and I've said this to members of in this group, well, when you deal with Parkinson's, it's not managing the highs, it's managing the lows and how you get out of those tracks. Exactly. So, I guess I just ask the other council that members here, that while we're trying to be very optimistic, balancing with the knowledge that we all have to say so that people don't feel left out if they're not if they're in sort of that trial. Heather and then Sarah,

Heather Kennedy:

I just wanted to add to what Kat was saying about the small gratitude for simplicity and making that a practice. we deal with a practice here. Every day is going to be different every hour for some of us. I have been online when I've not been able to move. I've been almost para paralyzed. I've been online when I'm completely manic. We never know. That's the whole thing. We have to get very comfortable with this uncertainty and to be grateful for the little things like when a leaf falls out of a, from a tree and slaps you in the face or, for the rain. We've been, you know, and getting inundated with, in California, the trees are happy, you know, or maybe we're walking down the street and the sun comes out, so it's raining. We're looking for the rainbow. We can really savor these moments because that's what life is. A bunch of these little moments. Kat is spot on. Her book mentions this, and Kevin and Kat are two people who've spoken so far. And among, among all of you speaking, who really walk the walk, like, we're not just sitting here on camera going, everything's fine. You know, let me put on some lipstick and, you know, make everything look good. No, we're here saying things get real. And because they get so real and so hard, we need to have that gratitude. So, thank you so much for bringing that up. Thank you,

Kevin Kwok:

Sarah. Did you have something?

Sarah Zenner:

Well, that's a lot to follow up on. But I think I mean, I agree 100% that this is a practice and sometimes we, some days it is more apparent that this is going to be with us forever. And it's managing through that tough stuff and practicing gratitude, practicing hope is very important for us. And I feel like when I assign purpose to my hope, that the hope becomes more attainable. And my whole reason for being our, all of our reasons for being becomes much more meaningful. You know, for example, you know, attaching purpose to hope could be I'm hoping that I can finish Ride the Rockies this year. Okay? So that's one hope. What am I going to do today to make that happen? What am I going to do tomorrow? And it kind of makes me have a, a plan and get out of those dark spots and ruts a little quicker. So, for me, I'm kind of a doer and I don't like to let things take the ride. I don't like having Parkinson's because it has a mind of its own. So, I'm trying to manage it by putting purpose into it.

Doug Reid:

Amber?

Amber Hesford:

I think one of the things that helps me the most is having something to look forward to. And I mean, it can be the smallest of things. It can be looking forward to a nap after work or looking

forward to going to the movies, looking forward to the World Parkinson's Congress. As long as there's always something to look forward to, it really helps me get out of those ruts, you know, yes, I'm having a bad day today, but tomorrow will be better. And I have this coming up this weekend, going out to dinner with friends or, and sometimes you don't want to do it like the apathy is really kicking you and you don't want to get up and do it. But once you get out there and you do it, you find that you enjoy it, and it just revives you. Yeah,

Sarah Zenner:

I agree with that.

Doug Reid:

Kristi.

Kristi LaMonica:

I think that, so I like to tell my students that not every day is going to be awesome, but there's something awesome in every day. So, there's always something great that you can find of every of every single day. Every day may not be perfect. It might be far from it, but there's still something good that happened in that day. And also, I think that by calling a day a bad day, you're giving it power. So, if you just call a day, so I'll say to my husband, I'm having a day, I'm not going to quantify it, I'm not going to qualify it. I'm not going to do that because then that's going to put me into a bad day for a few days. So, it's just a day,

Doug Reid:

Brian, and then sir, and then Kat, then Heather.

Brian Reedy:

I just love, it's like I want to come to everything everybody's saying because they're also beautifully spot on. and somebody had written in the chat, I noticed briefly about it being a choice. And it is, and yet at the same time, you know, with Parkinson's and us not having the what's that thing that we can't make any more in our brain?

Amber Hesford:

Dopamine.

Doug Reid:

Dopamine.



