



**The Victory Summit® event: Newly Diagnosed
How to Advocate for Yourself**

Recorded on Feb 20, 2021
Davis Phinney Foundation

Polly Dawkins (Executive Director, Davis Phinney Foundation):

My name is Polly Dawkins. And I work at the Davis Phinney Foundation and it was probably nine years ago that I had the pleasure of meeting with Steve Hovey. And we have the opportunity to meet one another on a week-long bike tour in Colorado. That was a fundraiser for the Davis Phinney Foundation. And it was a fairly small group of us. So, I got to know Steve pretty well. He taught me quite a bit about cycling about psychiatry, and then years later I had the opportunity to meet Nancy. And I think of Steve and Nancy as really terrific examples of living well with Parkinson's. They are, they're advocates, they are parents, they're grandparents, they work, they are businesspeople, they're incredibly generous with their time and really inspiring to look at how they have navigated living with Parkinson's for so many years and advocating. So, I'd like to turn it over to you, Steve and Nancy, and you have the floor now.

Steve Hovey (Davis Phinney Foundation Ambassador and YOPD Council Leader):

Okay. Thank you very much. Like I said we, we did a PowerPoint, but unfortunately Nancy has a new computer, and I am not the most tech savvy person in the world and I can't figure out how to get the darn thing, plus it's a Mac and I'm a PC person, which makes it even more, anyway, I can't get it up so we will fumble our way through it. But good afternoon, everybody. And I want to thank you for you know, coming in and listening to us and, and also thank you to the Davis Phinney Foundation for giving us the opportunity to share my thoughts. You know, when I was asked to lead this discussion, I thought, Oh, sure, you know, I'll just go pull up some old notes and brush them up and be good to go.

But as I started doing my research and one thing led to another and one, I went down one rabbit hole and ended up going down another, the next thing I knew everything was changing and it's a completely different discussion and I've realized how important advocacy is. And so, I'm going to try to cover, Nancy and I are going to try to cover in 30 minutes, what we could probably talk for hours about. So, what does advocacy mean for yourself? And from a Parkinson's perspective? Well, I think simply put it's taking actionable steps to, to help enrich the lives and make the lives of not only yourself but other people with Parkinson's better. You can do this by fundraising. You could do this by getting involved in local studies, clinical trials. You could do it as being a mentor, a teacher, instructor, or taking the time to be able to lead in a Parkinson's support group.

It's really the difference between being a patient or being an advocate for our Parkinson's cause. And, you know, I understand that everybody's in a different place. So, you know, sometimes you can't get as involved as you'd like to, but just, you know,

really doing what you can. I chose to get involved because I was inspired by others to do so, Davis being one of them, who I met about two years into my diagnosis. And what these folks inspired me to do is, life gave you Parkinson's, so you know, it gives us a sense of purpose and cause to help others. So, let me begin by saying that there's so much within our power, to live well with Parkinson's, but it does involve advocating for yourself as well as for the greater Parkinson's community.

Now if you had the slide, you would see, what I call the cornerstones of Parkinson's, it's a beautiful presentation. And it's knowledge, community, medical team, exercise, and attitude, the five components. I know we talk a lot about exercise, and we talk a lot about attitude and they're incredibly important, but we're going to focus on the first three: knowledge, community, and medical team. So, starting off with medical team, having the right medical team, it's a starting point about advocating for yourself. In my role as a Davis Phinney Ambassador, I've had the privilege to meet with people from all over the country, and a lot of them have been recently diagnosed, and they're just struggling to get the right guidance. And some of the frustrations that they've shared with me is that they they're just not getting the advice that they need.

So, I was thinking of an analogy and I'm thinking like when we go to buy something, like you're buying a car, for Nancy and me, it was a couple of weeks ago, our refrigerator just died and all of a sudden, our food is going bad. And we're like, well, what kind of refrigerator are we going to get? And I didn't realize how many types of refrigerators there were, but I wanted to get the right one. So, we, you know, we checked out Lowe's, we checked out the local appliance store, we checked out pricing, you know, ratings, everything. And we spent all this time to buy the right refrigerator. But so often when we get sick or something like this happens, it's like the doctor will say, go see Sid. Or, you know, I heard of this guy or the insurance brand says, this person is in network and that's the person you see.

