Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work, and how you can help speed a cure at Michaeljfox.org.

Speaker 1: Welcome to a recap of our latest third Thursday webinar. Hear directly from expert panelists as they discuss Parkinson's research, and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at Michaeljfox.org.

Larry Gifford: Hi everyone, and welcome. I'm Larry Gifford. I'm a member of the Michael J. Fox Foundation Patient Council co-founder of the PD Avengers. Like many of you, I'm living with Parkinson's Disease, was diagnosed in 2017. I had DBS surgery in 2023, and over time, I've learned just how important it is that the right people around you. Today we're diving into something that affects us all. How to build your best Parkinson's care team. Whether you're newly diagnosed, or years into your journey, your care team plays a huge role in how you manage day-to-day, and long-term. It's not just doctors, it's therapists, family, friends, the community you surround yourself with. It's also about knowing when to add new people to your team, and how to get the most out of those relationships.

So, this conversation is actually part of our Parkinson's IQ + You series that travels across the US. I've had the honor of moderating those in-person events before, and I can tell you this topic always sparks great questions, and stories. Before we begin, I want you to think to yourself, who is one person, medical, or otherwise you couldn't face Parkinson's without? All right, let's get into it. I'm thrilled to introduce you to today's panel. First we have Christie, and Prentis Brooks. Christie was diagnosed with Parkinson's disease in 2013, lives in Arizona with her husband, and care partner, Prentis. Hi folks.

Christie Brooks: Hi.

Prentis Brooks: Hi everyone. I've been part of our care team from the very beginning, and I'm glad to be a part of this program.

Larry Gifford: Great. Next we have Dr. Rachel Dolhun. She's a movement disorder specialist, a lifestyle physician, and a principal medical advisor at MJFF. Hello, Rachel.

Dr. Rachel Dolhun: Hi, glad to be here.

Larry Gifford: Next we're joined by Dr. Cristina Colon-Samenza. She's a physical therapist, and assistant professor of kinesiology at the University of Connecticut.

Dr. Cristina Colon-Samenza: Hi Larry. Hi everyone. Glad to be here. Thanks for having me.

Larry Gifford: And finally, please welcome Dr. Jessica Galgano. She's a speech language pathologist, and co-founder of Open Line Speech and Communications.

Dr. Jessica Galgano: Hi Larry. Hi everyone. Thank you for having me. I'm happy to be here today.

Larry Gifford: So, what is a Parkinson's care team? Let's start with the big picture. When you think of a care team, what does it mean to you personally? How has it changed your needs? How has yours changed as your needs shifted over time? What kinds of roles show up on your team beyond just medical experts? So, because Parkinson's doesn't just affect movement, it can affect mood, memory, sleep, digestion, speech, and more. It takes more than one doctor to handle it all. That's why the best care isn't solo, it's team-based. Think of it like this, you are the CEO of your Parkinson's journey. Your care team is your all-star executive staff, each with their own superpower, all focused on helping you live well.

Whether it's during your neurologist fine-tuning your meds, a physical therapist helping you stay strong, or speech therapist, making sure your voice is heard. Everyone plays a role in supporting your health, independence, and quality of life. Remember, the person with Parkinson's is guiding the care team. It is not a passive role. All right Prentis, and Christie, when you think about your Parkinson's care team, formal, or informal, who's the first person to comes to mind, and why?

Christie Brooks: She really reflects what we want from everyone, and what we want. The message we want.

Larry Gifford: The movement disorder specialist?

Christie Brooks: Yes.

Larry Gifford: Yeah. Would you agree with that Prentis?

Prentis Brooks: Yes. And we are very fortunate to have a very good movement disorder specialist, and she is kind of like the quarterback of Christie's team, and we rely heavily on her to guide us through this whole journey since we've been here in Arizona.

Larry Gifford: Great. And Rachel, someone doesn't have access to a full care team, what's a good first step? What's a small action they could take to strengthen their support system?

Dr. Rachel Dolhun: It's interesting because I asked this question to my followers on Instagram, where are you with your care team? And about a third of people said, "I don't even know where to start." And so I think for a lot of people, Parkinson's, or not, we go to the doctor, and I think sometimes we just think that's it, or that's the full care, and there's so much more that is part of care in Parkinson's, or that can be part of care in Parkinson's. So, I would say the first step of course is your doctor. That's your first in into care, but then it's about asking the question. Like I said, I think a lot of people don't even know that there's a broader team accessible to them, or what that should look like.

And you don't have to know what that should look like, but you do have to know to ask about it. So, if you're seeing a Parkinson's specialist, or a general neurologist, or even your primary care doctor for your Parkinson's, ask, "Who else can, or should be part of my team?" And that starts the conversation, and the discussion about, and when you should add other care team members.