Brian Reedy:

Thank you. When I forget the main words. But when we, you know, we don't have the dopamine, so it's a little harder sometimes to get that posited up. But that's where you have your community and your friends and people you can share with or find a way to get out yourself. Like I think it was Sarah who was saying, you know, have a purpose, have something to do or somebody else saying, you know, get outside. But it's a choice. And really good guy that I used when I used to teach my students about positive choices is Charlie Widmeyer had written in his book, you know, we all have a choice. We can throw our own pity party, feel miserable and make everybody around us feel miserable. Or we can choose to be positive and choose to find something better in it. And positiveness isn't some kind of you know, hallmark kind of thing. It's a real thing. It's a real choice and it's real genuine. And the more you can find the people that you can surround yourself that with that can help you with that, the better you are.

Doug Reid:

Sorry, did you have something?

Sree Sripathy:

Yeah, well, speaking to being grateful, I was very grateful this morning that I wasn't the couple that decided to lock themselves in dog crates and couldn't figure out how to get out. I don't why they did that.

Heather Kennedy:

But was this on the news or this was on the news?

Sree Sripathy:

This was on the news. It was local news. Oh. They both locked themselves in dog crates and they realized they were locked in, and they had to wiggle around. So, the dog crates faced each other and somehow they got out. So, I'm very happy that was not me.

Kat Hill:

Sree, I need to watch what you watch in California.

Kevin Kwok:

That's what they do.

Sree Sripathy:



That's California Bay Area craziness. And then I'm also grateful that the pincher bug that fell from the roof and landed on my bed, it happened while I was still awake and not asleep, and I didn't accidentally eat it. So, I'm very thankful for that.

Kat Hill:

It's the little things

Heather Kennedy:

Darwin awards right now, you guys.

Sree Sripathy:

It's true, it's true. And then I thought I killed it. I'm sorry. I hate to kill these bugs, but now it's escaped and it's somewhere on the bed again. So, I'm going to have to either sleep on the floor, the sofa or figure out what to do. Haven't figured that out yet. But all that said, this has actually been, the last two weeks have been really tough for me. It's been my dyskinesia has been all over the place. My meds haven't been working. I've had a lot of facial freezing and I still had to go out in public and work and interface and keep working when I realized, oh crap, I left my meds in the car, and if I, and I'm a photographer, so if I don't capture this moment, then I'm going to miss out on my assignment. So, what do I do?

Do I just push through it? Do I ask, hey, do I have time to go back to the car? And it was like, it made me more anxious, more crazy, more frustrated. And then I just pushed through it and then I realized I need to take better steps to make sure I have my meds on me, to make sure I have a support system around me. So, when I have moments like that that I can't get out of and I don't want to, like, the sound of music isn't working for me. Seven brides for seven brothers are not working for me. Frank Sinatra isn't doing anything. Diplo no thanks. I call my friends and I reach out. And what I'm really grateful for, the third thing I'm really grateful for is that I'm lucky to have built a community of support around me. And that didn't happen automatically.

That took effort, that took years, that took time. And that's the wonderful thing about Davis Phinney, the Davis Phinney Foundation, is there is a network here to support everyone. And if you ever find there isn't, you know, reach out to an ambassador, reach out to the team, and let them know that you're struggling. So, I'm really grateful for that. Because if it wasn't for that support system and the lack of isolation because I realized isolation is one thing that makes the disease worse, it makes everything worse. And you can think you're not isolated, but when you haven't talked to a friend or seen a friend in a while, whether it's on social media, a zoom call in person, that really does affect your mental state. So even if you're someone who doesn't like to socialize a lot, I think, you know, you know yourself best. But some socialization is needed to just touch somebody, touch a voice, touch, touch a person. And I think that really helps with this disease in particular.

Sarah Zenner:

Just ask a quick question. You know, I've, I've talked recently with a few people that have contacted me through the Finnie Foundation that are newly diagnosed, and this is new, and they haven't communicated, they don't, they're not sharing it with people. And I guess I'm, I'm wondering if there could be people that are tuning in today to this to hear your suggestions on what Sree just brought up, is the importance of connecting with people to, to bring that hope and to bring that light into their lives. I feel like it's really necessary, especially this time of year.