And maybe that's the person you see in the beginning. But my advice to you is if you go to see, especially in our case a neurologist, they're basically just helping you with medicine and with little else of substance, make a change. Find a Parkinson's neurologist, especially one that his specialty is in movement disorders. You need to ask around, get references. This is a really important decision. Now I know earlier this person, I can't remember the doctor that spoke, but he mentioned that, and it's true. Some of us don't live in a metropolitan area where we have a whole lot of choice. But the importance is still there. The idea of telemedicine, which is, you know, the one, I think positive thing of COVID is we've learned that that actually can work. Find a doctor even is that doctor's a hundred miles away.

Maybe you can visit once a year and work with them remotely. The other visits during the year, but it's a critically important part of your care team and as is any other doctor, whether it be a your physical therapist, or, you know, any doctor. You want to get folks that you feel are in your corner that are really part of your team and they care about

you. Now sometimes insurance gets in the way, and I understand that. If you have the ability to shop insurance plans, do so. I know the plan that we're on, we're actually paying more per month, but in the long run, we save a lot of money for the year because of what they cover and what doctors and medicines they have that I can get in the plan. If you find the right doctor or therapist, and they're out of network, try to work with your healthcare provider and your insurance provider to see if they can work something out where you get charged an in-network fee.

I've actually had some success doing that. I've had some failure doing that, but I've also had success doing that. So, it's not a guarantee, but you be surprised. And it's the same thing with prescription drugs. About two or three years ago, I started taking a slow-release levodopa it's Rytary® basically. And it works very well for me, but the copay was extremely high. So, working through my pharmacist, I was able to get that the \$150 a month, this was three years ago, knocked down to like \$25 a month. And that was just working through, you know, my pharmacist and going directly to Rytary. So, again, you may have some luck doing that, so don't be afraid to do it. You must advocate for yourself.

Knowledge, and Polly knows me back in those years. I kind of went about life in my early years of having Parkinson's like everything was okay, like nothing was wrong. And for the most part, I got away with it, but as time went on, I started noticing the progression. That was when I decided that, you know, I'm going to take this a little bit more serious and I really wanted to learn about the disease and to help yourself, you need to understand it. Now, I'll be honest with you. I don't know the medicines, like some people mentioned the MAOB inhibitor. I don't know what that all means. I listened to my doctor in that case, but I'm talking about things like, you know, understanding how my medicine is reacting with me, really taking notice of that.

How does my mealtime react with the medicines? What I ate, the protein and the dopamine, that sort of thing I really have been paying a lot of attention to. So that's a big part of taking that responsibility upon yourself. Unfortunately, the slide that I had a lot of our really go-to websites for knowledge and inspiration. If that's of interest in you, let the Davis Phinney Foundation know, and I'll get those slides over to you. The next area is community. I believe the community starts with family and friends. And over the past 14 years, I can say that their love and support helped me in so many ways.

They understand my condition and they understand my limitations, and they understand that because we're comfortable talking about it. Now, I wasn't comfortable talking about it early on, and I don't think they were very comfortable talking to me about it early on, but it seemed like once we talked about it, the pressure was off. And the dialogue just became very, very good and they understand my limitations and my challenges. For instance, I have a very close family. We do a lot together. If we're getting together, I'm going to be the first person to leave the gathering. I'm not a late-night person, but I'm



also the first person up in the morning. We have to time meals around my medicine. So, I may be eating before everybody else or eating after everybody else.

And so, we've come to the understanding that I don't care. It doesn't bother me. I want you guys to have a good time, and they understand that that's what's best for me. And so, it really, really works well. Those are all the ways that I see us advocating for ourselves. Now, this is what I'd like to challenge you to do, is to think beyond yourself and just to see what you might be able to do for the greater Parkinson's community at large. To start with, I think the most important thing you can do is get involved in a local Parkinson's support group. And if you don't have one, then maybe get a couple of folks that are also interested in one and start one.

