



**The Victory Summit® event: Newly Diagnosed
Welcome and Inspiration with Davis & Connie**
Recorded on Feb 20, 2021
Davis Phinney Foundation

Davis Phinney (Founder of the Davis Phinney Foundation):

Thank you, Mel. If everyone can hear, welcome to our Victory Summit. We're certainly happy to be here. And the only downside of not seeing you all in person is that we can't high-five and give hugs and all that, but we'll do our best to make this as personal as possible. So, newly diagnosed is the thing which can be a very daunting place.

Connie Phinney (Care Partner, Board of Directors Chair, Davis Phinney Foundation):
Yeah. I want to welcome everyone and thank you for joining us. It's a beautiful Saturday here in Boulder, Colorado. And everybody's calling in from all over. We got to check in when you were first signing on and it's fun to see from Saskatchewan, from England, from New Zealand. Yeah. All over the place. It's really a lot of fun to see that. And I think that, you know, what we really want to do is just embrace everyone and welcome you into this tribe that you are now fully a member of, and everyone just kind of take a moment and really be here with us. You know, let's do that first before we jump in. And before we say too much and do too much and overload your brains, let's just take a moment, everybody together, all, you know, five, six, 800 of us, however many are here, you know, we're in our living room, but really, we're all together. Okay. So, let's just, you know, take a breath, everybody together, we're going to inspire together.

We're not going to expire together. We're going to exhale together. So again, breathe in and out and just be here, be right here with us, because this is a big day and a big moment. And for so many of you, it may be your first time and, you know, really confronting this diagnosis. I saw that a number of you had been diagnosed within the last year, and it's always been my intention and my hope that we would be able to bring a Victory Summit like this to you; you that are newly diagnosed, you that are so much in need of community and inspiration and information. So, I asked Davis, I really challenged him this morning to think about, and you know, we actually had a little bit of a disagreement over how to tackle this conversation and welcome you because I wanted him to be really honest about what it felt like in that first year.

And for Davis, it was in the year 2000, it was 20 years ago, you know, 21 years ago. I'm at the age of 40. So, he was very young, and it was a really big shock for our family. We had two young children at home, ages six and ten. And you know, he was really hitting a stride in his career, when, you know, I will say from my perspective, he was just inordinately tired. That was the first, I mean it wasn't a giveaway, you know, you don't guess that you have Parkinson's because you're too tired. I just thought he was traveling too much. He'd been in Australia and Switzerland and, you know, he just couldn't keep up. He'd come back from all these trips, working television or doing other

jobs and just be exhausted. And with that, you know, I missed some of the actual early symptoms, which he had a very rigid arm, he kind of carried it like a wing. He was stumbling a lot. But there were a lot of indicators that now I could maybe spot in someone with Parkinson's, but I certainly didn't know that then. And I think going on in your body, you were just feeling exhausted.

Davis Phinney:

Well, right. And at the time, I mean, what spurred me to get a diagnosis was a TV event that I was covering in Australia and I couldn't hold the microphone still and the camera man was like, "Hey, Davis, what's going on?" And you know, it was 40 degrees out.

Connie Phinney:

Yeah. Yeah. You weren't shivering! And you weren't nervous!

Davis Phinney:

And so that really spooked me. But then the process of diagnosis was at that time, very difficult.

Connie Phinney:

And it still is for a lot of people.

Davis Phinney:

Because there just was not the information that there is today and nor the examples of young onset. And so, as a 40-year-old in Boulder, Colorado who had this reputation of like...

Connie Phinney:

Superman!

Davis Phinney:

Well yeah, you can say that. But, in any case, yeah, most of the neurologists that we saw were not willing to look at me in that light.

Connie Phinney:

Yeah, we went through quite a journey during diagnosis phase, as everyone does, I think. And I saw a few people had chimed in on the chat earlier saying that they weren't diagnosed yet, but their neurologist was thinking that way. And, you know, it's unfortunate that there's not just a little dipstick you can put in, like a pregnancy test to know yes or no. But the fact is it does take some time and it's a difficult diagnosis as well. But you know, when Davis was diagnosed, there was no real access to information. Just to give you a sense of the timing of it, it was right around the time that Michael J. Fox had announced that he had Parkinson's, and of course he'd been suffering with it for probably a decade before he announced it.

