



**The Victory Summit® Virtual Event:
The Parkinson's You Don't See: When Your
Autonomic System Goes Off-Track**
"Living Well with Parkinson's"
Davis Phinney Foundation

Connie Carpenter Phinney (Founder, Davis Phinney Foundation):

It's great to be here and thank you, Polly, she's our intrepid leader of the Foundation and in charge of our phenomenal staff that allows us to do such great work for all of you. But we're happy to be here and we're happy to get that little intel on who's there, cause normally we'd be greeting you in person and we'd be standing at the front of the, a crowded room and we'd be asking, you know, you to raise your hands and

Davis Phinney (Founder, Davis Phinney Foundation):
and I'd be singing.

Connie Carpenter Phinney:
You'd be singing. Let's hear it.

Davis Phinney:
Oo I need your love baby. I hope you know it's true.

Connie Carpenter Phinney:
He does that because this morning his voice has been a little rough, as many of you can relate to and has had kind of a hard time modulating pitch. So, we've been singing for the last half hour. You've got it going on.

Davis Phinney:
Sort of.

Connie Carpenter Phinney:
Sort of. Anyway, we're happy to be here. We're happy to kind of ground you in the experience of being here today and prepare you

Davis Phinney:
And welcome all our first-time visitors. These summits are really we've been to innumerable ones, how much you can learn about this disease and there's, it's a complicated disease.

Connie Carpenter Phinney:
Yeah, really?



Davis Phinney:
Yeah.

Connie Carpenter Phinney:
You know what we were talking about this because there's this whole notion and you'll hear this if you haven't heard it before, you'll hear it many times amongst people talking about Parkinson's is that there's a constellation of symptoms, which to me in my imagination sort of leads me to think about, you know, looking at the night sky and identifying Orion, right? Like as if you know, oh, there, there it is.

Davis Phinney:
Or the big dipper.

Connie Carpenter Phinney:
Yeah, exactly. And the thing is, is that you, when you look at someone with Parkinson's when you're living with someone with Parkinson's, when you are someone with Parkinson's, what you realize is that it's not as tangible as looking at the night sky, which is in many ways, not that tangible, right? So, the complication of Parkinson's is that is kind of like looking for the constellations I think through a cloudy sky, we can't quite see it all. We don't quite grasp what's there and what you see on the outside isn't exactly what's going on on the inside. Which is, you know, Davis's problem with his voice. And sometimes people have that inability to give you the time and space to answer questions. Right. Speaking of which I need a glass of water.

Davis Phinney:
And so, what we, our question is, is how many of you have been watching the Olympics? We have. We're Olympic junkies.

Connie Carpenter Phinney:
Olympics junkies. And I should note that we're taping this now. So, some of you will be watching it later, but we're sitting here talking to you on end of the second week of the Beijing winter Olympics.

Davis Phinney:
Right. And so, as part of that, you know, there's all this speed and flights and amazing daring due that the athletes are doing, but that doesn't really connect necessarily with us and our current abilities. And so, Connie and I were discussing it and we had the idea that actually curling is a sport that maybe those of us with Parkinson's could metaphorically relate to.

Connie Carpenter Phinney:
Hey, wait a second. We got a lot of Canadians listening today. So, they can really relate to this cause this sport definitely came out of well, it actually came out of probably the far reaches of



the north, which includes Canada, but also England and Norway and Scandinavia. But I wanted to back up a second because 50 years ago I competed in the winter Olympics for speed skating.

Davis Phinney:

That's right. She was two years old.

Connie Carpenter Phinney:

Thank you honey. And I was thinking, I actually asked the question this morning, what's changed about the Olympics, which over 50 of years, a lot has changed and there's a lot of new events. And of course, you know, 50 years ago we didn't have snowboarding. We didn't have aerials. We didn't have a lot of the events that you see today and we didn't have curling.

Davis Phinney:

Yes.

