



Interview with our Community Action Committee Members

An Interview with Debbie Callahan and Lorraine Wilson

Davis Phinney Foundation

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

Gabriella Dimotsantos (Community Engagement Manager, Davis Phinney Foundation):

My name is Gabby Dimotsantos, and I am the community engagement manager here at the Davis Phinney Foundation. And I am joined by Debbie Callahan and Lorraine Wilson. Debbie has been living with Parkinson's for a little over seven years now. She is from the northeast area of Pennsylvania and has been there for over 38 years at this point, Debbie's also a retired occupational therapist who is a certified hand therapist and actually worked with people with Parkinson's prior to her own Parkinson's diagnosis. Amazingly enough, a type of story that we're hearing more often today. And then we're also joined by Lorraine and Lorraine Wilson. She's been living with Parkinson's for about six years now, living in Texas, and is a retired teacher. So, both of these lovely ladies on the screen here with me today are really extraordinary at leading efforts in their communities based on what that local need is.

And that's kind of what brings us together here today, Debbie, a fierce advocate for what is right and making sure that people are treated the way that is fair and equitable, and they deserve to be treated and has a CAC, a community action committee that she's been working with to help aid in her work. And Lorraine wearing all of the hats with us here at the Davis Phinney Foundation as an ambassador. Also, a community action committee leader leading all sorts of different wellness programs within her community and awareness-building activities. And you've probably seen her on screen many o times before for some different webinars or joy breaks. So, thank you both for joining us today. I know your time is so valuable and precious, and we appreciate it that it's spent here with us to share these stories just to, I think we reflect on this process.

And then I want to invite Lorraine to share how your experience impacted her as this kind of next side is. I just think it's amazing how much you were able to accomplish from having such a terrible experience, having horrible side effects, really not being within your own abilities that you're used to, and losing so much of your independence to. Then it was March of 2022, reaching out to us and saying, hey, something needs to happen. I don't want anybody else to go through this. What can we do? Can I work with you? And we were able to post your letter on our blog in July, and we shared it out in our healthy Parkinson's communities newsletter. And you've shared your story so many times with so many different people. And I think that you've had such a significant ripple effect probably far beyond what you've been able to know so far.

And with that leading to, I think a really beautiful moment that we had earlier this year where, or I guess it was at the end of last year, what is time anymore where you were sharing your story during one of our online gatherings with other people within the healthy Parkinson's Communities initiative, whether they be ambassadors or fellow community action committee leaders. And Lorraine said, hey, you wrote that letter. And so, I, Lorraine, I want to open it up for you to share your experience and kind of how Debbie's letter impacted you, just as an example of what somebody in their community can do when they see Debbie's story.

Lorraine Wilson (Ambassador, Davis Phinney Foundation):

So, what impressed me about the whole way this unfolded was part of Debbie's humility saying, well, I didn't know if I was an advocate and never thought of myself as an advocate, but by being courageous to share, because she didn't want other people to go through it, what a beautiful story of advocacy. It really moved me. And we had just completed a community event and the chief medical officer from the local health system was at that event. And so, I then, you know, read Debbie's story and was able to visit with him and say, we don't want this to happen here. And he goes, you are correct. We don't want this. And that's helped us locally plan events where we can talk to nurses or other persons in the hospital and not to go back and question whether you treat the headache or do you treat the high blood pressure that's not, you know, it's not that singular, but it's like, what are we treating?

What do we know about the meds? And I don't know about other folks. But I happen to use an app on my phone that lists my Parkinson's meds and then allows me to type in anything. If the doctor says, well, let's give you this. I go, let me check. And now I stick in my little word and say is this spelled correctly? You know, how medicines are? And it will tell me if there are interactions or not to be concerned about and other, other drugs that might be offered. Now, do I know if it's a perfectly accurate app? No, I don't know. But it's what I tend to use. So, you know, the medical community, because I know so many folks, including Debbie, you know, as an OT, that's the medical community. They're humans, they're wonderful persons and sometimes they're stressed and confined, you know, to deal with things in a certain way. But you know, when it comes to that kind of suffering, that was not called for Debbie, you might want to explain what you, you, you told us a little bit about what happened, but you might mention, or maybe I just wasn't listening carefully, but how long did you really have these repercussions after you were given that mat?

Debbie Callahan (Ambassador, Davis Phinney Foundation):

I would say the first three days, I mean, it was slowly getting better, but the first three days were really bad. I have a small powder. I had a small powder room on the first floor. I would use the bathroom. My husband had a po, a kitchen chair in between the toilet and the sink. Cause if I stood up to wash my hands, I would fall down again, a static intolerance. So that eventually went away. I did go to this course happened close to a weekend and I followed up with my family doctor and he said to me, well, that medicine's out of your system right now. But I don't

think it was, because it took a lot of days before I take a phone call from my children and for weeks I didn't feel right at all.

Gabriella Dimotsantos:

So definitely, at least for weeks is what it's sounding like. And I vaguely remember when you had reached out to me march of last year, you said things are still not quite right. Like you were feeling a lot better, but you still felt off. And so, I do remember that sticking out in my mind pretty strongly. And I think what really out- Lorraine, go ahead.

