



## **The Victory Summit® Virtual Event: YOPD**

### **Welcome and Inspiration**

Recorded on June 26, 2021

Davis Phinney Foundation

Amy Montemarano (Davis Phinney Foundation Ambassador, YOPD Council Member):  
Hi everybody, and welcome to the Davis Phinney Foundation Victory Summit Event today where we're going to be talking about living well with young onset Parkinson's. My name is Amy Montemarano and I'm gonna be your host for today although we have learning this morning that my computer and my zoom connection are having difficulty so I might end up freezing and coming back, but we are going to solve that problem as we go, I apologize in advance. One of the things that being diagnosed with Parkinson's forces on a life is the need to shake off some things that don't matter, the small stuff, and this is some of the things I would consider the small stuff. So, I'm hoping the technical difficulties don't get the best of us. Another thing that Parkinson's forces on a life is the need to reassess the things that you say no to in your life and the things you say yes to. I have been saying no to a lot of things that I normally would have said yes to before my diagnosis, but when it comes to the Davis Phinney Foundation it is always a yes. I always say yes, and that has improved my life immeasurable and that's a really easy choice. So, I really want to thank the Davis Phinney Foundation for this opportunity. I love everything you do, I'm happy to be here and happy to be part of it, thank you so much.

I was diagnosed six years ago at age 48. And like many of you, the diagnosis came as a complete surprise. I was otherwise in the middle of a very healthy, active, busy life. I was still, am married and working full time and my two kids were in middle school.

Six years later, I am still working in the same job full time that I was before. I'm a faculty member at a law school here in Philadelphia. And I have also started some coaching on the side, career and life coaching that has morphed a little bit into travel coaching, so we're having a lot of fun. And, well, my life has been made harder, of course, by having Parkinson's. But there are many ways in which Parkinson's has made it better.

And I want to put a disclaimer on that at the end, but in the ways that life is good, right, in strengthening relationships and finding purpose and meaning and personal growth and finding your own strengths and creating new things and helping other people and realizing the power that you have to do some good in this world, those are the things that Parkinson's can turn from good things into exceptional things in your life and I know that that's how it has happened for me.



You're going to be hearing today from a bunch of panelists who come from different roles in the Parkinson's community. Some are doctors and some are the wonderful people who work at the Davis Phinney Foundation, and others are people like me who are people with Parkinson's, and they are all incredible but they're also ordinary people who have who have turned their post diagnosis life into one with meaning and purpose and joy. And that's what we're here to talk to you about today, and I think if there's going to be one theme that bubbles up over the course of the day it's going to be this; Being diagnosed with Parkinson's is not the end of you. It's not even close. And I have personally received enormous gifts of spirit from being involved with the Davis Phinney Foundation and I want to encourage any of you who are out there in the audience who are newly diagnosed, to give yourself permission to not only grieve what you've lost, which is a really important step in moving forward but also celebrate the fact that there will be joy, there will be laughter, there will be freedom. There might even be some lightness of being after your diagnosis and the rest of your life and I want to encourage you to not just give yourself permission to enjoy that and celebrate that, but I also want to say because I'm kind of a preachy person, that you owe it, you owe it to the world, you owe it to your loved ones and to your family, and you owe it to yourself to enjoy the rest of your life in the ways that you can, and to live the hell out of life because you can, and others cannot. So, um, that's my lecture.

And before I turn it over to to Mel and, and everybody who's coming next, I do want to say that the messages that you're going to hear today are going to be overwhelmingly positive about living the rest of your life after being diagnosed with the young onset. We don't want to sound tone deaf, we definitely recognize that having Parkinson's is really difficult, and that many of you and many of us struggle on certain days very much, and the message is not that you need to disavow that suffering or ignore it or pretend that it doesn't exist. The message is that it takes some work and daily practice to shift your mindset to something more positive.

And in that sense, a particular quote by Mel, it's something that I actually put up on my mirror and I look at every morning and that is, quote, "You cannot think your way into different behaviors, behave your way into thinking differently," which I think is exactly what is needed in our post diagnosis lives.

And with that, I have the pleasure of introducing our first speakers today, although they probably need no introduction, Mr. Davis Phinney himself and Polly Dawkins who is the Executive Director of the Davis Phinney Foundation.

I am sure that Davis and Polly have a lot in common that I don't know about but the one or several things that I do know that they have in common are that they're both extremely resilient people who challenge themselves to their limits and have enormous hearts.

Mr. Phinney as you know is a former professional cyclist who turned all of that grit and strength of character and discipline that he used to become a professional cyclist into building this very organization after he was diagnosed with Parkinson's at age 40 over 20 years ago.