Kat Hill:

Okay. I'd, I'd love to tackle that. Is that Doug? Am I Yep. Am I okay to go? Yeah. So, you know, there's lots of growing evidence that being isolated or feeling alone is not good for us. It's really, it's not good for anybody, not just people with Parkinson's, but anybody. And so, learning to find a community reaching out to foundations like the Davis Spinney Foundation local support groups church groups your community is so important to find support. And it helps us to navigate not just Parkinson's disease, but the rest of our lives. So, I think it's vital that people have permission to do that, whether you have Parkinson's disease or not. I think having Parkinson's or any chronic illness makes us feel very other. And even if you're not talking about your Parkinson's disease, building a community and being intentional about that is really important.

And we know it's healthy for us. and I want to touch on one other thing with a gratitude practice. You know, we practice something, and we get better about it, but we, there's also such good evidence that when we do that, we build neural pathways that make it easier for us to come back to that positivity to come back even to even to remember to call our friends. We're training our brains to find those things more quickly so that each time we do it gets more automatic. And so, you know, you can treat, teach an old dog new tricks. I promise if I can learn to do it in my forties and fifties, I'm, you know, we can do it. Yeah.

Doug Reid:

Heather, did you have something, then Kevin?

Heather Kennedy:

Yeah. There's something in meditation groups or Buddhism called lojong training. I believe that's how you say it. And it's in training the mind. Just what Kat's talking about, developing those new pathways, those new habits, you know, what they say, it takes a certain number of days or times to create a new habit. That's the part that we can control. What we can control is a few other things that I wanted to mention too. But first I also want to say a few more things We can control. One, we can choose to be in service. So, by helping others, which you all have taught me, by the way, I'm, this is not an original thought you've shown me. I mean, KA came to



help me with brain surgery. Kevin always shows, you know, all of you have been, have, have been there for me in every way.

And we take turns carrying each other. Like Rick Ram Dass said, we take turns carrying each other home. You know, we're just all doing this over and over again. One of us falls, we picked them up, we carry them for a while, then we fall, then we get picked up and we carry. It's kind of a neat thing that happens. But I also want to make the distinction as we're talking about positivity here. We're not talking about toxic positivity where we're like, oh, you're being negative. I'm not going to talk to you. I'm going to shut you off. No, because people take turns falling. We just mentioned that. And remember, when you're on the bottom rung of the ladder, you know, remember how people treat you. When they're up top because it's going to be their turn next. That's just how life works. Suffering is universal. You know, we're all going to have bad times. And to develop a little bit of compassion for ourselves and a little bit of relatability to others is a real good thing. When we can be in service, that's how we can learn this. So, I just want to mention all that too. Thank you

Doug Reid:

Kevin, then Brian.

Kevin Kwok:

Yeah, I mean, I'm carry a theme that's repeating here, but this theme of helping others and providing service to the tribe, to me is a best medicine I can take. You know, I just feel better when I'm with someone and talking to them either on the phone or live and it's infectious. The karma begets good karma, right on there. But I did want to share a story which star stems from the very beginning of today's conversation where I mentioned that I was really looking forward to skiing season. That is not a trivial thing for me. I actually got an injury last March, which I thought would not allow me to ski again. And that was really weighing me down along with a lot of other personal things that were going on. And as I was coming into the fall, I was really feeling like I was in a dark place.

You know, friends of mine were advancing with their Parkinson's, and I was feeling sorry for myself as I was advancing. But what I can say happened was, is the system of setting goals and processes or procedures, and this leads into this week of skiing where if you see me back in December, there's no way you would've let me out on a slope. I mean, I would've been dangerous to anyone on there. I couldn't walk, couldn't talk, basically. Couldn't see with Estonia in my eyes. And what was really interesting was friends of mine met me in the gym back in January and we worked out on very simple things like balance d, dexterity, stretching, and basic strength drills. And for 13 straight days, I worked out every single day, you know, and I was getting to the point where I thought maybe I could go out and thank God my friends who were with me stayed with me through that.

