

The Victory Summit Virtual Event: Motor Symptoms and Parkinson's Living Well with Motor Symptoms Davis Phinney Foundation

Polly Dawkins (Executive Director, Davis Phinney Foundation):

And now, I am absolutely delighted to welcome to the stage our founder, Davis Phinney. You may have met Davis. You may know about Davis from various events that you've checked in on before, you may have met him at an event in person that we've done, or maybe even on a bike ride. Davis is the founder of the Davis Phinney Foundation. He and his wife Connie founded the Davis Phinney Foundation back in 2004, with the idea that people, really people with Parkinson's deserve to know more about living well and quality of life with Parkinson's. And that is the inception of the Davis Phinney Foundation. Prior to being diagnosed with Parkinson's at the age of 40, Davis was a professional cyclist, but for the last 20 some years, he's really become a Parkinson's advocate and leader in the Parkinson's community. Yay Davis! and in 2015, he was honored at the white house as a champion of change in the Parkinson's community. So welcome Davis.

Davis Phinney (Founder, Davis Phinney Foundation):

Thank you, Polly. And let me say hello to my people out there. Hey everyone. Thanks for joining us today.

Polly Dawkins:

Great.

Folks, you may say hello to Davis in the chat. If you've got questions for Davis, we'll take those as well. Davis, I thought we could replay the whole video since we were without sound. Would you like to play out that entire thing?

Davis Phinney:
Yeah.
Polly Dawkins:
Sorry folks. You're getting some thumbs up reactions. Feel free to use the reactions folks in there. We'll send a link to that video. So, for those of you who missed it, you can see it after the fact. So how are you feeling today?
Davis Phinney:
I feel great. Thank you.
Polly Dawkins:



Davis Phinney:

I slept reasonably well and mindful that I was getting up to speak to the Parkinson's nation, I went to bed early and took care of myself like I would as if I was going into a bike race or something today. So yeah, I feel good. Thanks.

Polly Dawkins:

Super. So that's one of the things that I wanna focus on today is with you is the things that you do to feel better, especially as it relates to your motor symptoms. Would you tell us a little bit about your routine, what you've learned over the last 20 some years? What do you do every day to help with your symptoms and feel better?

Davis Phinney:

My primary complaint for motor control issues is balance. I mean originally it was tremor and I mentioned that in the video, but that's been well managed by the successful DBS procedure over 14 years ago. And so, it's more balanced and having my feet sort of stick to the floor when I'm trying to move around the kitchen or put dishes away, things like that. So, I find that I need to be mindful as possible of what I'm doing, and even there's a split of what you and your Parkinson's are managing and what you're trying to accomplish with your hands like putting a dish away and not breaking and so I would say that that being mindful of whatever I'm doing and not introducing any more distraction into the equation is helpful. For sure.

Polly Dawkins:

Yeah. That's interesting. We had Dr. Jay Albert's speaking this week for us, a webinar on postural instability and freezing of gait. And he was mentioning that we're always dual tasking. Even if you're trying to reduce the number of distractions, as you're mentioning to a bare minimum, what you're talking about you're thinking about your feet, and you are trying to put away a dish. That's dual tasking.

Davis Phinney:

Yeah. Exactly. Well, and then when your feet are sort of stuck to the floor and you're twisting your upper body, you're, it's a recipe for a bad outcome. But so, I've found that a lot of it is being aware of tactics. And so, my tactic is to wear a supportive house shoe that's not so sticky, but not necessarily completely slippery either. And that works well for me to not have my feet sort of have the feeling that they're glued onto the floor.

Polly Dawkins:

So, what does a house shoe look like for you? It is just something you can slip on?

Davis Phinney:



Polly Dawkins:

Yeah.

Well, and what I like about this is that it has a foot bed, which is supportive of my dystonic foot, where my left foot, my toes tend to curl under. And so, I need some support for my toes.

Polly Dawkins:

Yeah. So, somebody's just asked in the chat, what is your exercise routine? You talk about going to the gym and doing this sort of circuit that you have created.



Davis Phinney:

Oh yeah. I mean, I'd have to show you, it's hard to describe, but we have elements where we have light free weight in our hands, and then we're balancing on a bosu ball. Yeah. If you know what that is.

Polly Dawkins:

Those half, those half balls.

Davis Phinney:

Half balls. Yeah, which makes it a less stable platform. And, you know, and you can do the weight as you see fit or just hold them in your hand. Or, and sometimes we'll throw something to each other. And we're always practicing our mind games, like name that tune, for whatever song is playing and the band and things like that. And or we set up a sort of grid pattern on the floor, with jump ropes and we'll do various foot drills between the squares. And I find having that grid is very helpful as a cue because, you know, again, my feet are reluctant to lift off the ground of their own accord. And so, I think it's really helpful to have a visual cue on the floor.

Polly Dawkins:

Yeah. That makes sense. And so, in addition to your gym workouts, what are other practices that you do to help with your motor symptoms and just your Parkinson's in general.

Davis Phinney:

Well, I mean, my background is cycling, and cycling is proven to be so good, not just for me, but for so many folks and Jay Albert's work has shown that. And so, I try to get out on my e-bike right. I mean, I make it a little bit easier for myself. I use an electric bike, but that said, I can still go as hard as I need to go and go up into the local hills and just enjoy being outside. And so, there's that. There's some amount of walking and hiking that I do with my wife. And so, you know, I mean, it's mostly just being active, and I feel like that's the vital piece that, you know, everyone hears from us about exercise, exercise, exercise, but it really is shown to be the one way that you can take back some power over this disease and the course of this disease.

And I feel like there's a multitude, variety of ways that you could achieve that. And if you're in a boxing class or tai chi class or dance class, those are all great forms of movement, but it's just the key thing is that you've got to keep moving and you've got to be active. And to a degree, the more that you can do that, the better you'll be served. And the longer you'll have a period of wellbeing. I mean, I've had Parkinson's for 20 years diagnosed, 22 years diagnosed and I'm still kicking pretty big, taking some big bites out of my kicks. So.

Polly Dawkins:



Well, good. Davis, thanks for sharing some of your tips and what you do to be active.

Davis Phinney: Well, thank you.

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