And he is personally responsible for an enormous amount of good that he's done in this world and tipping the world's energy into something that's really exceptional and remarkable, I just want to thank him for that. His sheer force of nature, himself, that's doing all this, and I think it's been so fabulous for this community.

And, Polly Dawkins is, will not remember this and probably doesn't know that she is my personal hero, but I met her when the Victory Summit was not virtual, when it was going around the country and they came to Philadelphia where I live.

And she was on stage, and she not only was an enormously powerful speaker with a great message, but I was obsessed with her boots that she was wearing, so much so that I went up to her afterwards, and just I wanted to know more about her boots I couldn't get enough of them. At the same time, she is someone who can finish the Ride the Rockies bicycle ride, which is over 300 miles, 20,000 feet up on a bicycle. And I think it was last week, maybe two weeks ago, in that hundred-degree heat right, so I mean, thus my personal hero, someone who can do a ride like that and also rock that fabulous pair of boots on stage. That's Polly. So I'm going to turn this over to Davis and Polly.

Polly Dawkins (Executive Director, Davis Phinney Foundation):

Thanks, Amy. I don't remember that, but thanks for that. Good morning everyone, morning Davis. We got to get you unmuted so we can have a conversation here.

Davis Phinney (Founder, Davis Phinney Foundation):

Yes, the proverbial zoom. Thank you, Amy so much. Can you hear me?

Polly Dawkins:

Perfect.

Davis Phinney:

All right. Well I'd say that we should almost straight away give a victory salute for Amy.

Polly Dawkins:

Ready?

Davis Phinney:

Yeah, 123.

Polly Dawkins:

So, Davis, we have 20 minutes here to chat together today, and help our audience understand who you are a little bit more deeply and why we do the work that we do thanks to your leadership and your vision. So the first thing I'd like to ask you is, it's been 20/21 years since you

were diagnosed, but if you could take a journey back to the day when you were diagnosed, and the initial months after that. Can you tell us all what was going on in your head?

Davis Phinney:

Well that's an interesting question because I almost have to back it up a little further and go to the days when I was searching for diagnosis but hadn't yet found one. And that search was proved fairly exhausting because my wife and I would go to various specialists. And I'd have to tell my whole evolving health history, and never getting the right answer but having some alarming conversations with like a neurosurgeon who said, I don't know what's going on, but we better get inside that skull and find out. And so that being said it was kind of, it was almost a relief to have a diagnosis that wasn't like terminal brain cancer. And so, I would say that then going from that one conversation which proved correct, my diagnosis, that was, it was sort of the start of my learning to accept having this disease.

Polly Dawkins:

Great. Davis, what was the catalyst for you to seek a diagnosis?

Davis Phinney:

Well, I mean I had struggled for years with physical ailments that I couldn't resolve via my normal athletic ends but really it was when I was working in Australia and this camerawoman was shooting me doing what you call on TV, a stand up. And I was sitting there shaking like a leaf and she was like, "Davis, what's wrong with you mate, it's not cold it's like, it's boiling hot here, you know, there must be something going on." And so, in that observation, and that feeling of having this uncontrolled tremor in my body led me to go home and start down this adventurous path that I've been on.

Polly Dawkins:

So at that time, it sounds like you weren't professionally, you were retired from racing, and you were a sports caster? Tell us about that.

Davis Phinney:

Well, yeah, I mean, I had been retired from racing for almost seven years at that point and had involved myself in too many endeavors almost. I was in perpetual motion and constantly traveling and going to events and broadcasting and working in sports marketing, and Connie and I had our bike camp business, and two small kids and I was like the proverbial soccer dad. So I was just going like so fast and so I had to sort of take stock at that point and figure out A, how I could maintain an income stream, but B, what jobs I had to let go of as they weren't going to be conducive to my good long-term health.

Polly Dawkins:

Which jobs did you choose to stay with?



Davis Phinney:  
Relinquish or stay with?

Polly Dawkins:  
Yeah, to stay with.

Davis Phinney:  
I mean the choice was between suffering for my job, which was mainly in television, and the travel and stress there. And I'd already noticed a decline in my ability to come across naturally, and what not. And so that job went but the job that I hung on to for almost 10 years longer was the bike camp business that was controllable to a degree and my wife was the architect of those camps.

And in a large way what the camp provided for me was somewhat what the Parkinson's community is now on a much greater scale, which is that I was able to connect directly with people and get them enthusiastic about cycling and change their lives in a positive way.

And that I felt was really powerful for me, for someone who was starting to lose ability in various areas, just to have that capacity to still inspire, is what's gratifying.

Polly Dawkins:  
Sure. So when you were diagnosed and you were going through the process of deciding what you were going to keep in your life, your career, your kids were young, you said, you were 40. Tell us a little bit about what resources were out there when you were diagnosed, and what were you told to do.