Of course. And so, as I described the other day when we were driving out at five 30 in the morning, we all had our game faces on three of us had Parkinson's disease for more than 50 years combined. And what I saw was this really cute act action where three men walking into the ski lodge put their game face on, didn't talk, and struggled to put our boots on as we were drooling into the, it was hilarious. And when we got done, we all were beaming with grids. This process and procedure that we were going through, which most people would've said is insane, led us to four hours of skiing where we all felt disease free, and we had speed back again. And so, you know, it's not this thing that's just to say that go ski. You got to set up goals and processes and procedures and by accomplishing that procedure, it's amazing how uplifting that can be for you. It's the baby steps to get to the goal.

Kat Hill:

Yeah, that's beautiful.

Doug Reid:

I think it was Amber that said something about having something to look forward to. And for me, that rings so true. Just having something on the horizon to look forward to when I'm down, I can think about that next event, and it'll lift me up. Brian, did you have something?

Brian Reedy:

Well, look, I can follow that. I lost all my thought.

Kat Hill:

Kevin,

Brian Reedy:

I'm just so impressed. That's amazing. I'm so excited. I know I was going to say something about, you know, it's not always pie in the sky. You know, we say all this stuff, but we struggle and suffer. I've had two of the worst emotionally depressing days I've had in a long, long time up until I got on the message thing here on the panel here. But this is what picks me up. It's like, I don't want to miss this. And it's a matter of just slugging through the days to find that energy, to get that better thought or to get outside or get those things. So, we struggle as much as we throw the positives, we struggle too. And I think the saving grace I have is I learned through the toughest things going through my wife's cancer and hospice time.

My God, we laughed every single day. We found a blessing in everything, and we found joy. And that to me is the choice that we all have no matter how bad things get. And we saw bad, we also saw good. And it's just, you've just got to be willing to make that choice. And it's challenging as hell. I know because I'm doing it. I'm, I'm not doing it well because I don't have

anyone here. But at the same time, I keep hearing the tribe in my head and I keep getting to talk to people that keep me back on the focus. And it's usually all my friends with Parkinson's because they understand it. It's the people who don't have Parkinson's and haven't taken the time to understand it that have abandoned And so we choose our tribe, and we make them our family.

Doug Reid:

So true. Kat and Brian.

Kat Hill:

Yeah. That's beautiful. And I, and I think those of us that, you know, I haven't met a single human that doesn't struggle with something, right? And so those of us that have deeper struggles and loss, it can be the touchpoint for such amazing joy. There's this juxtaposition. And I think like we said earlier, none of us are on here to tell, tell everyone that. You have to be happy and positive all the time. I think to be authentically positive and to find really that rich joy you have to honor and grieve the losses and hold space for that. And trust that you've laid down a life that can help you claw your way back to joy. And, if we claw our way back enough, maybe we can live more in the joy than in the despair. Right? and you know, these are not new ideas. These are, you know, it's the premise of Buddhism, you know, life is suffering. But, but, but I, but I really am learning to believe that and even to try to, when I am the most down, saying perhaps I get to have some real light at the end of this tunnel

Heather Kennedy:

Test by Woo. Yes, Sree. Yes.

Sree Sripathy:

Yeah, I was going to say that what's been really bothering me is my face freezing now. And that's been something that's very difficult to kind of get used to. Yeah. And that was, it wasn't so evident when I first joined this council, which is like a year ago, year and a half ago. Whenever it was some time ago. And I was hesitant about getting online even then because I didn't want people to see my face not look like it. I'm used to it looking. And once it started freezing, I'm like, I don't want to be out in public. And then I was out photographing an event and this kid came up to me and he just looked at me. He said, why are, why are you shaking like that? And I was like, oh, I wasn't even where I was shaking, right? And I just said, oh, because my body does that sometimes.

And then I thought, I need to become comfortable with this is my new reality that I don't know when my dyskinesias going to sit in. I don't know when my face is going to freeze. I didn't know when that's going to happen. So how do I get comfortable with that? So, I put myself on TikTok



and on Instagram, which is something I never thought I'd ever do. I did it just very recently. And so now I'm looking at my face constantly and I'm finding that I still actually love my face. It's a process. It's a process. But that's what's giving me hope. It's actually learning to appreciate myself with this new frozen facade. And then I realized, oh, my upper lip is not moving. That must be Parkinson's. And then it looks back at old videos and I'm like, oh, my upper lip never moved. This is terrible on Parkinson's. This is just unfair.