Larry Gifford: I think this is a very important point that we should acknowledge. Not everybody will have access to a full team, and that's okay. The goal here is to help everyone find what works where they are. You can do a search with just one trusted provider, or care partner, Christie, and Prentis. So, Christie, who is on your care team?

Christie Brooks: So, we have a MDS, and we have the neurologist, and I have PT, and ST.

Larry Gifford: And Prentis of course, how has your role evolved?

Prentis Brooks: My role is that I help coordinate a lot of the activities between the people on her care team. We meet once every three months with the movement disorder specialist. We meet weekly with the physical therapist, and also with the speech therapist, and about three times a year with her urologist. And I would add there's another support system. We're part of a group called Moving Not Parking, which is members of the community similar to your Larry, the PD Avengers. And they're at a very important part too as well. And we meet with them several times a year.

Larry Gifford: Oh, that's great. I was diagnosed in 2017, as I said earlier, my care team includes my wife, Rebecca, and my son Henry who was six, and now he's 16. So, his role has evolved. Before I was like, "Just your role is to let me know if I'm tremoring." Now, it's obviously changed a lot. And as the quarterback of my care team, my tap my family, Dr. Ramon, my movement disorder specialist, Jonathan, my pharmacist Abe, and a collection of therapists that I rotate in as needed. Rachel, why is it beneficial to see a movement disorder specialist for a general neurologist?

Dr. Rachel Dolhun: Well, again, caveating that as you said, that not everybody will have a movement specialist near them, or accessible to them. There's a shortage of movement specialists, so they're just not available in some areas, or for some people. But if possible, seeing a movement specialist, a movement disorder specialist is what we recommend simply because movement disorder specialists are general neurologists who've gone, and gotten extra training in Parkinson's, and related disorders. So, they've done extra work to get that extra experience in diagnosing, and managing, and caring for somebody who has Parkinson's. So, it's a numbers game. They simply see more people with Parkinson's, whereas a general neurologist may see some people with Parkinson's, but they're also caring for people with all kinds of other neurological conditions. A movement specialist is really focused on Parkinson's, and related conditions. So, you're more likely to get somebody who knows all those nuances of Parkinson's can help you assemble that full care team that we've started talking about, and maybe more likely to be up-to-date on the latest advances, and research opportunities for you.

Larry Gifford: And as you first meet a patient, what kind of conversations help you figure out if it's a good match?

Dr. Rachel Dolhun: Well, I think there's no specific conversation, or one question. It's really about, we often liken this to dating, right? So, it's about building a relationship. So, you are talking to the other person, and getting a feel for how they respond, and if they listen to you, and if they open space, and time for your questions, or for emotions you might have around this, or for following up. And so we say try to get to somebody who's a movement specialist so you have that expertise, and they're available in many areas of the country. And then once you get that expertise, it's really about the person, and their approach. And again, whether you feel like you can have a good relationship with them because you are establishing a long-term relationship. So, it's about do you feel heard?

Larry Gifford: I have one more question for Christie, and Prentis. How did you pick your MDS after you moved to Arizona because you moved after your diagnosis?

Christie Brooks: Well, we pick her, [inaudible 00:09:49] gave her to us, referred her to us, and we went with it.

Prentis Brooks: Yeah, she was highly recommended from the friend that worked at the same organization that we worked at. And once we met with her, and we've been with her the whole time, it's been a very good match. She's been really supportive of Christie, and she also has been supportive of my role part of Christie's care team as well.

Larry Gifford: That's great. Thank you. My MDS was thrust upon me during my diagnosis process. I didn't even know what an MDS was, or what it did. I got very lucky. My gait was a mess. So, he recommended physical therapy right away I showed up with an attitude like fix me. That was not the right attitude by the way. And learned quickly that there are remarkable things that physical therapists can do, but you do have to do the work on your own. Cristina, when you first meet a patient, what kind of conversations help you figure out if it's good match?

Dr. Cristina Colon-Samenza: Right. So, I would just echo what Rachel was saying. So much of it is about building rapport, but at the center of that is understanding what the patient's goals are, and what matters most to them so that then you are together working towards that common goal that is most important, and prescient for that patient in front of you, that person in front of you. So, really aligning your treatment, your efforts, your activities along with that patient's goal. And hopefully that starts to then build that rapport naturally. So, really goals, and what's meaningful in their life, and what's front, and center for them are the questions that I'm going to be asking when I first meet with an individual living with PD.

Larry Gifford: And Cristina, if the neurologist that you're seeing, or your MDS does not recommend a team until a problem arises, what's your advice to those folks?