Lorraine Wilson:

I was just going to say, and if there's more than one takeaway, but for me, if there's only one takeaway that everybody remembers, it's to befriend might not be the right word, but know who in your local community at the hospital system or the medical offices depends on where you are. You know, who would you speak to try to talk about preventing this from happening? Who is interested in knowing, you know, how do we want our medical community to always act in the best interest of the patient, which we hope they do. But, you know, again, it's hard.

Debbie Callahan:

I had another doctor say to me, you could ask for the pharmacist to clear the medication.

Lorraine Wilson:

Excellent.

Debbie Callahan:

At that point, if you're in the ER patient.

Gabriella Dimotsantos:

Yeah. And I think there are a few things that were said. And before we continue to dig in further, there's one moment that I do want to reflect a little further on from when we were talking to the staff from Geisinger, because that was a, that felt like such an important moment for this, that you reached out so many times. You followed up, you sent an email, you'd followed up with an email. You, I think you had a couple voice messages that you sent. And it wasn't a simple, I reached out, I immediately got a response, and I was heard. It was this constant persistence of you begging to be heard for the sake of other people as well. And then when we finally got into that space, it was really reassuring to hear the people on the screen say, hey, we checked into the system.

Gabriella Dimotsantos:

We noticed that this is where it was lacking. But there was still that missing piece of what's next, as you said, which is what we're still trying to figure out with them. Okay, but what, what is going to happen to make sure that other people, whether they have Parkinson's or not, are not going to encounter a contradictory medication that could have quote unquote been easily avoided. And so, I thought that was a really important moment. And so, before we start to kind of dig into this, we talked a lot about systems. So, before we really dig into this systemic side of this, I'm wondering if there was anything else that you wanted to add or reflect on, or if that felt, felt good?

Debbie Callahan:

Well, I think when we had the meeting with the big chief of medicine and there was a guy there, I kind of felt intimidated. Oh, my little Debbie, you know, and this, these people in church. And I wasn't in a normal flighty saying like, well, how are we going to know this? That's what introspect would've said that at, everybody puts their-

Gabriella Dimotsantos:

Yeah, I love that. And I think about that often how you reflected, and you said, oh, I was kind of intimidated in that moment. And I think the reality is both for us looking back on that situation, but then also for anybody else who might be looking to consider how they can influence the medical systems within their community is actually we're all humans. We all are. And we're all doing our best and we all can continuously find ways to improve ourselves. And that doesn't mean that every interaction's going to be perfect or, you know, leave that meeting where you felt intimidated and say, ah, yeah, I really, I really gave it to them like, it's okay. We're, we're doing our best at every step. And every little moment has an influence. And so, I thought that felt really important. So, thank you, Debbie.

Debbie Callahan:

When I was taking rock steady boxing in northeast PA, my instructor recently from that wrote me and she said, you're a tiger, Debbie.

Gabriella Dimotsantos:

I'll follow that up. We'll have to get you some kind of tiger memorabilia, something so you can remember how, how fierce, and influential you are. Well, and I think also, Lorraine, you had mentioned, you know, everyone's doing their best and I think we all are, and everyone even within the medical system is, and we often see these moments in so many different communities where something could have been better. Somebody was given a treatment that was not aligned with their needs, like Debbie or a decision was made that wasn't the most effective. And as you said, and as we talked about previously, it's not that they're bad people, you know, they mean well and there, and everyone's coming to do a really important job and it,

and it's a system that's really overworked. And I think about this note about listed as an allergy, it's like, well, it's not an allergy.

The way that the system is set up is most effective to roll with the system by lining this as an allergy. And I think this is one of many moments for us to say, this is an area where the system's actually not serving anybody. It's not serving the people who are providing the treatments, who are there with their whole hearts and trying their best. And it's also a system that's not serving the people who need medical care, whether it's emergency or if it's day-to-day. And so, I'm curious if there are any other reflections that you have from that you know, beyond our discussions that we've had off of this recording. Yeah.

Lorraine Wilson:

One of the things that strikes me as well is that Debbie admitted, you know, she was under stress from this reaction and wasn't really understanding why, what is going on. And that's a high blood pressure. We're all going to agree with that for sure. But how do you advocate for yourself when you might not really be clear minded? You know, what do, what, what do we rely on now? She had her husband, okay, do we always have a husband or a spouse or a significant other? You know, not necessarily does everyone have someone there to accompany them? And so, you know, besides, you know, the medication app, I also have an ID that identifies me as a person with Parkinson's and to please check in my wallet for this list of meds. Because, you know, my phone has password protection so they can't get any it for that list.