Heather Kennedy:

We love your face too. Sree. We love your face.

Sree Sripathy:

That's all.

Brian Reedy:

Well, that's one of the keys. You got to have humor, you got to be able to laugh at things. You got to like, I'm sitting here right now with my disc crazy name thinking, good thing my camera stabilizer's working because I don't look so bad as I feel, you know, you just got to laugh at things.

Heather Kennedy:

Is that what's going on? What do you have Parkinson's or

Kat Hill:

Something? So, I just want to chime in. One of my favorite things about living in the trailer is I can own, there's a tiny mirror. I don't look at my face very much anymore.

Heather Kennedy:

It's not one of those magnifying ones, is it? Those are horrifying.

Kat Hill:

No, no, it's just this little strip, you know, on the Airstream. Some other people have like full length mirrors in their trailer. I avoid those at all costs. Right? So, I'm like. Yeah, Amber. And then Kristi.

Amber Hesford:

I just wanted to echo what Sree was saying. I try to find ways to laugh all the time. Mostly at the expense of Parkinson's or myself. I too have a TikTok and do Instagram reels and much people's

dismay. I make fun of Parkinson's because I think people look at me and they think she's too young to have Parkinson's. She's just making fun of it. Yeah. So, it prompts a lot of conversation to where I am able to have those conversations and educate people that no, I do, I am old enough to have it. So having that outlet has really helped me is something that I would've never in a million years done before. I'm very introverted. I'm very socially awkward and shy. And so, the fact that I have what I have now is unbelievable to me. But it's really helped me cope and manage because otherwise, I don't know where I'd be if I didn't have like that outlet to talk about it. And it's brought me to meet people like you guys different foundations, different groups. It's gotten me involved in. So, finding that outlet I think is super important, and trying to maintain that humor.

Doug Reid:

Kristi?

Kristi LaMonica:

Amber, we, you just said about being too young to have Parkinson's that is like, it annoys me so much. I hate when people say that. Yeah, I wish that someone told my brain that because yeah, that's great. Very helpful to say. Very, very helpful. But back to what Kat was saying, that it's okay to sit in your, have a pity party for yourself, get down, just sit there for a whole day and cry. But then you just got to figure out how to move on and find something awesome in the next day and just figure out how to get through. That's, I forgot what else I was going to say. So, sorry. That's where brain was.

Kat Hill:

The disease, brain disease.

Kristi LaMonica:

I know. I don't know what's wrong with me there.

Sarah Zenner:

You know, some of us don't have a lot of the outward symptoms. Don't, I mean, and that is a real struggle. I, my heart goes out to you Sree and I understand how you feel because I have, like, I have non-motor symptoms, right? A lot of non-motor symptoms and there are a lot of us out there that have both or stronger non-motor symptoms. And it's a real, it is hard. And I'm like, how am I, how am I've got Parkinson's, but I don't necessarily look like it. A lot of people don't know that I have it. And the struggle is how do I lift myself up with this internal battle of how I don't even know how to say it. I don't look like I have it, but I do. And I am having hard days and hard weeks, sometimes hard months.

And I mean, like, I could start crying right now thinking about it. And it is going back to that practice, like we've been talking about the practice of gratitude and the practice of, you know, figuring out how we're going to have purpose in our lives to make it meaningful and to get over, get over these humps. I know I'm not making a whole lot of sense right now. But it is, it is real for a lot of people out there with Parkinson's that don't look sick. And the worst thing you want to hear is, well, I'm not sick. I'm, I'm not sick. I feel really well, but you know that you look so great. You know. So, I don't know. I'll stop rambling. Heather.

Heather Kennedy:

I wanted to mention there are a lot of diagnoses. Before I was diagnosed with Parkinson's, they told me I had Lyme disease, then fibromyalgia, and then I had lupus and then I had chronic fatigue, and then I had this and that and the other. And I already have a celiac disease, which is a problem when someone gives you like a pizza, which is a full gluten crust at the place when you were going to the Brian Grant walk at the restaurant there, you know, and you vomit it for three days and then you can't keep your meds down. It becomes a bigger problem than it seems. It's not just like, Ooh, I can't have gluten. It's like, I'm going to be sick for a week or two or three or four now. So anyway, these shadowy syndromes, let's say that you have chronic fatigue syndrome.