Dr. Cristina Colon-Samenza: Right. Thank you so much for that question, Larry. I really appreciate it. So, one of the models that we like to use here in my lab, and that is really a model that is taking more hold across the US in terms of management of Parkinson's disease is engaging with a physical therapist Very early on in the disease process, I so often hear individuals living with PD say, "Oh, I don't need a physical therapist. I'm doing really well." And so I say, "That's wonderful. We want to keep you doing really well." So, we highly recommend that the same way that you engage with your movement disorder specialist, or your neurologist at diagnosis to engage with a physical therapist at diagnosis because the same way that the medication that you take to help you manage your Parkinson's disease will evolve over time. So, will your exercise, and physical activity needs evolve over time with your disease process, your goals.

So, having at least a yearly check-in with your physical therapist will allow you to even get baseline measures. So, if you're doing great, you were just diagnosed, you're not having any problems, wonderful. Meeting with a PT now will allow you to understand what is my strength like? What is my balance like? And we have some objective measures to help record that, and then be able to track that over time so that if we see changes, we can act accordingly.

Larry Gifford: Well, for so many people, at least for me, I'm going to extrapolate out, I didn't realize I could gain motor function back. My walk was wonky, and my arms weren't working right. And the physical therapist really helped me almost rebuild my walk.

Dr. Cristina Colon-Samenza: Yes. So, yeah, thank you for bringing that up, Larry, because often when we hear a progressive neurological disease, the thought is, "Well, there's nothing I can do about it." And that's what's so amazing about engaging with your physical therapist. And what I love, obviously I'm biased about physical therapy, is that it really is empowering the person living with the disease to take some control over an otherwise uncontrollable situation. So, just like you said, Larry, you're like, I realized I had to do the work. So, we as physical therapists are often giving the tools to the individual living with Parkinson's disease to take some control back over their lives. And I think that helps with both the motor, and the non-motor symptoms that you often face. So, yes, change can happen, you can get stronger.

Larry Gifford: Yeah. [inaudible 00:14:09] Okay, now it's time for you, Jessica. Are you ready? I've taken speech therapy, and I believe it's one of the reasons why my voice as strong as it is, it was fading in the afternoons, but I really took it before people said I needed it because it's just like Christie was talking about. And so when do you recommend someone talk to a speech therapist, and how do they know who to trust?

Dr. Jessica Galgano: Two very good questions. Well, I'm very much in line with what Dr. Dolhun, what Christine, what we're both saying, the sooner the better, and especially with speech pathology, and what we cover, those thinking, communication, swallowing needs, we want to prevent versus treat when we can. And so it's so important I think upon diagnosis to see a speech, and language pathologist really to get a sense of that baseline level of performance, or skill that you have in maintaining that loudness you need to be heard, and to be understood, to make sure that you're feeling comfortable about your executive function, how you're paying attention, how you're remembering, how you're communicating with language, and then also how comfortable you feel with your swallow.

We don't realize how those little things that we're nervous about swallowing a pill, drinking thin liquids, or trying to gulp, and having one swallowing issue at one point can scare the heck out of us, and then make us feel like we're having swallowing problems when maybe we aren't. So, these are really great times for you to reach out to the speech pathologist who hopefully you've been in touch with from the beginning to make sure that she, or he, or they can provide you with the education, the comfort, the confidence that you need to stay strong to be heard, to be understood, to swallow safely.

Larry Gifford: I found out last year that I've been swallowing pills incorrectly my whole life.

Dr. Jessica Galgano: Oh, no.

Larry Gifford: Yeah. So, I would throw them in there, and tilt my head back, and swallow. And that closes your throat off, and let them float back with water, and let swallow that way, and you won't have as many problems swallowing.

Dr. Jessica Galgano: Right. Yeah. And there are so many different strategies, it's so individually based considering what you're experiencing, what's happening at the level of your body, and also your mind because that can have such an impact. So, yes, I think that working with someone, and as Rachel was saying, voice, whatever's going on with you, talk about it with your team, and they will either address it themselves, or point you in the right direction so you're able to get that care that is likely out there.

Larry Gifford: Yeah. Rachel, when do you decide to refer someone to a specialist?

Dr. Rachel Dolhun: One if they have challenges that we know a specialist can help with. So, you heard Jessica talking about speech, if speech changes, or if you have any kind of swallowing. Cristina was talking about any kind of walking, even if you want to just get started on an exercise program. So, if we see anything where we know a specialist can help, and, or medications, or current treatments don't fully address those symptoms like walking, or speech changes, then we're quick to refer. The other time is when people ask. So, again, a moment to feel empowered, and to ask, should I see a speech therapist? Should I see a physical, or occupational therapist? What can they help me with? And then two things I just wanted to underscore from our conversation to this point is, one, as Cristina was saying, even if your doctor refers you have a goal, and you can come up with that goal with your therapist, or with the physician that you talk with.

