

**The Victory Summit® event: Newly Diagnosed
Keep Calm and Carry On**
Recorded on Feb 20, 2021
Davis Phinney Foundation

Kat Hill (Davis Phinney Foundation Ambassador, YOPD Council Leader, YOPD Women's Council Leader):

Hi everybody. Welcome. What a great day. Thanks for hanging in there, and to the very end here. I hope I make it worth your while. My name is Kat Hill, and I was diagnosed with Parkinson's at the age of 48, almost six years ago. At the time I was a busy midwife delivering babies in an inner-city hospital in Portland, Oregon, and raising teenagers at home and caring for an ailing mother. So, the diagnosis kind of rocked my world and I'm so tickled to be here with the Davis Phinney Foundation and the opportunity to talk about being newly diagnosed and remembering so well what that felt like, and what a shock it was to my world. It was not something any of us planned for, right? It's not anything we asked for. It's not something we put on our Christmas list.

But I'm hoping by the time I finish today, you've already heard a lot of great speakers, Linda Olson. Oh, what a hero of mine. And she's got such an inspiring story, so I'm hoping by the time you walk away today, you have some tools in your back pocket that might help you feel a little bit more ready to carry on and to stay calm after your diagnosis. So, I by no means am an expert. But over the talk, I'd like to share a little bit of my clinical background, both as a nurse and a nurse practitioner, and my understanding of the nervous system, my experience with having family members with Parkinson's disease, my dad passed away at 83 due to complications of Parkinson's and my own challenges over the last six years.

So, I'm hoping you have a few tools to take with you today. Like you've heard, a diagnosis may be a time that can be a re-evaluative of time. Again, it's not something we asked for, but it can be a time to take stock of things. And as you heard Linda so eloquently discuss, how we have choices after things happened to us, right? We have absolutely time and needed time to grieve and be sad and to move towards acceptance. So, by no means am I saying that those steps can be skipped, but once we've done that in our work of grieving and accepting, okay, this is my new life, you have a choice about what you do with that. And for me, I chose to leave my clinical practice right away. It was a good choice for me. It was a difficult choice for me.

But I was doing the long call hours and was delivering multiple patients in labor at the same time. And some of that executive functioning skill and that multitasking skill, I was feeling impacted with the Parkinson's and I felt like it might be time for me to step back and reevaluate. I was the primary breadwinner of our house. And so, it's taken some creativity to think about how I might still contribute towards retirement and still not work at the age of 48. We have three kids currently in college and we've gotten creative

about how we manage that. So, once you make a decision that you're going to pick yourself up off the floor and get on with things, you're going to start moving and exercising, right? You've heard a lot about that today and all of the reasons to exercise; to keep us feeling better, to keep us socialized, to keep our muscles limber, to stave off all of the other diseases that that Dr. Mike talked about. And also, what Dr. K talked about earlier today, too.

Some of what it does for our feeling good, you know, it releases endorphins, helping us with sleep, all of those things are helpful. So, I'm not going to harp on exercise. We're going to move past that. What I'd like to move in and talk to you a little bit about is why it matters that we learn about our nervous systems. So, Parkinson is a neurologic disorder. You've heard a lot about it today. You've heard a lot about the medicines, and I'm not going to talk about medicines. I'm going to talk about some other strategies that you may think about to help to calm your nervous system. And probably all of you already know noticed when you get nervous or excited, your symptoms might be more exacerbated.

If you have a tremor, it might really go to town, sorta like mine. So, when I'm not nervous, so I'm a little nervous, right? Because I'm talking in front of people. So, it just takes that little bit, and my tremor comes back. And you might notice more symptoms if you just almost get rear-ended or have a close call in the car. You know that jolt of adrenaline might amp you up. It puts us into our sympathetic nervous system where we're in that fight or flight mode. A lot of you might know about that already. It increases our blood pressure, our heart rate, our eyes get more focused, blood goes to the vital organs so that we can run from the bear or, you know, historically or biologically, that was our imperative to stay alive. Right? But it doesn't necessarily serve us well in today's world, where a lot of things can stimulate that adrenaline rush, that jolt of a lot of what people call stress.

We need some stress in our lives, but when we have too much stress, it tips us sort of into distress where we're producing that adrenaline all the time and staying in that what I call an activated state. Delivering babies was one of those kinds of jobs. I'd get excited. It was very exciting. I was managing a lot of things. A baby was being born. All of that's wonderful. It's good stress, but it's still stress. So, for me, it was better to leave that practice and learn how to do things that calmed my nervous system. And that's all great. Right? You read about it. People say, well, let's learn to meditate. You know, find gratitude, all of these things that are just like, Oh, just do it. And that was a difficult process for me to step out of this busy adrenaline filled world and try to learn how to calm myself.

