

Live Well Today Webinar Series

November 2023: Living and Working with Parkinson's

Davis Phinney Foundation

Note: This is not a flawless, word-for-word transcript, but it's close.

Devon Fulford (Director of Education):

So, first of all, thank you so much for joining us today on this Friday morning or afternoon or night depending on, on where you might be located in the world. My name is Devon Fulford. I'm the director of education and content at the Davis Phinney Foundation, and I am so excited to be the host of this amazing panel today with the Davis Phinney Foundation staff.

So, our amazing webinar today is called "living with and working in Parkinson's." So, these are all folks who have a personal connection to Parkinson's in their life. Let's get started. I would just love to have Rebecca kick us off, and I'll just go around the screen. I'd love for all of you to tell us your name, where you're located, what your relationship to Parkinson's is, and what your role at the Davis Phinney Foundation is.

Rebecca Reifel (Events and Development Manager):

Sure. I'm happy to kick us off. So, hi, everyone. My name is Rebecca Reifel. I work here at the Davis Phinney Foundation in the development team. I'm the events and development manager, so if you've ever been involved with Team DPF or any of our exciting events fundraising events around the country, you may have seen my face on an email or maybe even in person. But my connection to Parkinson's is my father. He has passed away. I think my person with Parkinson's connections may be a little bit different than everyone else on this call, but my father lived with Parkinson's for about 10 years. He passed away a couple of years ago, and so he is the reason I am in this work and in this field, and I think about him every day. Oh, and I am in Louisville, Colorado. I'm not at headquarters. I actually live just a few miles down the road from headquarters. Yep.

Devon Fulford:

Thanks, Rebecca. How about Chris?

Chris Krueger (Program Manager- Content):

Hi everybody. Thanks for being here with us. I'm Chris Krueger. I am the program manager for education and content. So, I write a lot of the things that you read that the Foundation produces, and I also do some of the video content. My connection with Parkinson's is that I live with Parkinson's. I was diagnosed in March of 2020 at a time where there was nothing else going on. So, that was a really easy time. In March of 2020, I was diagnosed, and I was 37 at the time. So, that's my connection.



Devon Fulford:

Thank you, Chris. Samantha.

Samantha Narciso (Program Associate- Education and Content):

Hi everyone. So, I saw somebody wrote in the chat, but my name is Sam Narciso, and I am our program associate for education and content. So, if you come to our webinars, I've probably spoken to you. I am always in the chat, sending you all the links. I started working for the Davis Phinney Foundation about a year and a half ago. I am from New Jersey, and my connection to Parkinson's is that my lovely father has had young onset Parkinson's since I was born. So, this is my life, and it has been about almost 30 years, and he's still kicking it. And [is] possibly here, I am not positive.

Devon Fulford:

Thanks, Sam. Beth.

Beth Chatterton (Director of Marketing):

Hello everybody. Thanks for being here. My name is Beth Chatterton. I am the director of Marketing, and I'm in Centennial, Colorado. My relationship is similar to Rebecca's. My mother-in-law had Parkinson's. She was diagnosed at 48 back in 1996, I think it was. She will have been gone 15 years here next month. So, she lived with it for, I think, about 20 years. She was also in Canada, so we had a little bit of a different aspect of not getting to see her all the time, but I got plenty of insight and experience with her when we did visit here and there. So, shout out to all the Canadians as well. So that's who I am and my relationship to Parkinson's.

Devon Fulford:

Thanks, Beth. Claudia, you're next.

Claudia Martinez (Hispanic Community Engagement Manager):

Hello, everybody. My name is Claudia Martinez. And I live in Phoenix, but I am originally from Columbia. And my relationship to Parkinson's is through my dad. He had Parkinson's, and I was his main care partner when I was still living in Columbia. He passed in 1999, but he inspires me all the time, and that's why I've been working with the Hispanic Parkinson's community for about 16 years now. I joined the Davis Phinney Foundation for a little over a year, and I love being here, working here as the Hispanic community engagement manager.

Devon Fulford:

Thank you so much, Claudia. Next, we have Dani.

Dani Smith (Ambassador Leadership Program Associate):

Hello, everyone. My name is Dani Smith. I live in Boulder, Colorado, so I do get to pop into headquarters from time to time, which is wonderful. I am a program associate for the community engagement team, so I work directly with our Ambassadors and ship out materials. So, if you've ever received a [...] or all of the educational materials we have, probably I shipped them. My connection to Parkinson's is that my mom was diagnosed about six years ago with Parkinson's. So, I've been aware of the Foundation for a long time and am very lucky that I get to now work here. So glad to be here.

Devon Fulford:

Thank you, Dani, and Edna.