But at least we could see another young person out there and a young, vital person that had Parkinson's, which helped it to sink in, but it was way before he ever started his

foundation. And even then, that was geared toward a cure. And so, I want to tell you something about our foundation and kind of the beginnings of it. A big part of it had to do with my mom. My mom had multiple sclerosis and she was diagnosed when I was five. She was 30. And at the time there wasn't a lot of treatment available or information for people like them as much less support for the family, but both Davis and I really admired my mom and her ability to live with her disease for a long time. She raised four children. She kept a great attitude.

She cultivated a wide circle of friends, but who I really learned a lot from was my dad. and my dad was for caregiver especially in the later years of her life. And I feel like what I learned from my dad, and I want to share this with you because I think it's important, is two things. One, it really helps to have a mentor. So, if you're in this, either with Parkinson's or as a caregiver, the best thing you can do is find someone that has walked this path before. And it doesn't have to be with Parkinson's. It can also be with other chronic illnesses. You will learn a lot from other people as well. But what I learned from my dad was that, you know, he said at one point that he felt when my mom was diagnosed, that he had lost his ambition.

And he meant that in a business sense, but in the true meaning of being a good dad, what he committed himself to and what his ambition was, was to raise his kids, his four children. And he did a great job of that. And he did a great job of looking after my mom. So, if I could tell you one thing in this diagnosis space is don't be afraid to shift your ambition. You know, as you come into this, it doesn't mean you're going to leave your job. Many of you are already retired or maybe your best work years are behind you, but some of you are young and you're in the throes of it. And don't be afraid to reconsider what that ambition is, and this is a great opportunity to evaluate how you want to live your life.

And I think what Davis and I chose above everything else was quality of life. And because we couldn't, with my mom, we couldn't, you know, they kept saying a cure was around the corner for MS and Davis and I didn't want to just wait for a cure. His whole ethos with the foundation, and the whole mission of the foundation is to help people with Parkinson's live well today, not to wait for tomorrow. So, think about that when you make decisions out there, you know, about your job, about your family and just make every day the best you can.

Davis Phinney:

Because the choices that you make now early on in your diagnosis will last and have ripple effects for years to come. And so, if you can make good choices and make informed decisions that will help you so much. As I say, and Connie put it well, to live well with Parkinson's.

Connie Phinney:

Yeah. And you know, let's also talk about a couple other things. Like I asked Davis, to write down a few things, what he thinks are the most important things to know in this initial phase, I wanted to also say that when you are diagnosed, you're diagnosed by a

specific doctor, and you might think that that's your only choice. We have some great doctors on today. You'll see their styles, but I don't know about you, but not everybody resonates with one doctor versus another. And so, I would encourage you to make sure that that diagnosing doctor is actually the doctor that you want to be on this path with and see what the choices are out there that are available to you. You know, we're all limited by geography and insurance and all of that, but in this time of growing telemedicine, you know, probably the best thing we've gotten out of COVID restrictions is the easing of access to telemedicine. And, you know, we've been pushing for that for a long time in the Parkinson's community, to be better served. And so please, please, please look out there and see what's possible for you. And I can tell you that after 20 years living with a person with Parkinson's, that we still continue to learn ways that we can better manage this disease for Davis at different times in his disease progression. Keep that in mind too.

Davis Phinney:

Because Parkinson's is a moving target. And it's very hard to adapt to the medicines, at least in my case, early on, when I was first diagnosed and the doctor was kind of throwing darts it felt like and saying, well, try this and try that. And I ended up shooting almost all medicine for a few years just because I hated the way it made me feel and it was not helpful. So, I felt like I was stumbling around in the wilderness for a few years until I finally found a good movement disorder specialist.

Connie Phinney:

Yeah. And understand that too, that there is a distinction, and maybe one of the docs will talk about that today too, between a general neurologist and a movement disorder doc, who has special training, an extra year of training working with people just like you. And I think that's a big bonus if you can find that person for you. And it might mean that your neurologist is more handy to you or whatever, but you may want to consult at times with a movement disorder doc. Don't rule that out and then maybe a long wait, but that's okay. You've just been diagnosed. So, if your appointment isn't for six months, that's okay. You know, you've already gone through the initial phase and you're working with someone but make that appointment and really look out there to see what's available.