And I think the two takeaways that I love to share are ways to learn mindfulness, which is what the Davis Phinney Foundation is all about. It's about being well today. It's about being present today. It's about learning to live well today, and it means not thinking about yesterday and not planning for tomorrow while we're in this moment. Now, that

sounds really lovely. And I had a very hard time learning how to do that. And so, as I was going through my diagnostic process, leaving my practice, sitting on my couch, trying to figure out how I was going to do that. I was reading a lot about people who had started gratitude journals or started to look at gratitude, and that seemed like a pretty tangible, concrete thing that maybe I could do. Maybe I could write down three things in my planner every day that I was grateful for.

I needed something that simple and that linear at that time to help me move past some of the grief and on towards getting on with my life, frankly. So, I did that over a course of several weeks. And what I started to notice was that first off, I could always find three things I was grateful for, even if I was having kind of a crummy day. I might be grateful for indoor plumbing. I might be grateful that the garbage man picked up the garbage. And I don't know if any of you have ever lived anywhere where there's not garbage service, but I used to have to haul lots and lots of garbage to the dump. So, every Wednesday morning, I continue to be really grateful for those guys that pick up my trash. Other days, it might have a more spiritual meaning. Maybe I was really grateful for a phone call with a good friend or a particularly perfectly toasted piece of toast back when I used to eat toast.

But I think all of us can agree. We could probably find three things to be grateful for. And, just by doing that, over the course of time, what I noticed was I wasn't focusing so much on all the details in my life that weren't going well. I was committed to collecting those three things every day, writing them down, and I wasn't thinking about like, Oh, gosh, that paint, you know, that paint on that window's chipping that really needs to be replaced, or, Oh, my gosh, my son's room is filthy again. Instead of making mental notes about some of the negative, I was making mental notes about the positive and that simple shift really made a difference in how I was viewing my world. So, I started to expand on that. I'd never been a journaler. My mom wrote beautiful poetry, taught English. She was so good. I was always very intimidated by the blank page, right? Like I've got to write beautiful paragraphs and make it all, you know, all grammatically correct.

I started though, bullet journaling. I just wrote dashes of things. So, I'd write the three things I was grateful for on one corner. And then I started to use the other page for other things, things that I needed to do and got accomplished. And maybe a couple of goals, even though that's not as much mindfulness, but some positive things. I couldn't write anything negative in it. I could journal, negative thoughts in a corner if I needed to just mind dump, but in terms of planning, it needed to be something that I was working towards being positive. That list started to look like exercise, regular exercise. I was a walker and a runner for many years. And so, I started to do more walking. I was dragging my foot, so I was a little reticent to run on my own.

But I thought that I could at least engage in regular walking. And I started reaching out to some exercise groups in my area. You all heard about lots of different things. I found a group that was doing rock steady boxing. And I couldn't believe that I was going to go try boxing. I am the most passive person. You know, I just don't hit anything. I would never play guns with my kids. I thought, how on earth am I going to put on boxing gloves and go box? Well, I went and just kind of observed a couple of classes and I just fell in love with it. The interval training worked really well. I didn't have to think a lot while I was there. There were stations of things to do. And I met the most phenomenal group of people.

From that group, I also met a fellow young onset woman who we started a support group together. We couldn't find one with others like us in our community. So, we thought we'd start a happy hour group. And that became part of my goals. Slowly I started to collect some of these positive things and it's not like I had a long-term focus to speak for the Davis Phinney Foundation or to speak around the world or write a book or have a podcast. All of those things I've since done. But I had small goals and it gave meaning and purpose to me. So, in the gratitude space, I think it really helped me to learn mindfulness, being in the moment, trying to focus on the positive, even when I didn't feel great. I also started changing the words that I would tell myself. My husband would come home and say, did you have a good day or a bad day?

I'm going to stop using those words. I don't like good and bad. How about if you're asking me how my Parkinson's symptoms were today? I might have a lot of them, or I might have a little of them. We all know it's a day-to-day thing. And so instead of labeling a big symptom day as bad, I just labeled it as I had a lot of symptoms today. Changing that language got really significant because calling something bad, we all know there's already judgment attached to it. So, it changed the way I looked at things. It changed the neural pathways that I laid down in my brain about how I was thinking about myself and my disease. I was taking ownership and I wasn't making judgment about what my body was doing. It has made a big difference in how I view what I do and how I view my day, because I can have a really crummy day.