Edna Togba (Donor Engagement Manager):

Hello, my name is Edna Togba. I'm calling in from Chicago despite the San Francisco background, but I really like the bridge, and I used to live in San Francisco. My connection to Parkinson's is that my dad also was diagnosed with Parkinson's at the very end of his life, which was during COVID-19, which is when he was in the facility. And this period of time is difficult because this was when it was the nearing the end of his life two years ago. So, I'm just really grateful to be with everyone today.

Devon Fulford:

We're so grateful you're here, Edna. I can't thank all of you enough for being here. We do have one other panelist who is having some technical difficulties, so hopefully, our friend Shane is able to come on. And if so, we'll pause a little bit and have him introduce himself to everyone.

But otherwise, let's start talking about life in working with and living, working in, and living with Parkinson's. So, the first thing that people might want to know is what is it, other than the obvious, about Parkinson's and this world that interests you in working at the Foundation, and maybe also something to consider how your person with Parkinson's feels about that. And anyone can just feel free to jump on in.

Samantha Narciso:

Well, I assume I should go first because I am the talker. So, hello. I would say for me, the thing that is most fascinating about working in the Parkinson's world I guess for me is learning more and more. I've gotten the opportunity to learn from a lot of parents as I've worked here at the Foundation as a part of the Living with Parkinson's [meetup] panel. I'm not really a part of it, I'm just in the background, but all of our panelists are so generous and giving great advice and becoming my friends, and I've learned a lot from them, from their perspectives as parents and what it's like to be a parent who has young onset Parkinson's. And for me, that's actually helped me a lot understand my father's perspective on raising me and my younger siblings and how he kind of relates his Parkinson's to parenting. So, that's been really fascinating. As a person myself, I'm always going to be an advocate outside of the Foundation for children whose

parents have Parkinson's. But it's really great to work within a Foundation that I get to meet people who help me navigate that kind of role. I hope I have answered your full question.

Devon Fulford:

You are amazing.

Edna Togba:

I can go next. For me, what's fascinating about working for the Foundation is being able to connect with people who have Parkinson's and who have loved ones with Parkinson's. As I mentioned, my father passed away two years ago. This is at the height of COVID-19, and we were unable to see him, actually, until right before he passed away. And so, it's been really, I don't want to say rewarding, but it's been really great to be able to see people who are living with Parkinson's, how they handle Parkinson's in their everyday life and being able to connect with their loved ones in a way that I necessarily and my family members weren't necessarily able to do because of all of the restrictions around COVID. So, I don't take any of that for granted. I really do, I just feel very grateful.

Rebecca Reifel:

I can go next. I have kind of a fun story about how I ended up at the Foundation. My father was still alive at the time, and he was struggling. My father had gotten a Parkinson's diagnosis and a terminal cancer diagnosis within months of it. He was diagnosed with cancer, and then a few months later diagnosed with Parkinson's. And he always saw his battle as primarily a battle with cancer. And he tended to ignore his, the Parkinson's side and the living well piece, and apathy kicked in, and denial kicked in, and depression kicked in, which I'm sure many people watching this panel today can relate to. As his daughter and as someone who loved him very dearly, I saw my father change, and I knew that he needed to do something.

And so, I was researching different organizations, Parkinson's organizations, that could help my father. And I stumbled upon the Davis Phinney Foundation just after a Google search. And I was scrolling through it, scrolling through it. And if you were here at the beginning of the webinar, you heard me say, I live in Louisville, Colorado. Well, I scrolled to the bottom of the page; it's the Davis Phinney Foundation based in Louisville, Colorado. And I was like, are you kidding me? I Googled it. It was a half mile; the headquarters is a half mile from my house. And I was just so blown away by our resources. And the way we talk to the Parkinson's community is so different than other nonprofits. It felt so personal, and so it didn't feel stuffy; it didn't feel clinical. It felt like a friend talking to a friend.

And I knew that would resonate with my father, and I happened to cold email my resume to the Foundation. There were no job openings at the time. I just sent my resume and said my background's in fundraising and volunteer management, and I would work here in a heartbeat. And a few months later, I got a job. So, it was very personal. My journey here to the Davis Phinney Foundation, it was, that I was not job hunting. I was not looking to get into this field in

particular. Life and my fatherhood experiences brought me here, and I've just cherished every moment since.

Devon Fulford:

What a great story, Rebecca; I didn't even realize that was your introduction to the Foundation! That's so cool. Opening it up a little more, just in general, what would you all say are some of the big-picture benefits that you feel like you might have from working at the Foundation?

Claudia Martinez:

I can start, and I would love to because of the way I came to the Foundation and talk about the benefits that I perceive of someone being part of the minority community. I'm Hispanic, foreign-born, and I had the opportunity to learn about and work within collaboration with the Davis Phinney Foundation when I was working at another Parkinson's organization. And I just love, back then had two opportunities working in the Victory Summit in Phoenix, Arizona, and then the one in Tucson that happened just before the pandemic in December of 2019. I love the way that the Foundation really makes the effort to be inclusive, especially in my case with the Hispanic community. And not only inclusive in the sense of making sure that we can participate, but also in the sense of giving the opportunity for the members of the community to be represented, for their voices to be heard.