People think that you're being lazy. They make all kinds of assumptions. we make assumptions on-site by how people appear, by how they react. If we have the frozen face, that's another layer. If we can't speak clearly because of the DBS or whatever, that's another layer of communication gone. So, we now cannot tell what the other person is doing by sight, either sometimes. And human beings are just natural to judge to sort of assess the situation, to try to see the commonalities or to see the differences. And so, we do, we get judged, we get pathologized constantly. And this is the most upsetting part for me. I actually get enraged about this. I was recently pathologized by someone that was very close to me. I felt that way anyway. I'm not sure if that's what their intention was.

And I went absolutely that, you know, that crazy, I really did. I went off the deep end and then I had to double back and apologize and make some amends, which I'm still doing, and I'll probably be doing for a long time because I really overreacted. Cause it was like, not you too, you know, I thought that I was only going to get stabbed by strangers here. But if you do have one of these syndromes that is not well known or you don't have a name for what you're feeling, it can be incredibly isolating. We really feel for that. Those of us who are dealing with all, all ranges of this disease. Because yeah, it's hard to communicate. So, thank you for letting us talk to that.

Doug Reid:

Kevin, did you have something? Not at the moment. Okay, Brian, and then Kat.

Brian Reedy:

And along those lines of trying to communicate, Heather, it's spot on because I have a brother who's asked, you know, well, so what are some of your memory issues? Well, you know, I go in a room, and I forget why I'm in the room and I'm looking for something, but I'm holding it the whole time. I'm looking there, you know, he says, oh, I do that too. I'm just getting older. It's like, you know, they can, and they want to help, but they contextualize it to things that are happening. I said, well then take that, put it on steroids. But it's really hard to explain. It's the same thing with depression, you know? Well, you get sad lot. Well, you just think about things too much. You worried too much. You just got to change that. It's like, oh, okay, great. I'm cur you know, everybody wants to help.

And it, what I've learned is I've just got to understand that they're not going to understand. And, but that's the hard part. and when you're going out to the store and you know, you've had a really rough day, but you're doing okay now because you're up and walking and somebody sees you and says, oh you look great. You know, like you were saying Sarah, and they don't have any idea of what's going on internally. I think we've just got to find a way to be at peace with the fact that this is so hard to communicate to anybody what it's like. And until they get into this world, they're not going to understand this world.

Kat Hill:

Yeah, I agree with that Brian. And I think it's been an interesting journey. You know, one of the things I'm most grateful for is my wonderful husband who, we've been married almost how many years now? I don't even remember what year it is. Almost 33 years I guess in March. forever since I was born. We've been married. But it, but it's been interesting. Even, even the folks that are closest to us sometimes don't see things. And he, it's been interesting as he's transitioned to working less. Now that we're traveling, it's been interesting to hear his perspective on my Parkinson's disease. He's realizing that it has had more impact than he realized. And part of what I realized that I have done is tried to schedule my on times around his off times right? His off-work time. And so, he, it's interesting to see it through his reflection.

I'm trying to shift that into a positive light about how we're going to navigate the rest of our trip and travel. Because I think it's important that our, our care partners are able to continue to find joy and positivity in their worlds. Even if that means doing some things differently or without us, or us doing it with them in a different way. You know, maybe I go on the hike, but I park myself partway and do some sketching while he does the other few miles and then circle back around to get me. Because I think learning to navigate that as a couple, and Sarah, you know, now that you're among the old married people, not old, excuse me, young married people. It's, I just think it's interesting because I think you have to find positivity with the people you're on the journey with too. and sometimes that takes more work when you're different than you used to be.

Sree Sripathy:

Sorry. I met a friend recently, one of my closest friends. I've known her for decades and we talk quite frequently. But when I went to visit her after maybe two to three years, something like that, she's visited me before. And when I got out of the airport into the car, I wasn't really talking a lot. And she said, oh, maybe you'll feel better once you are eating something. I said, no, I'm just waiting for my meds to turn on. And she said, oh, what are you on medication for? And I thought, huh Parkinson's disease. And then she said, well, why do you need medication for that? And I thought, wow, one of my closest friends. And there's like a disconnect. And so, I'm like, clearly I have not been communicating my Parkinson's effectively to everybody else. And maybe like Kat was doing, you know, with my friends, I'm only talking to them when I'm on or when I'm fully functioning because I try to hide.