I'll tell you days at home with teenagers can swing just like Parkinson's symptoms can. Right? So, my day, whether it was good or bad, may have little to do with how my own body was doing. The other thing that I learned while I was laying on the couch is how good meditation is for us. Wow. That was a tough one for me. Clear my mind of all my thoughts? I thought there is no way, things go too fast in there, I just can't possibly learn how to do that. So, I read a book, "10% Happier" by a guy who was a journalist who had kind of a nervous breakdown. And he talked about how learning how to meditate made him 10% happier. He now has a podcast, too. And it was a really practical guide about how to incorporate moments of stillness in your day.

He also said nobody ever totally clears their mind. Well, that made me a fan right away. I thought, well, maybe I can do that. So, what I started to do was try in my shower.

Sometimes it was the only time where mom wasn't available, the door's shut. Teenagers aren't going to come bug their mom in the shower. It's the last thing they want to see. And I liked the noise of the shower coming down. And I started just a few times to just count to 10 when I was taking a breath in and out. Just, that was one, that was two. You get the idea. So, my brain is thinking about, okay, was that two, was that three, I'm staying on track. And at the end of it, I would tell myself, well, I am one human being and I'm doing the best that I can do.

And that worked for me. And some people say, well, that's a mantra. And I said, well, that's great, I have a mantra now. I'm one human being I'm doing the best I can do. What it did was give myself permission to just go about my day and do the best that I could. That that practice has grown. I still meditate in every shower. I've also learned how to meditate with some of the apps. There's a calm app. There are tons of them out there that can walk you through a process. I don't expect my mind to clear all the way, but what I noticed is, it settles my nervous system. If I can have 10 or 15 minutes of that still time where I'm either just counting my breaths, I'm saying I'm one human being, I'm doing the best I can do.

Some people will take a breath in and think about peace and then the other breath out, they think about love, and they may name somebody that they love. It. It doesn't really matter how you do it. It's just learning a practice that can kind of calm things down. It has helped me, the practice of gratitude, mindfulness, and that meditative piece have severely decreased the number of times that I get very activated with symptoms. The exception will be when I purposely do something that makes me nervous, like speak in front of other people. But I even find that after those times I can calm my system better. And people will say, Oh, Kat, you're just, you know, you're a positive person. You just take this in stride. This is just who you are. And, and I do believe a lot of that's true.

I think that some of us are inherently more chipper or more positive, but I also think that even those of us that are inherently that way have to work on it, especially with some major life blows. And I do work at it. And I do know that by choosing those pathways in my brain over and over again, by choosing the words that I use to define what's happening with my body, but also what's happening in my life makes a huge difference. We have a son who was diagnosed with type one diabetes, very young at the age of seven. And I did not have Parkinson's at the time. And he has since been in and out of the hospital for several different reasons, he's doing fine. He manages his diabetes well. The story ends very well. But what I've noticed is since I've learned these techniques, this summer he was in the hospital and he's a young adult now, and it was during the time of quarantine and I had to leave him there. Because A) I couldn't go in, because he was an adult and that was a first, and that was a very, very difficult thing for me to do. And no matter what my mindset was or what words I told myself or what meditation I had done earlier in the day, it didn't matter a whole lot while I sat out in that parking lot.

But what I noticed afterwards, after we had heard from the docs and he had been admitted to the hospital and I knew he was okay and I went home, is that I was able to get ahead of a horrible pit in my gut of leaving my child alone at the hospital and move towards solutions and really being present for him on the phone. Instead of falling apart myself, I felt it and I had tears and I had sadness, I got through that more quickly, and I know it was because I had those pathways. I knew the way to get back to it and to get out of the rabbit hole. And, oh, I wish I didn't have that comparison. You know, I give it every ounce to trade places with him and do the work for him, but I've had some tests and I've made it to the other side, and I've managed it better than I could have before I learned these techniques. So, I don't tell people I'm grateful for Parkinson's because I'm not going to be grateful for a disease that's progressive and degenerative. But I am so grateful for the tools that I've learned since being diagnosed. I'm grateful for the community that I've been blessed to be a part in.