Connie Carpenter Phinney:

And so, we started thinking about curling and if you've seen curling and if you haven't, I would challenge you to go, just look at YouTube or just check it out later because it's a very interesting sport. It's a team sport, it's a team sport. So, what they do is one person is tasked with throwing a 40 pound, not throwing, but gliding, a 40-pound stone, a granite stone down a sheet of ice toward the goal, the home, on the other side, anyway, as you watch, it seems very like, what are they doing? Because you'll see them release the stone. And then there's two people on either side with a broom.

Davis Phinney:

That are heating the ice to ease the passage of the stone

Connie Carpenter Phinney:

And actually curl the stone. And that's why it's called curling, but it's to change the trajectory. And so, we started thinking about how fascinating it was that curling requires tactics and skill and communication.

Davis Phinney:

And communication.

Connie Carpenter Phinney:

What else requires tactic, skill, and communication?

Davis Phinney:

Yeah. Living with Parkinson's.

Connie Carpenter Phinney:



Living with Parkinson's.

Davis Phinney:
Especially living well.

Connie Carpenter Phinney:

So we started thinking about that, you know, that the it's metaphorically, it really works too, because if you think about it, there's like this manifestation of, you know, the person with the stone, that's the person with Parkinson's and the people around them that are helping them to curl the stone are your caregivers, are your medical team, are your, you know, your other people with Parkinson's who are helping you. And that's one of the things we lose when we're on zoom together is we don't get to look across the table and meet other people with Parkinson's or other caregivers, and really get to share our stories one on one and grow our team. So that's why you're here. You're here because you're trying to improve your tactics and your game.

Davis Phinney:

And if you picture the stone as Parkinson's, then that's what works well for the complete metaphor. Only, I would say that you're not trying to knock other people with Parkinson's out of their ring.

Connie Carpenter Phinney:

Off their trajectory or out of their winning target. Yeah. It also doesn't work completely, but because we're in the throes of the winter Olympics and really enjoying the accomplishments of others, we thought we'd try a little light on that. Shine a little light on that. Yeah. And get you thinking about something else besides Parkinson's, cause we're gonna do a lot about, a lot on the topic of Parkinson's today and we're gonna talk about symptoms and really potential symptoms that you may or may not be experiencing now. You may never experience. And that's also part of what's so uncanny and so confounding about Parkinson's is that not everyone will have the same journey toward the end game. And that makes it complicated and we're not, some of the things you're gonna hear today may frighten you, you're gonna say, I don't have that, or I don't know what you're talking about. Put through questions in the chat and file some of this in the back as just gaining information and expertise for what may come down the road or what may never come down the road. But it's just important to know what could happen or if it's happening how to manage it, because so much of Parkinson's is manageable. And your path like that curling stone going down the ice is correctable, right? Yes. And it takes management and, here at the Davis Phinney Foundation and the biggest thing this guy does is exercise, keep moving. And that's kind of number one. It's not for everybody it's for most of you though. And I think for most of us caregivers help by moving, keeping going. And that's really why we call this the Victory Summit because we're all focused on the small victories as this guy will say, the arms up.



Davis Phinney:
Lifting those arms up.

Connie Carpenter Phinney:
We'll do that at the end.

Davis Phinney:
I know. I couldn't help it. Just hearing the V word.

Connie Carpenter Phinney:
Yeah. I know. Yeah. So, we're here to bring you that winning mentality and to help you demystify a very complicated journey

Davis Phinney:
Especially on today's subject.

Connie Carpenter Phinney:
Yeah. Because you know, having the autonomic symptoms, if you have pain or you have digestive issues, which is me as well as other aspects so like NOH, the dizziness and whatnot, then we have some very good speakers today who will talk specifically about those issues. And then in our short interim between topics, we have people who are addressing specifically how to deal with those issues from an exercise standpoint. Movement breaks.

Connie Carpenter Phinney:
Yeah. And I think just to say to all of you, we're just so grateful that you showed up today. You're showing up for yourself and for everyone around you by taking this journey and kind of expanding your own bandwidth and ability to deal with it. So, thanks. Thanks so much for showing up, know that you're not alone. And that's really why we at the Davis Phinney Foundation are here.

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