I had the luxury of being involved in a great Parkinson's group in Albany, New York. So, I've never been involved in putting one together, but I know folks that have, and if you need help with that, I'm sure that there's people at the David Phinney Foundation that can point you in the right direction. Also get involved in programs like, you know, exercise programs are great, like dance class, pedal for Parkinson's, boxing, you know, whether it's rock steady or a local Parkinson's boxing program, yoga, there's a lot of different things. You'll make great friends, you'll have fun. It'll be really good for you. Also get involved if you get asked, if there's a local a research opportunity with your Parkinson's center, do that. And if you get asked to get involved in clinical trials, you know, I encourage you to try to take advantage of that as well. And like I said, you'll meet some great people. You'll have a lot of fun. And I think you'll feel really good too.

Now the next slide has pictures of all these great things that Nancy and I have done along the way. The Davis Phinney Foundation has been a big part of that. And I don't have it. So, you're not going to see it. And then there's great pictures of us doing it too, but there, there are lots of opportunities for us. They get involved with, on a local, on a national, or even a global level. I mean you know, this past, what was it, October of 2019, we went to Kyoto, Japan for the World Parkinson's Congress. And it's just amazing. Three years before that we were in Portland, Oregon. The next year, it's in Barcelona. And, you know, hopefully the COVID situation will be behind us and we'll be, we'll be going to that too.

It's just amazing, but that's a big trip. There's lots of other things you can get involved with. But on a larger scale, I want to talk to you about some reasons why we need to advocate for Parkinson's and why it's so important. So, think about this. This is like, when I tell you about going down the rabbit hole, this is the stuff I was looking at. There's a million people in the United States who are, you know dealing with Parkinson's, well, are diagnosed with Parkinson's. Taking into consideration caregivers and family, there's a lot more than that. There's 60,000 people diagnosed with Parkinson's a year in the United States. There's 10 million people worldwide diagnosed with Parkinson's. And that's more than MS, ALS and muscular dystrophy combined. There are currently 145 registered in ongoing clinical trials for therapeutics targeting PD.



88 trials are focused on therapies for symptomatic relief and the Michael J. Foxx Foundation, who we all know and love, they're currently funding five drugs related to the alpha-synuclein. Now that these are, these are the clinical trials, that hopefully will either find a way to stop the progression, or at least slow it down. So, these are really, really important clinical trials.

There's six drugs related to levodopa delivery, which is incredibly important, especially when you start getting in the later years with Parkinson's. It really makes a difference. There's two clinical trials addressing dyskinesia and two clinical trials addressing gait and balance. And again, this is just what the Michael J. Foxx Foundation is working on. Now, the reason that I'm sharing this with you is you can see that there's a real robust pipeline of disease modifying therapies in clinical trial right now. And it is believed that by the end of this decade, we may finally have the therapy, some people say will, I'm going to go conservative and say may, a therapy that will either significantly slow or stop the progression of Parkinson's.

And I mean, for somebody like me, and you know Davis, and we've had this condition for a while now. I mean, that's so encouraging, and it's something that we've been praying for. And when I think about that, I think about stories of my great grandfather who had Parkinson's in the 1930s, and probably passed away by maybe early forties, very early forties. He had nothing to address the symptoms. There was no Sinemet. There was no levodopa therapy to help him. And I just can't imagine what he went through. Then flashing forward to where we are now. It's just amazing. Even when I was diagnosed in 2007 as well as everybody else at that time, there were options, but they were much more limited than they are today.

And back then, there really wasn't a lot in the pipeline. Now, fast forward 14 years, and the options to address the symptoms are exponentially greater. And based on the current clinical trial landscape, it looks like we may have a lot more options on the way. Now with the prevalence of Parkinson's in my family, incidentally, my dad and my uncle who are both still alive, that's my dad's brother, they both had Parkinson's. So, I worry about my own family. But I know heaven forbid if they should, my children or my grandchildren should be diagnosed with Parkinson's. I know that that's a much more promising scenario than ever before in the law. And so, I also want to, the last point I want to make, has to do with funding. At the end of the day, it takes money to do this this work and this funding is critical. And we, in the Parkinson's community, need to be aware that money is also a driver to fund the Parkinson's research. Now we've made strides in Parkinson's research and development, because we personally been involved.