You want to hide when you have facial freezing tremors, whatever, and you want to cuddle up in your bed and stay away from society. But that's actually, and sometimes that is okay. Sometimes that is fine. But a lot of the times it's one of the worst things you can do. Cause that's when you want people to come around you. And I find for me that when I'm surrounded by people that love me, family, and friends, it actually gets better. My symptoms get better. I'm not saying that happens every time, definitely cannot say that. But that is the case. So, then I decided how can I communicate this effectively. Because it gets draining to tell everybody constantly what's going on. So, I decided to do a little newsletter update, and then that's when I decided to post a video of myself masked, unable to really move my face, and post it on my more public account where anyone can see it.

That's a family or a friend so they can kind of see guys, this is what it is. So, when I have resting RBF, am I allowed to say the B word? I don't know, I don't know, I won't say it. Instead, a resting B face, I say sometimes I'll have always B face. So, it's not you, it's me. But it's really you. I mean it was kind of you 10 years ago, but it's you now for a different reason. So yeah, I realize that we have to communicate effectively to friends and family because they just don't get it. What's obvious to us that we live with every day, they might not take in and you just do it to the best of your ability. You communicate as long as you have the energy to communicate.

Kevin Kwok:

It's important that we don't give up on our family and friends. It's hard for even us to understand it as we're living this journey. And so, to expect automatically someone else to read our minds and predict how we're going to be as an unfair request. So, I think what we have to learn is temperance and patience in a way.

Brian Reedy:

Well, and keep in mind what Kat was saying, you know, sometimes they've probably only seen us more on the good times. You know, my right. They hadn't seen my off times until after my

wife passed and my sister came to take care of me, and I cried when I saw her face see me often looking so bad. It's like I had no idea that I've not let my family see that. So of course, they didn't understand.

Kevin Kwok:

Yeah. I think by nature we are people that lied to have other people not worry about us. And so, we like to put up a good front to show we're strong, we like to exercise to show that we're fit and all these things. But in some ways that can almost be your double-edged sword.

Heather Kennedy:

Yeah. Also, it takes a tremendous amount of energy to hide these symptoms, whether they're non-motor or motor symptoms. I mean, think about that. I was getting some tips from Brian Grant once, and he was sitting on his hands shaking and he is like, I can't put them in my pockets. That would look weird. You know, I mean there's so, there's only so much we can do. I can't lie and say I'm not depressed if I can't get out of bed. I mean, some people have clinical depression where they can't get out of bed for like a week. I've never experienced that, but I can't even imagine that's the worst. You know? I think compassion's necessary instead of judgment. So,

Kat Hill:

And compassion for yourself also, Heather, I want to say that that's, I think that's integral and I, and I think you know, kind of back to the positivity too and that it's toxic if we're up here saying we're always positive, and I think all of us really want to share the message that we really aren't, that we're human and that we, that none of us can really find that beautiful positivity and joy. And I love that the hope and the linking action to hope without the hard times and Parkinson's gives us opportunities, for those hard times in different ways. Yeah. I would say, yeah, Kristi

Kristi LaMonica:

Like to capture that Kat. So, this morning I, when I was coming to life, I posted a picture on Instagram, Facebook of what the sky looked like. I got to witness the beauty of the sky and it was wonderful pinks and purples, but I was witnessing that because I couldn't move from the couch as I was waiting for my meds to kick in. So that's the, you know, both, both parts of the coin there, the good and the bad. So, I get to see really good stuff for really bad reasons.

Doug Reid:

Yeah. Years ago, when my daughter was probably five or six, I was at an event, I think it was one of her friend's birthday parties, and I was feeling self-conscious about my dyskinesia and

my tremor and one of my daughter's friends came up and said, what's the matter with you? And my daughter chimed in, and she said, oh, he's got a disease that makes him wiggle and shake, but he's still awesome. And it just warmed my heart. Yeah. Sarah, do you have something?