And I just loved that time when I was not working at the Foundation and when I had to make a change in my lifestyle due to long Covid. Then, the first thing that I saw that I thought about was that I would love to work with the Davis Phinney Foundation. If I have to leave my current job, that will be my go-to my first goal. And I'm just so happy that it happened and [I've been] at the Foundation since August last year. And one of the benefits is that I not only get to do that for myself, but for the whole Hispanic community. Because we are currently working, our Hispanic community engagement program is open to anyone in the Hispanic community, whatever they do daily. So, I think that's pretty awesome.

Chris Krueger:

I'll talk a little bit about some of the benefits that I experience. And I'll say a little bit more about the first question or a little bit of an answer to the first question, too. So, I landed at the Foundation. I went to the website, and I found a job was open that seemed like a good fit for me. And I reached out to Polly, and it didn't work out at that time. But it was a great process. I enjoyed meeting Polly and the rest of the folks I met. And, down the line [...], we just stayed in touch. And actually, I was driving across the country to move to Bend, and I reached out to Polly to say, hey, I'm going to be passing through Denver. And she invited me to just stop right by for a cup of coffee.

After that we just kept in touch and then something else came up. And here I am. I share the perspective, that the Foundation's materials and the approach that the Foundation took made a positive impression on me. And that's why I wanted to be here. Because I just found it to be

such a different tone than other resources I was finding. And also, in some sense, a more, more detailed tone. The EVC manual was a great resource that I encountered, and I was like, wow, this is, I wanted this when I was first diagnosed, and I didn't find it immediately, but I just was really impressed by that. So, as far as benefits-

Devon Fulford:

Chris, can I pause you for one second? Can you explain more about what the EVC is in case the audience doesn't know?

Chris Krueger:

Yeah, so the EVC is, as far as I know, still the only resource. It just provides basically any question I had in the early days of my diagnosis that I wish I had had an answer to or for is in the EVC. And so, I was looking at all these journal articles, and reading all this research material, which was very challenging for me. And I love doing it, but it's challenging. A lot of those answers that I found in detailed articles were in the EVC and much easier-to-understand language. So, as far as benefits, I think the number one benefit for me is just being exposed to the community. Not only the community of people at the Foundation and the people I get to work with but also the people that I get to meet in the Parkinson's community nationwide and even globally. My exposure to great ideas and passionate people is so much more pronounced now than it was before.

And that's just a really, I mean, it's amazing and I'm really grateful for that. And yeah, that's the main benefit for me for sure, is getting to meet all the incredible people with so much energy and so much passion, so many ideas.

Samantha Narciso:

Can I jump in really quick? And I'd like to say one of the main benefits that I've really experienced in the past few months, and I hope you don't think this is facetious, but it really is working with Chris. So, another thing that has been a huge benefit for me is because my father had young onset Parkinson's; I didn't really know anyone with young onset Parkinson's, (not sure, Claudia). So, it was really difficult for me to kind of see what other people's journeys were, what they were feeling, and ask questions because I didn't necessarily want to be harassing my father all the time. What are you feeling? What's going on right now? But Chris is more than welcome to be harassed. But he's also just so great in helping and helping us all kind of understand what we need to say to you all as well. What information are you guys looking for? And Chris is like, well, I'm looking for this because I have Parkinson's. And I think that he's just such a huge asset to the Foundation, and I'm so grateful that he's here. I will take any opportunity to compliment him.

Chris Krueger:

Well, thanks, Sam. I mean, that's kind of exactly; I could say the exact same thing going the other direction. I learned from everybody on the panel now and from people in the community more generally every day. And it's really a blessing because my experience is not the only experience. And so, I get to learn other approaches I might take to improve my own quality of life, and also just get a sense of what else is going on in the world for people that have a similar circumstance to me. So, that's really, really a blessing. And I appreciate you too, Sam. So, thanks for being here with me.

Devon Fulford:

I love the love fest. There is a lot of love amongst the Davis Phinney Foundation staff; I think we all feel it every day, no matter what our job role is or what our situation or connection to Parkinson's is. I did want to pause for just one second. Chris kept saying "EVC": That is our Every Victory Counts manual. And Polly dropped that into the chat for you. It's a free resource. We also have an Every Victory Counts manual specific for care partners, a completely separate manual, but you can put in a request for either one or both using the link that Polly provided. And maybe we can have somebody else drop that back in the chat again, so you don't have to scroll all the way back up. But Chris said amazing things about the EVC. It really is an incredible resource. And yeah, we encourage you to grab one if you want one.

Anyone else want to share any of the wonderful feel-good things, the benefits about working at the Foundation?