And also, because we donated money and we've led fundraising events for Parkinson's organizations that we've embraced. But in addition to that, we need to be vigilant as far as letting our elected officials in Washington know that this funding is needed and important. For example, when we were in Washington with the Michael J. Foxx foundation, a bunch of people from all over the country came, and we all met with our



elected officials at the Capitol, on one specific day, it was an amazing event, but it was also shortly after the Trump administration did come in and they were looking at the budget and there was a real concern that they were going to cut funding to the NIH.

So, they ended up not doing it. I don't know if it was because of our efforts or not. I'd like to think it was, but anyway, it is important, and we knew we just really need to be very cognizant of that. So lastly, it's simple, it's really up to us to make sure that this research continues. We are here today because of the efforts of the folks who have been doing this work before us people like, like Michael J. Foxx, like Davis and Connie, and the people at the Davis Phinney Foundation and people like you and me. So, I urge you all, if you're able to get involved to please do so. And I promise you that if you do, you'll be very glad you did it. It's a very rewarding community. So, at this point I will turn it over to my wife, Nancy, and she has a couple of points that she would like to make.

Nancy Hovey (Davis Phinney Foundation Ambassador):

Okay. So, I was asked to talk about advocacy in relation to the caregiver. What I really feel is important in self-advocacy is to take care of yourself first, which sounds very selfish. It sounds like you want to be the one that's that everybody's looking at, but I really feel that it's like when we go on an airplane or when we used to go on airplanes and the stewardess would say, make sure you put the oxygen on yourself first, before you put it on the person next to you who you're helping, because if you don't have that oxygen for yourself, you really can't help that person next to you, or in our case, our loved ones with Parkinson's. So really, if you can't remember anything else that I've said today, I think that's a really important thing to remember. Give yourself time, give yourself the pleasure of the activities that you enjoy, that make you happy. Whether that be for me, I enjoy tennis. I love being with my grandchildren and those kinds of things just make me feel strong and well. Because if I can't be a strong caregiver, then I can't give to Steve what he would need or what I would like to give for him. Also be with friends who are supportive of you, who lift you up, you know some friends are great to be around and some friends you're like, okay, I need a break from them, but be with those who are able to make you feel good so that you can move forward and be strong as well.

Also take care of your health, just like the person with Parkinson's. You want to take care of your health and your body as well. You need good sleep. We all need to eat well. And of course, we all need to exercise, exercising meaning whatever it takes for you to move. Whether that be a sport that you enjoy, or just a walk or pedaling a stationary bike or swimming whatever that might be. Also, and again, this is just advocating for yourself, try to reduce stress wherever possible. You may need to take some things off your plate. If you have a big busy schedule you might need to ask for help, which a lot of us aren't always used to doing, many of us like to give help, but it's tough to ask for help, but if you're feeling like you just have too much on your plate, you need some time for yourself, make sure you do ask friends, family or maybe some support within your community and acknowledge your limits.

Try not to put too much on your shoulders that you feel like you can't handle. Another big thing that I remember when Steve was first diagnosed is that I was just wanting to learn everything all at once and I think it's important to give yourself the gift of time. This disease doesn't move along rapidly. It's somewhat slow. So, take your time, adjust. It may take a couple of years before you hit your stride. And you, you will get through this initial phase, but just give it time and have some patience with yourself. Okay. So, quickly, just being an advocate for the community. It's very much like what Steve has already said. When you're looking for resources, make sure they are reliable. Do find them and again, we'll send you those resources that have been helpful for us, like the Davis Phinney Foundation, Michael J. Foxx Foundation.

There's a lot of really good ones out there and attend conferences that are interesting, that have been recommended to you. Again, support groups are wonderful. This is also that you then gain your knowledge to be able to go out to help others. And when you are ready to get out and start to either participate in fundraising clinical trials, maybe just lending a shoulder to somebody that you've met through the Parkinson's group. You'll be ready because you have gained or know these resources and to be able to share what your knowledge is. I think, just really briefly, some of the things that we've done are things that I would never have had in my wheelhouse. And that is to attend the event in Washington. I am not a political person and for us to go there was really stepping out of the box for me, but doing it was really satisfying and enjoying. So just, again, we can't choose this disease, but we can choose how to live with it.

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