Sarah Zenner:

Yes. That's really sweet, Doug. You know, if somebody asks me why I do all the stuff I do, you know, why do you keep, why do you, why do you keep, what keeps you going? What My answer to them is that I do have hope in a medical breakthrough in our, in my lifetime. And I do all the things that I do today to preserve myself so that I can be the best version physically, emotionally, mentally, when there is a medical breakthrough. Because there's a lot, I mean, we've got so much, so many smart people out there working on our behalf right now, and I want to be a good candidate for that medical breakthrough when it comes out. And so that's, that's what I would tell somebody.

Doug Reid:

And speaking medical breakthroughs. I was reading an article this morning; I believe it said there are six potentially disease-modifying drugs that are in phase three trials now. So that's something to be optimistic about. There are the vibrating gloves. If people haven't seen that, maybe Sam can put something in the chat. But it's Stanford University vibrating gloves vibrating.

Kat Hill:

Wait, what kind of a panel is it?

Doug Reid:

Grant something or something?

Kat Hill:

And I'd like to tag on that. I think that we all have the opportunity with this illness to slow down and to and be more present with ourselves in the moment. Be well today, find joy today, try to find positivity today and hope that tomorrow that there's an answer to some of the physical challenges for sure. And I, but I do think that I work really hard to not wait to do what I want to do today in the hope of a cure tomorrow because I think that sometimes is sort of like that delayed. Yeah, exactly. Take your meds right now, Heather, to re Yeah, but I try to not because for a while raising a child with a chronic illness, he would get really invested in the cure and like, I don't want to put stuff off just like once I get better, better I'm trying to accept myself as maybe I'm the best today that I'm ever going to be. Although I would beg to be different

because I really wanted to get mascara on before the panel and I didn't bring it, so I really tried. So, I'm need, I'm so sorry that my eyelashes are weak, got extra for you. Can me say Baker was here?

Sree Sripathy:

I just had one last thing to say and learn from my experience. Never do this on your own. Do not drive in the rain. Listening to rage music and eating peanut brittle at the same time. Not a good idea guys. Not a good idea.

Heather Kennedy:

Where do you live? I'm staying off that road. Yeah.

All:

Talking over each other

Kevin Kwok:

Stay out of dog crates.

Kat Hill:

Aren't you glad you tuned in here with us today.

Heather Kennedy:

Vibrating blobs and dog crates. What's going on over here? Kevin?

Polly Dawkins:

What a great way to bring our hour to a close, laughter and levity. Doug, did you have some closing comments, or would you like me to wrap up around?

Doug Reid:

You can, you can take the reins.

Polly Dawkins:

All right. Thank you all. You have added so much joy to my day today. I love seeing your faces and the comments from our community and laughing with you all and listening to your experiences. Thank you for sharing them. And I too can't wait to see you all at WPC in, in July. For those of you watching, we will be back here in a month's time. And in the meantime, we



will share this recording and the show notes and the transcripts and any links that we shared. Also, if you have questions or you'd like to be connected to the community, I know some of you are saying how do you get connected? Reach out to us to one of the ambassadors at the Davison Foundation. Many of the faces here are ambassadors for the foundation. Or write to us@blogatdpf.org and we will respond to you. Thank you all for being here, sharing yourselves and thank you for all of the visitors in the audience. Take care. Good

Kristi LaMonica:

Show y'all. Watch Heather's video.

Kat Hill:

Watch Heather rap. Yes.

Polly Dawkins:

Oh, Heather, we got a minute or two. Rap for us.

Kat Hill:

Yeah, do it.

Heather Kennedy:

They call me slim, slim, shaky. I stand up even when I feel ay, they call me shaky. Shaky, slim, slim. Even when I'm out, I'm in, or something like that. You know who do you know who designed this whole rap? Is Sequoia Low. I will send it to you guys. You can learn it. We can all sing it WPC together. It is going to be a blast.

Kat Hill:

Awesome.

Heather Kennedy:

Do not forget that name. You're going to hear it again. Thank you so much. Thank you all. You're rockstar.

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