Dani Smith:

Yeah, I can speak a bit about, just because my journey to this role is sort of similar to Chris's in that I connected a few years earlier with Polly, our executive director, and chatted about what it would be like for me to work as a part of a team that at that point I think it was creating content. And it felt a little too personal for me at the time, just with my mom had only been diagnosed for a couple of years. We were still trying to figure out what the future was going to look like. And I decided not to move forward but stayed kind of stayed in touch. And then I saw this role open on the community engagement team, which I love figuring out ways for people to engage in their own communities and find ways that we can support them and create the materials and whatever else the support structures they need to live well with Parkinson's. And I think that it helps so much like seeing other people live these really wonderful, robust lives with Parkinson's. My mom lives in California. Like I said, I live in Boulder, Colorado, and it helps to have this experience of seeing all these other people so that I can go back and take all this information or all these wonderful stories that I learned from our community and my coworkers. It's amazing and so beautiful, and I get to take that back to her and share these different ways that she can maybe enhance her life. So, it really has been a truly like extraordinary experience.

Edna Togba:

I'd like to piggyback on what Dani shared. When I was asked to be a part of the panel, I originally said no because I was grieving. As I said, it's been two years, and this was kind of like he, my father, passed away in December, and this was like the start of the wind-down of his life. And it's just been very difficult. And I didn't think I was able to, I wasn't going to be able to be able to participate. Because it, as Dani shared, it felt too personal. And also, because I was, I was away from him during that period of time when he was diagnosed when he was kind of alone in his facility because of COVID. And I think for me, the bigger picture is being able to share resources with people so that they are able to live their best lives every day. Whether that's like I had breakfast with my husband, or I am going to go see my granddaughter's play, or I went for a long walk today, or I woke up today, whatever it's just, for me, it's just always reassuring every single day to get that kind of reminder of how precious life is. And no matter what you're going through or dealing with, you have other people who are also going through things. But this community is like very transparent and very.

I don't know. I always just feel good after experiences with my, either my colleagues or with donors or with people who have Parkinson's and helping them to connect with different resources to help their lives be better. So, that's kind of like the big picture for me. So, thank you, Devon, for continually nudging me about this panel. I appreciate it.

Devon Fulford:

Only in the gentlest way possible. I anticipated getting choked up during this panel today. And Edna, thank you, you've done it. It means so much that you're here, and I'm trying to keep it together here on camera. Phew. Good stuff.

So, now that we have passed through how wonderful things can be and how much we love each other, let's take a deep breath and delve into maybe the more challenging aspects of working in Parkinson's when you also have such a close, intimate connection to Parkinson's. If you're, if anyone feels comfortable tackling that, I figured you would be you, Samantha, let's go.

Samantha Narciso:

Well, yes, of course it would. So, I have kind of gone up and down like a rollercoaster with this. It really kind of depends on the day and what I'm learning. So, as a part of the education and content team, what I get to do, I get the great privilege of taking Chris's beautiful written words and then putting them on our blog, on our website. And sometimes I learn something fun and exciting. I learn about new medications, or I learn about [...] pumps or something like that. I learn really cool things. But then there are other days where I have to help write articles about advanced Parkinson's or about dystonia, which is, my dad predominantly suffers from dystonia as opposed to dyskinesia. And those days can be really, really hard, especially because I also don't live in the same state as my father.

And that's really difficult for me not to be next to him because I'm just always worried about him. That's kind of what happens when you spend 28 years knowing your dad is sick. I mean, well, whatever. So, those are the really hard days when I have to deal with the fact that I'm like,

okay, I'm reading about this. This is physically happening to my dad right now, and I'm having to witness other people dealing with it, and I can't go home to help him. I will say one of the things that has made it a little bit easier is I asked my dad to become one of our ambassadors. So, now, during Leadership Conference, when I have to go even farther from him, he gets to come with me. And that's pretty nice because I like my dad being next to me pretty much all the time.

Chris Krueger:

So, I have something that's kind of related to that. Something that's hard for me sometimes is that I know so many people now, and I see so many different ways that Parkinson's can go in a person's life, that it's hard for me to like to think about my own future. Sometimes, I don't know necessarily. I know everybody's trajectory is different. I think most people with Parkinson's are pretty well acquainted with that notion, but it's a little disorienting sometimes to see all the things that could possibly be the way my trajectory goes. And that's a little hard. Another way that that comes up for me personally is that I see this role for myself as, as one of, of like really immense responsibility because I can, I feel like I'm a little bit of a representative for the broader community of people with Parkinson's.

And I have like a huge microphone that I can amplify concerns with. And so, one of the things that's really hard is that my personal firsthand experience gives me this perspective on how hard this is living with Parkinson's. And I want to. I just care so much about that experience for so many people, and I want to be responsive to all the concerns that people raise and all the things I see people dealing with. And there's just, I mean, I could say so much about this, but the simple thing is there's just not enough time to give as much energy to all of the different ways that Parkinson's affects people's lives. So, I always feel like I'm a little bit not doing enough. And it's just, that's a challenge. [...] I'm never going to win that battle because there are so many ways, and there are so many people with so many concerns.