Davis Phinney:  
Resources? What resources... I mean one reason that I started the Foundation was to help guys like me, who were middle aged or, at some point midstream in their lives and had had this big interruption. And to help to provide answers for some of the questions, because I felt like I was very much alone in those days, and that was not a good feeling.

Polly Dawkins:  
Yeah. So, when you've talked about starting the Davis Phinney Foundation, when you were diagnosed for a few years, when did you realize that your own experiences and the tactics that you were employing to live with Parkinson's and your voice could ultimately help others with Parkinson's?

Davis Phinney:  
Well, I mean it was a few years from diagnosis to the Foundation starting, and even in that the Foundation didn't start with quite the same vision that it has today. But again, I mean my basic



personality is to be able to inspire people, I mean that's what gives me energy and whatnot. And I would see people, and they would remark that you know, geez, you look pretty good.

And I would think well I must be doing something right. And so, those kinds of interactions, as well as running into people who would say, well, I'm just waiting for somebody to cure me. But while they were waiting, they were precipitously declining because there was no action oriented in that way.

And so, I felt like if I could stimulate my own neurons to fire more to behave a little bit better that maybe that same protocol would work for others.

Polly Dawkins:

Was that grounded in your experience as an athlete and how have you used that perspective to live with Parkinson's?

Davis Phinney:

Yes. I mean, that's a great question because I think that all my life, I've been training in a sense to live well with Parkinson's.

And the way that I define how you live well, and what you need to do, is to stay active and stay engaged, and as Amy said, stay positive. And it's not one thing. It's all the things that you do throughout the day. And it's all the engagement and it's not saying no, again, as Amy said, it's not saying no to the invites, to do a class, or get involved or in some way, find those moments of joy. And that's what I would say equates to making every victory count.

When I was a bike racer, making every victory meant every town sprint sign that you'd go by in a training ride was like an opportunity that you couldn't let pass up. So the group of riders who were just out for a training ride would all sprint for these town city limit signs and you know, yeah, if you did that sprint, that counted for something.

And so today, living with Parkinson's, it's quite a bit different, but the feeling of victory can be somewhat the same if you give it the attention. And you're able to focus on the little things whether they're, you know, your daughter coming upstairs as she does because my daughter lives downstairs from us and she'll come up just seeing her smile, that's a victory. You know or taking the dog for a walk. You know, whatever it is, if you give that positive spin then I feel like that's a way of living well on a consistent basis.

Polly Dawkins:

Have you approached living with Parkinson's exactly that way for 20 years or have you grown into that perspective?

Davis Phinney:



I've grown into it because you know initially when you're diagnosed, you end up, I mean I ended up floundering around a little bit, because it was not as the doctor advertised, which was the, you know, once you take meds, you'll feel as good as you ever have.

And that was not true, but also at the time, conventional wisdom said that Sinemet was something to be avoided until you had gone through your choices, but the agonists didn't work for me. And so I ended up kind of falling off a cliff in the beginning, and I had to scramble up and climb back up and figure out how to deal with this disease but again, I didn't have the information, which the Foundation now provides to find those answers to the difficult questions.

Polly Dawkins:  
You must be proud of that.

Davis Phinney:  
Yes, exceedingly.

I mean, I feel like you and others give me too much credit for being the namesake of the Foundation. But if there's one thing I've done, it's been true to the vision of how do we help people the most to live their best with this disease.

Polly Dawkins:  
So if you were to look back over lessons that you've learned and thinking about our audience today of what seems like a lot of people in their 40s, maybe recently diagnosed or living with young onset Parkinson's for some time, what would you say are three pieces of advice that you would give to our audience as we wrap up here today?

Davis Phinney:  
I would say again, to reiterate, just be consistent, create healthy, sustainable habits, and then stick with those habits, and define how you've achieved your best day recently and then focus everything on recreating that.

So that would be one piece of advice. And I agree with Amy that attitude is so important, and if you can manage to stay positive and stay upbeat and use your smile to fight the mask, then that's another critical component of living well.

And lastly, I would say, if you can connect to this wonderful community, which is our Parkinson's tribe, then that is as important as anything to know that you're not alone. And that you can reach out to someone, and they'll have, and they'll be a friend or give you an answer to your question.



And so, connecting with the community, especially in this time as we transition out of the pandemic, the pandemic has certainly been hard for all of us, but I feel like if we can count on each other and back each other up then that's an important point to true.

Polly Dawkins:

That's so true. Wise words from Davis Phinney. So, I heard, create good healthy habits, stay positive, your attitude and connect with your community, this community. Really sage advice from the one and only Davis Phinney.

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