I've been really lucky. I have been invited to speak internationally about being well and being resilient. I just finished a book; we're trying to get it published. You know, I've learned a lot of new things and I learned how to do a podcast and I'm the least techie person on earth. Talk about neural pathways. Boy, that was, I think I added a good 10 years to my life learning how to connect the internet and the podcast and how to do it to iTunes. And my podcast is called PD lemonade, and I like to talk about how we can make lemonade out of lemons. And I want to stress again though that you can't do it unless you do the hard work of grief and acceptance. And so, I don't want to minimize anybody that is feeling in that place, because until you get to that sort of acceptance of, okay, this was Kat before PD.

I called that Act One. And actually, I used to go by Kathy. So, I was Kathy, the midwife, Act One. I'm Kat, the advocate, author, and podcaster in Act Two. And somehow it helped to denote it for me. I'm not suggesting everybody go out and change their name, but I think words matter. And I certainly, I don't know, Gabby, do we have time for questions, or thoughts? Anything you're seeing in the feed? I have more content, but I want to allow people to ask questions if they want to.

Gabriella Dimotsantos (Community Engagement Manager, Davis Phinney Foundation): Yeah. We have about five more minutes before we need to transition back. So, it's up to you if you'd like to open that up for some questions. We just had one chat about your podcast, and I was able to get that link in there.

Kat Hill:

Oh, thank you. And I can certainly chat a little bit more too. If you guys want to hear a little bit about the wellness model that we propose in the book, I can talk a little bit about that. In terms of expansive possibility, I'm not here to tell you that I know the way to wellness. I'm just going to tell you the model that in my brain works really well. And at the base of the model is the rabbit hole. And we all know the rabbit hole, right? You go down, you don't want to be there. It's a hard place to be. It's filled with disses, disability,

disease, dysfunction and the scariness, the rabbit hole's unpleasant. When we lay down those neural pathways with all the things that I've been talking about, the gratitude, the word choices, trying to calm the nervous system, the quicker we get out of that rabbit hole and that's science, that's not me, that's not my theory. We know that to be true. The wellness spiral that we talk about is with the rabbit hole down here, and then expanse of wellness up here.

If you choose the words, I am well, I choose wellness. I will be well. Oh yeah, I have Parkinson's. Yes, I check that box when I go to the doc, but I believe that we tell ourselves a story and our story can be, Oh, I've got Parkinson's, I'm disabled. I'm putting up my disability placard. I'm confined about what I can't do. I think you can wear your disability placard proudly and say, these are all the things I'm able to do. I am able to walk still. My hands don't work very well. I have a lot of dystonia, so I've had to learn some work arounds. I am able to sing, not really well. I am able to paint, kind of okay sometimes if my hands are cooperating, but I'm going to focus on my abilities and that is expansive. In that spiral, we can move from the rabbit hole. We give ourselves compassion; we grow acceptance. We find community. We find likeness. We find others in our world that support our journey that are kind, that reciprocate, whatever that means to you. We maybe avoid those relationships that are more one way or always taking. And we all know we have those in our lives, right? So, we make choices about who our community is. We look for joy and resilience and we've all got it. My goodness, if we don't have it after this year, you all showed up here, you are all resilient people. Showing up to a webinar at the end, you know, after this year of warranty, and you've heard lots of ways to build resilience and ways to manage disease. Then you can get to the expanse of what I call intentional wellness.

My writing partner and I believe that you can intentionally be well, if you focus on the things that you can do, instead of focusing on the things that you can't. Linda talked a lot about that earlier today. And she was certainly an inspiration behind some of what we talked about. I had the privilege of hearing her speak in Kyoto, Japan. We spoke there in 2019 and I think also grabbing onto those stories of people who inspire you. You know, Muhammad Ali, who did we hear about? Jack Lallane. I love Jack Lallane. I mean, I know he didn't have Parkinson's. My dad was, you know, one of my heroes. He was a dentist for many years and was a mayor for a while and he got Parkinson's in his mid-seventies, but he was still up on his horse roping until he could no longer do it. I think he was about 77 when he finally got out of the saddle.

You know, focusing on what we can do, there's a lot, we can still do. We can love each other. We can enjoy our grandkids or nieces and nephews. And we also set the stage for how our families will age. Life is progressive and degenerative. Parkinson's is progressive and degenerative. You know, we don't get out of it alive. I'm sorry to say, no matter how much meditation you do. I think we're all gonna meet our maker someday. Right? So how you choose to live while we're still here, I think is what's going to define you and make your story. So, I think I'll leave it on that. I think we've got one more



minute, if anybody has a question. I hope it's been valuable to hear my story a little bit, and I'd love to connect. My website's kathill.org. If you ever want to reach out, I'm an ambassador. I love to talk to people who are newly diagnosed.

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