But I just want to say that it's a, it's a challenge, but I'm so honored to be trusted to tackle it, and I want to invite anybody who has a concern that they think they want to want support with, or they think maybe might be worth highlighting, please let me know. And just be aware that it's something that's hard to, for me, always to filter through and get all of this, all of the work that I really want to do. But I love the fact that I'm trusted to do it, and I feel so honored to be in this role and to be able to help as much as I possibly can.

Beth Chatterton:

Yeah, I think kind of to what Chris was saying and working with Devon and the rest of the team, it's really hard, right? Like, it's not an easy path. The community here and the staff is so inspirational. It's so tight. I told myself I wasn't going to get choked up, but here I am. It's hard to find a balance sometimes of talking about the hard stuff, right? But yet again, this community is so powerful and inspirational and upbeat and positive, and that's what thrives me to come to every day to make sure that we continue to support you guys the way you need to be supported and give you the resources and the community that you need and connecting

everybody. But it's hard, it's hard work. And this team is really passionate about what they do. Fifteen years later, I still get worked up thinking about my mother-in-law, right?

If she only had half of the resources that the Davis Phinney Foundation provides today, she might still be with us. She like, very similar to Rebecca, she got cancer like Rebecca's father. So, she had multiple things that we're fighting with her, but I truly believe she'd be here today. She was 60 years old when she passed away. But if we just had some of these amazing resources that are here today, her life could have been extremely different. And so that's what is so hard, but so beautiful about working here, in my opinion.

Devon Fulford:

Thanks, Beth.

Claudia Martinez:

And I totally can relate to that, Beth, because when my dad had Parkinson's, as I said, we were living in Columbia, and at the time, there was absolutely nothing available. I mean, nothing is nothing, not even information or a flyer, nothing that is for him or for our family. And at the time, I was working as a family practice physician, and that wasn't as helpful as I thought it was going to be. So, it was a sad experience for him; it was a sad experience for our family. And but I also felt sad about that, but many times, I also feel so thankful that I'm able now to help so many other people who otherwise will be living the difficult path that my dad had to walk on.

So, I am trying to balance the sad feelings with all the time, saying we can do so much more now for the community that I am part of. And not only providing services or information, but also having them as leaders and having them guiding our steps. I think that's super, super important, and being able to empower this community. So, and I know somebody in the chat was asking about the possibility of listening to this in Spanish. So, if you send me an email again, Janet, I will be able to guide you in the comments section.

Rebecca Reifel:

Yeah. I can chime in next. I think I have very little to say that hasn't already been said other than I know that it is recognized within the Foundation for Staff by leadership of how difficult this is. And when I took this job, the final interview I had was with our executive director of Polly, and she sat me down, knowing that my dad was living with Parkinson's, and said, can you do this? Like, can you, can you live in the Parkinson's world? What in your personal life and in your professional life? And never have a break from it. And I thought about it at the time, and I was like, I think so. I think so. But the truth is you really don't know until you step into a role, and you're working 40-plus hours a week, and for a lot of people, it is too much.

And then, there are others who we find ways to work through it. But the thing that I get so much, same with Edna. My father passed away in the middle of the pandemic. He passed away two years ago. And it was very, very hard. It was very hard working at the Foundation, having

lost someone who was living with Parkinson's. But I had a community around me that understood where I was coming from and gave me grace and gave me kindness, and love. But I will say also after, like in the years that have passed, I meet so many people in our community who I see my dad in, and it doesn't make me sad. It brings me so much joy when this is going to sound; I hope this doesn't sound too strange, but like, if I see somebody who has the same Parkinson's gait that my dad had and they walk the same, or they talk the same, or they have the same facial expressions knowing that that's a part of their Parkinson's. It's part of their Parkinson's manifesting, but I see my dad in it.

And there's even been a few, I don't know if there's anybody watching now who I've said this to, but there have been a handful of people who I have said, oh my gosh, I see my dad in you. And it just, it's a piece of him in my life still. And that's really special to me.

Samantha Narciso:

Can I go off on what Rebecca just said? If that's okay. I was also asked that question when I was hired because that was another thing. And I believe Polly also asked me can you handle this? And I had the same thing. I was like, oh, I'm fine. I'm fine, I'm fine. It's all good. And then recently, my father, pretty quickly after I started working here, my father's movement disorder specialist moved across the country, and I'm sure every care partner in the chat knows that people with Parkinson's are stubborn. It takes them a while to go to the new neurologist. And he's finally in, and he's getting help. But it was really hard for me for a couple of months watching my dad degenerate again a little bit. He always calls this his progressively debilitating neurological disorder.