And a lot of times when you go to a movement disorder doc's office, you'll find other resources that are available in your area. And that's, I think another big point that Davis and I, and the Foundation like to promote as community. That's what we are today. That's what you need. Isolation is worse for you than smoking two packs of cigarettes a day. It's worse for your health than that. So, in this time of COVID where we've all been more isolated than normal, it's been especially difficult, but reaching out, staying available, staying open, staying curious in your life will really help you and help the direction that you're going to go with this disease. And then Davis is also going to add, stay active.

Davis Phinney:

Yeah, I was just going to say. I mean, my number one and number two advice for living well with Parkinson's is to stay active, to keep moving and to yes, exercise, if you can.



And that as well as is asking the Foundation to send you a free copy of our Bible on living well, which is the Every Victory Counts manual.

Connie Phinney:

And you might not be ready to read that whole thing right now. In fact, it may take you years to get through it, but you'll be able to scan through it. You'll also be able to show your friends and relatives when you're trying to explain the disease so that they can page through it. It's really, really helpful to have that document. And it's, you know, it's a good document with lots of information has been updated several times. We have a lot of guest writers in there, and a lot of people with Parkinson's that have weighed in and talked about these tough topics. The other thing I want to make sure you understand is that we have an ambassador program with the Davis Phinney Foundation that's amazing. We've met the coolest people not only in the medical community, because we do get to meet a lot of doctors and we have a number of them on stage today, and a lot of physical therapists, but we've also got these amazing people with Parkinson's who are in our group of supporters who are motivated to reach out to you and to answer your questions.

And it's really, you know, when I was a coach for cycling, as an athlete, I didn't know what I knew until I started coaching. And I think that's what ambassadors find out. They don't really realize what they know until they start helping other people to understand how to navigate this journey. And I think that's been the same for Davis. The number of people that he's mentored and helped through this, that you don't know what you know until someone asks you a question and you're like, you know!

Davis Phinney:

Well right, and that's part of the community aspect of the disease is that there's more people around you than you think that have Parkinson's and there's more of them who are willing or needing to reach out. And so, you know, the one thing that you should never feel like is that you're alone in this journey because thanks to the internet, we're all accessible so much to each other and that's vital.

Connie Phinney:

Yeah. Reach out. So, what else do we need? We got just a couple more minutes before we're going to launch this great program today. So, what else would you add?

Davis Phinney:

I would say that we listened to Sanjay Gupta, who is a renowned doctor neurosurgeon, and his number one advice for maintaining good mental health as you age for Parkinson's or anyone, was to take a walk with someone and have a discussion on some interesting topic.

Connie Phinney:

Nothing ages you faster than inactivity and isolation. Those were his two takeaways. From all the science, all the research, everything that he looked at, better than puzzles, puzzles on the computer, in your newspaper every day is conversation. And if you can't

see someone now because of COVID and because of the restrictions, you can still do this, on zoom, FaceTime, phone calls, across the fence, you know, sitting six feet apart in the park, if it's warm enough, things like that, you know, like just keep getting out there, challenge yourself, learn new things. Even if the new thing is just the news of the day, that's something new. You're challenging yourself. So, yeah, move, don't stop moving, keep moving. And if you have to set a timer to get yourself off the couch, do that too. We learned that from a friend yesterday with Parkinson's who said that he and his wife, every 90 minutes during this last year of COVID, they have a buzzer that goes off and guess what they get out and move just for five, 10 minutes. But, you know, it's a way of keeping yourself from just sitting because sitting is not good for anything.

Davis Phinney:

Well and lastly, what I'd say for you newly diagnosed folks is just to be open and honest about your disease with yourself and with your immediate circle around you. Because it's in accepting that you have this disease, that you start to be able to make the choices to go forward with it and that's so vital, and so, hopefully today you'll be inspired to accept and move forward.

Connie Phinney:

You know what the beauty is about today is you've made the choice to be here. You've shown up. So, we want to thank you for showing up. And we want to thank all of our speakers and our ambassadors and, you know, especially Mel and Polly and everybody at the Foundation that makes all of this happen for all of us and all of you. So welcome. Thanks for being here. Let's get after this day, are we going to start with a hands up or are we going to finish with a hands up?

Davis Phinney:

We'll do a high five.

Connie Phinney:

Yeah!

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