Lorraine Wilson:

But, you know, there are things we can do personally, and then we tell our support groups, and we'd tell our people around us. But you know that stress of being in an emergency room, and I used to teach first aid, CPR, AED, and one of the things I would start off would be to ask my students, these were college students typically. Have you ever seen an EMT, or a paramedic run? You might see them walk quickly, maybe you can see them run to go back and get something out of the ambulance. But part of their process of learning and then helping others is to be calm, cool, collected, follow protocol, follow a list. And the list won't change unless something is found to be better through education or through advocacy or through, you know, worse things,. So, I really you know, calling Debbie a tiger or me calling her courageous or brave sincerely, if it's that, you know, if we don't say something, who will, you know, if so yeah, we have, yeah, I love being able to advocate for myself and for others in the community.

Gabriella Dimotsantos:

Absolutely. And so, I think as we're, you know, kind of coming around on this conversation, I'm really curious about, you know, lor, you'd mentioned this app that you use, you have a card. What are, and what are some other ways that I think people can take some action if they're



feeling inspired by this story to do something in their community to, to make a mark? What would you recommend for both or of you?

Lorraine Wilson:

. Oh, Debbie, why don't you start?

Debbie Callahan:

Well, I know the route I took. I actually contact the people who treated you. Say maybe there's another way.

Gabriella Dimotsantos:

Yeah. It was really powerful to get, to get people together to advocate with you so that you don't feel like you're alone. And to share the information and bring awareness to what's happening and to kind of be relentless in making sure that your voice is heard. I think that's incredibly powerful. And then Lorraine, I saw you had something too.

Lorraine Wilson:

I would just say you know, there's that, there's that old adage or really, I guess it's a quote from some sport person, but never give up, never ever give up that concept of just because they're wearing a white coat or just because this is an event in there, on their turf, let's say. That doesn't mean you still don't have a voice. You have a voice always and supporting me. You know, the Davis Phinney Foundation, granted I love live well today and every victory counts. Those are just every day. I hear those in my head, and I love those. But I think it's all about how do we live well today? Well, we don't want medical mistakes like this. We want to be able to advocate for ourselves and for others. And for me, I'm so grateful that when I heard Debbie's story that I had kind of accidentally met this person recently, you know, that was the chief medical officer and then was very comfortable going to him making an appointment saying, hey, you need to read this. And his response was, hmm, we don't want that to happen here.

Gabriella Dimotsantos:

<affirmative>. And so, I think there's so many ways that this story can inspire action within different communities, different people with different capacities. If someone's watching this and they say, oh, I don't have the time with the capacity to be Debbie and write a letter and reach out and follow up and find all these people, it could be something such as finding a connection within the medical community and making sure that this story, there's awareness of this story and knowing that it's not just Debbie, it's so many other people that encounter these challenges. And really challenging the conversation to continue. Because even if you're just a conduit of the conversation and keeping it going, there's going to be somebody who hears it

who has that connection, who can say, ah, I know the medical officer in my community. I want to make sure that this doesn't happen.

Gabriella Dimotsantos:

Or I know something about how to work the system that the hospital uses so that we can make sure people don't have to list an allergy. That there's actually something else that will come up to notice a contradiction. So, I think there's so many ways that people can find creative ways to continue the ripple within their communities because this isn't an issue that is isolated to the hospital where Debbie went, this is something that we see and hear about in so many different communities and it's an important issue to address. So, thank you so much for taking the time to talk about it and not just flowing with the system that's not serving people. I really appreciate that. So, disrupting in the greatest way. Well, before we hop off for today, is there anything else that you would like to add for anyone watching?

Debbie Callahan:

I would just like to add that get, help spin behind me, really help me. That's what they're there for. They help us. Problem, diabetes visual group out there that can help.

Gabriella Dimotsantos:

Yeah. Thank you. And Lorraine, any final takeaways?

Lorraine Wilson:

Well, if I go final, final takeaway, again, my keen interest in healthy Parkinson's communities, because it's all intended, you know, to take down barriers to make sure there's access by everyone. And that access is not just an insurance issue or just a this, that, or other issue and that the medical community wants to pair up with the committee members or, or others in the community that are trying to make it a healthy community, not just for Parkinson's, although that's our focus, but anybody with these medical needs. Yeah.

Gabriella Dimotsantos:

Yeah. And to continue on that plug, I mean you can't have a healthy Parkinson's community without the baseline of a healthier community in general. And whether that's giving Parkinson's a seat at the table or being the person who brings together a diverse coalition of collaborators to change the system for the betterment of the aging community, including Parkinson's. There's so many different ways to get involved, which is my shameless plug for the healthy Parkinson's communities networks. So, both Lorraine and Debbie are community action committee leaders. And if you're watching this and you're thinking, ugh, there's something that I could do in my community, there's something that needs to happen in my community to make it a better and



healthier place for people with Parkinson's to live. Whether that's increasing awareness around something like what happened with Debbie, if that's bringing more programs to your community, if that's increasing access, we have ways to support your work and bring you together with people who are like-minded and leading similar journeys in their communities. And so, if you'd like to learn more or get involved, you can email us@communitiesdpf.org and we will happily and quickly get back to you and see how we can support. So, thank you both so much for your time. I really appreciate this. This is such a wonderful story to share. So, thank you.

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