He makes all of our T-shirts for our fundraising events say that. And it was really hard for me to see it become progressively more debilitating for him. And the thing is that, with my younger siblings, they don't process Parkinson's the same way I do because I'm the only one that really remembers my father pre-dopamine-agonists, pre-he-broke-his-shoulder-one-time-from-a-dyskinetic-episode, I believe. I'm the only one that really remembers him from that. And so, it was really difficult. And this was kind of just my favorite moment ever working at the Foundation. And I don't, I don't think the people knew the importance of it to me, but so, as I mentioned earlier, our Leadership Conference is when we take our Ambassadors and our HPC leaders, and we all come together, and we like to talk about what we want to do.

So, but this year, my mother could not come, and I was going to be my dad's primary care partner. And it was really scary for me because my mom has been my primary care partner my whole life. And every single person at work was like, no, go. You're fine. Go spend time with your dad. Where's like, people would give me updates throughout the day if I was doing something else. They'd be like, your dad's over here. They'd walk him to places. Nobody left him alone. And my dad has a little velociraptor hand, so people were helping him by holding onto cups and everything. And it just meant a lot to me that I didn't feel alone in care partnering, which I know since I worked for a Parkinson's foundation, of course I wouldn't. But it was so great to know that my team was behind me in that way that I wasn't alone in that.

And I think also that goes for, and I mentioned them again earlier, so I'm just going to go back to them, but I saw Kat and Doug in here. I have made such amazing friends in the Parkinson's community who have also; if I hadn't had this job, I don't think I would've been able to meet those people who, every day, make me just feel like, okay, I'm not alone in this. Their kids are in this, they're in this, their partners are in this, their friends are in this. We aren't all alone. And Kat is helping me write a book and I just send Doug cookies all the time because I love him. But I just think that this Foundation has connected us with such amazing people that make my life dealing with Parkinson's even as a care partner. So, much better.

Devon Fulford:

So, I want to take the question, Rebecca and Sam, that you just said. Polly asked you, "can you do this?" And I want to twist that a little bit about right now because obviously, you're doing it; you proved that you could do it. So, I'd love for everyone to tell us how are you doing it? What are your coping strategies? What are the ways that you're dealing with it when doing this double duty of living with and working in gets to be a little too much or too heavy for you?

Rebecca Reifel:

I'll answer that really quickly. I don't do anything. I say that because it's our community that does it for me. I won't call her out by name, but I got a text earlier this week from someone in our community who told me, who reiterated how important the work we do is, and I had had a tough day, and just out of the blue, she just thanked me for the work. And we get that it's you, you all, who are watching this. I don't have a coping mechanism, or I don't have great coping mechanisms other than just like hearing from the people who we change your lives. And you tell us that, what other job do you get to have where somebody texts you and says, you've changed my life. That's not normal. And it just is so beautiful when it happens, and it happens frequently.

Devon Fulford:

Not normal in the best possible way.

Rebecca Reifel:

Yes, yes.

Chris Krueger:

Yeah. I can answer the question really quickly, too. I mean, for me, the question is, do I get fatigued? And I actually, this is interesting. I wasn't asked this question when I was so, and my friends asked me the question, my friend, I have a friend who's a physician, and he, and at one point, early in my diagnosis, when I was recently diagnosed, he said to me, Chris, you have to stop. You are going way too deep into this. And I said, no, I mean, this is, that's just me. I'm going to do this work regardless of the circumstances that I'm in. I'm going to be researching,

I'm going to be writing about this. And so, for me, it doesn't feel like double duty. Is it just my life? I mean, it's like, it's not, it's not always great, it's hard.

I do feel tired sometimes, but I have this, I love to write, and I love exercise. This community is important to me, and I'm going to learn everything I possibly can about Parkinson's anyway. So, this is, it makes the, the challenge is certainly there, but I don't feel like I don't feel like it's too much, even though it is. I mean, it's all, it's too much because I have Parkinson's, right? I mean, that's the truth. But it's not, it's not too much because I'm working in it. It's too much because it's just so, there's so many things it's like such a challenge generally. But I don't feel the fatigue from doing double duty because I'm just living my life. And plus, I get to play with commas sometimes. It's also just, that I get to write. So, that's different. It's like not always Parkinson's; sometimes, it's commas.

Devon Fulford:

Anybody else want to share about what you like to do to balance?

Claudia Martinez:

Yes, I can share. I agree with Rebecca and Chris; that this is the perfect place for me to work. It is a blessing to be part of this community, but I also know that it is, for me, also a challenge because it challenges me to be the best version that I can. And sometimes also to represent a large community. But what I try to do is think that it's not just on me, and I just have to pass the baton to other people in the community who are amazing leaders, and those are now our Ambassadors or Hispanic Ambassadors. So, I just I'm just very thankful for them as well. And I know that sometimes what's hard for me is to stop working. I love it so much that sometimes I tend to overdo it, and my husband sometimes has to knock on my door to say, hey, it's time to get out and do something else. But I guess that's a good problem to have, loving your work but trying to balance it with at least going out to the butterfly garden that I like to have at home.

Devon Fulford:

I don't know if anyone's going to have a brilliant, compelling answer to this next question. Since you're all so invested in what you do, and obviously you're very happy to be here and are such an asset to this community, but if you didn't work at the Foundation and didn't work in Parkinson's, what would you want to be doing with your life?

Dani Smith:

I can speak to this one and tie in a little bit of my answer to the last question. So, I study counseling psychology in my free time, and I can get really caught up in like holding the, this space for other people in this, in this role and in my academic life. And if I do not like feeling my own feelings, then that can really catch up with me. And so, I just, yesterday, I finally determined like a phrase for this thing I've been doing, and I call them "feeling walks." So, I just like to put on my favorite like playlist or whatever and go on a walk, and I have a nice trail out

my back door, which is helpful and unique and a total privilege. But that it's this time where I'm just by myself, walking and feeling all the feelings that I didn't give myself space to feel throughout the week. So, if I weren't doing this work, I would still be holding space for people, but in more of a mental health capacity, which is something that we, I don't feel like people talk enough about in the Parkinson's community I think so my hope is to merge those two worlds kind of.

Devon Fulford:

Definitely. I love that, Dani.

Samantha Narciso:

I don't know if in this conversation we have realized that I am obsessed with my dad, but if we haven't yet [...] My dream career was that I was going to be an actress because he was an actor, and I wanted to be a professional actress like him. And then I ended up getting my own head trauma. And so, I couldn't do the full long days that he also couldn't do anymore. So, if I wasn't doing this, I would either; I might want to be a teacher again. I was a fourth-grade teacher, and I genuinely love disability advocacy. This job has really shown me that this is where my heart is. So, even if it wasn't Parkinson's, it would be for something else. Because I think as a Gen Z/Millennial think that our generation is really, really, I think what's awesome about our generation is that we're really strong about advocacy and advocating for everybody. And that is what matters the most to me. And so, if it wasn't Parkinson's, it would be something else. But this is what I love to do.

Devon Fulford:

Thanks, Sam.

Rebecca Reifel:

Well, I was going to joke and say that is winning the lottery an option and then riding full-time with team DPF, so I can actually get on a bike at a team DPF event and not have to work it.

Devon Fulford:

100%. Yes. That is an option.

Rebecca Reifel:

That's fine. I'm going to do that. I want to get on my bike.

Devon Fulford:

I love it.

Beth Chatterton:

I don't know, that's a hard one for me. I'd either have to go the sports route because I'm a huge sports fan. I played soccer through college, so it'd either have to be sports or, like kids, babies [...], or something like that. Everybody here knows I have a massive thing for children, especially babies. So, something with NICU or something with little babies that are struggling or young kids that need help. I would go one of those two directions probably.

Edna Togba:

I want to kind of piggyback on what Dani was sharing about her feelings walk. So, I live in Chicago, but I live on Lake Michigan, which is as big as the ocean. And it's really beautiful and calming. And I go for walks first thing in the morning, so I always see the sunrise. And I go for, like, during my lunch break, and then I go in the evening so I can see the sunset. And I studied photography. That was me. I was a double major in college, and I was like, I'm going to be a photojournalist. But I ended up doing other things. So, I think that if I wasn't working for the Foundation, I would probably be trying to find a way to share my daily photographs with people and sell my work more than I already do because I just feel such an affinity to nature. And I think it's part of that living well, like maybe you don't live on the water, maybe you don't live like at the base of the mountain, but you can go outside, and you can like get energy from nature, from the sun, from the air, from whatever. And that will improve your life. And that also have like a running soundtrack that goes along with that, with like different, because I used to work for an orchestra. I love classical music, so I'm always like playing whatever in the background. As I'm watching this, I'm like, oh, this is such a beautiful movie, I wish everyone can like, experience this 6:30 AM, great start to the mornings, great start to the day. So, I think that if I wasn't working at the orchestra, I would be full-time. I would be a full-time artist, really.

Devon Fulford:

And I want to encourage you to share more of yourself within the Foundation. I want to see it,

Edna Togba:

I'll share with more people. I feel like I share it with like a couple people here and there, but I will definitely start sharing it more. Cool.

Devon Fulford:

Chris? Or Claudia?

Claudia Martinez:

I was going to say just please [...] because I think I would be an artist as well, probably. I love painting and probably I will be working along with Edna and Sam doing workshops for people with disabilities. So, that could be something that I could work on.

Devon Fulford:

Yes, please. That sounds incredible.

Chris Krueger:

I don't know that I have a great answer for this question about what I would do if I wasn't doing this. It's kind of a perfect fit for me and I feel really blessed to be able to say that. But if I was going to, I have I'll answer the question a couple ways and I'll do it as quickly as I can. Everybody that works for the Foundation knows that I say too many things, too many for, I go on far too long. I'll try to be quick. I had an idea for a business, I would start, I'm not going to tell you what it is though, because it would, I don't want to give it away. It's too good of an idea. It might there's a couple ideas in that way. Anyway, so I want to say something that might be a little bit controversial to answer this question in a general way, but I want to just, just start off by saying one thing that's really great about the Davis Phinney Foundation is that we're super lean, we are very efficient.

We get a lot out of a relatively small group of people. But I don't think it's a surprise that, well working for in the nonprofit space, is it's not the best way to make a lot of money. So, that's a hard thing for me because it's likely that my career will be, my working years will be shorter. It's not necessarily the case, but it's a distinct possibility. So, for me, if I wasn't doing something that I so deeply care about, I would maybe want to go the direction of just trying to maximize the amount of money I can make and just do whatever it I can to get the most money just to give myself the best possible future. And that's a hard thing. That's a challenge for me with regard to Parkinson's generally.

Secondarily, I might go the opposite direction and minimize the amount of time I work to maximize the amount of time I can exercise and take advantage of trying to make the best my health be as well tended as I possibly can. So, I don't know what I would do, but those are the, those are the factors for me. And so, I'm really happy and certainly I found this middle ground where I have this, it's kind of a great fit for me, and I'm in an excellent organization working with such lovely people and getting to meet so many great people. So, I'm getting fed in these important ways. So, it's a hard answer though—hard question.

Devon Fulford:

I do have one more question I just want to shoot around the room really quickly. But before we do, I just want to thank everyone so much for joining us today and spending a little bit of time getting to know roughly a third, actually, this is almost a third of the Davis Phinney Foundation staff that you're seeing on screen today. So, there you go. Thank you so much. And so, for the panel, the final thing I would love to know, and I'm sure everyone would love to know, is just in general, because practicing gratitude is important, not just because we're going into a holiday week. For what are you thankful, in general?

Samantha Narciso:

I am thankful for my health. I am thankful that the SAG-AFTRA strike is over so everybody could talk about the *Hunger Games*. And I am thankful that I have this two second opportunity to please tell everybody who is young onset Parkinson's: Your kids want to love you, and if they, you tell them that you have Parkinson's, they will not hate you. They just want to love you because not enough people know that. And I have wanted to say that publicly for forever. I hope that you all know that your kids just love you and want to help.

Devon Fulford:

Thank you, Sam.

Edna Togba:

I'm grateful for the ability to have the space, right? Because sometimes we're not in that space, but I'm currently in a space of being very appreciative of nature and going out into nature as often as I can and sharing photographs with my friends and my loved ones. It's a small thing, right? To be able to be like, oh, look, the sun is rising. But not everyone is able to see that, and it really does help people. And it helps me. And I'm really grateful for just having the space to be appreciative of the beauty of nature, and then also wanting to share that with my loved ones.

Rebecca Reifel:

I agree with Edna. I am thankful that we work, and we exist in a space that we are allowed to be vulnerable. We're allowed to cry, as we saw today. There are not too many organizations that I think provide this type of space. So, I'm thankful for my coworkers. I'm thankful for this community. I think we've really built something really special here at the Davis Phinney Foundation.

Devon Fulford:

Thanks, Rebecca.

Claudia Martinez:

And I want to say that I'm thankful for family that when I mean families to be so blessed to have so many families: my family in Columbia, my friends, family, my Parkinson's family, and my Davis Phinney Foundation family. So, that's a real blessing.

Chris Krueger:

Yeah, I'm on team Claudia. I agree that I feel I'm so lucky in so many ways. And one way in which I'm lucky is my friends and family are like absolute rock stars. And so, I'm really lucky in that way, but I'm also really lucky that I had, like a very, so far, I've been very blessed with the care I've received with regard to Parkinson's, and I know not everybody has that blessing. And so, I just feel really grateful and thankful that that's the way my life has gone. And so that's,

that's something important to me. And then also just getting to work with such a great group of people. The people that aren't on this screen are just as incredible as the people who are on this screen. So, I'm really, really glad to get to know all of them, so that's great too. And my dog; my dog's awesome.

Devon Fulford:

Always shout out the dogs. Yes, very important.

Dani Smith:

Just briefly, I am super grateful. Yes, it's so nice to show up in person or on teams to a group of people who are just so fun and funny. Shout out to my community engagement team and just willing to, yes, give our energy to do work like this. And yes, I'm so grateful for my family and friends that I can turn to outside of this work for the support that I need.

Devon Fulford:

Thanks, Dani.

Beth Chatterton:

I am super grateful for my family and my five kids. I am super grateful for this team and my marketing team, who are fantastic and to serve you guys. I'm very grateful to be here.

Devon Fulford:

This has been amazing. This has been a really wonderful, roughly 60 minutes, and all of you, all of my fellow DPF staff on the screen, thank you for everything. Thank you for being here.

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