But Larry, you had so beautifully illustrated this with saying one of my goals was to be able to walk hand in hand with my wife without feeling off balance. Your goal can, and should be something like that that matters in your daily life. My goal might be to be able to have my spouse hear me, and not shout from room to room like we all do. So, whatever it is that makes that goal, and that therapy important, and tangible for you. And then I didn't want to leave out mental health professionals. So, we often default to thinking about physical therapy, occupational therapy, speech therapy, but mental health therapy can be so helpful throughout the journey, but especially at the beginning. And I think that's a place where people maybe aren't aware that that's available When you're processing a new diagnosis, or you're even wondering what your next step is, that's something that should be considered as well.

Larry Gifford: I did have an occupational therapy that was a lifesaver. I was so tired by 10, or 11 o'clock in the morning, and I couldn't figure out why. So, she walked me through my day. She said, "Okay, Larry, tell me if I'm wrong, but you have Parkinson's, you walk onto a slippery wet floor in the shower, you try to balance yourself, turn around, tilt your head back, close your eyes, and shampoo your hair. You've used up so much precious energy by just getting ready for the day, no wonder you're so tired. So, go buy a shower chair." It was life-changing, just those little things. And that's what great therapists can do is they can hone in on those little things for you. Christie, and Prentis, I want to hear more about your community, extended network of support, the friends, the community, the members, the support group functions as part of your care team. Talk about those folks. And you said you get together a couple times a year or?

Prentis Brooks: Yes. The group is, it actually started before we got here, and the person that recommended us to the movement disorder specialist, she was actually the leader of that, and she has since moved away. And what the group does, it's really, really impactful, because everyone has Parkinson's, or knows someone that is Parkinson's, that has Parkinson's, and so they get together a couple times a year, especially bringing new members on, and also supporting a lot of the fundraising events that happen here in the Phoenix area. And then also just getting together to talk about, "Hey, what's working? Is there anything that we can do to help you?" And it's a really supportive area. Then also some of the group, they come together, and they have lunch. They'll invite Christie to lunch, and they'll get a chance to get together, and it's a really good way of building community with other people.

Larry Gifford: Yeah, I have based on absolutely no scientific research, or data, I believe community is as important as exercise. It's just my personal opinion. But I think whether it's through improv, or through going to lunch, or dinner with somebody, or we had a supper with YOPD here in Vancouver where every quarter we'd get together at a different restaurant, or somebody's house, and it's great. And I think it's super important to stay in community because once you have those connections, you can rely on those people a lot, and they get it. You're not starting from zero, you're starting from 50.

Dr. Cristina Colon-Samenza: Larry, although you're saying that that's your hunch. Your hunch is completely in line with the evidence, and the data. There is just a strong, strong, strong body of evidence that supports community-based interventions, and how they are critical for both our mental, and physical health.

Larry Gifford: I want to get a little deeper now, and go into actually finding, and building this network of people. So, Rachel, what can someone expect for their first visit with a movement disorder specialist, and what questions should they ask?

Dr. Rachel Dolhun: Your first visit will, of course, be longer because your doctor's getting to know you, and you're getting to know your doctor. So, they're finding out all about you, about your Parkinson's symptoms, or what symptoms you might be having, how long you've had them, how they impact your life, et cetera. And then they're going to ask you all kinds of other things like any new doctor does about where you live, and other things that are important to you, and other medical conditions that you might have, et cetera. And then they're going to do a detailed physical examination. So, lots of things with movement in general, but they'll have you tap, and open, and close your hands, tap things like this where we're testing your movement, how big, and how fast your movements are because those tend to slow in Parkinson's. We'll watch you walk down the hall, we'll test your balance, et cetera.

So, it's a really detailed visit where again, we're really getting to know you, and your symptoms, and your Parkinson's, and we are evaluating you to see how those symptoms are playing out in your body, and what they look like. So, it's a lot of talking, a lot of going through exam steps. And then it's, again, on your first visit, like we talked about before, you're assessing your doctor, too. So, you're looking at how do they listen to you, how do they answer your questions, et cetera. And you're seeing too, if it's a right fit for you.

Larry Gifford: Yeah. Cristina, how can people find a good physical therapist?

Dr. Cristina Colon-Samenza: So, as physical therapists, we are all trained as generalists. That's what every physical therapist that's licensed in the United States will be. They will be a generalist. However, there is now a movement, and a trend towards residencies, and fellowships. So, you will find that there are some physical therapists that have some advanced training, and then they have obtained a board certification in a specialization. So, for example, I am a board certified by the American Physical Therapy Board, a specialist in neurologic physical therapy. So, that's something that individuals can do if they're looking for someone, a physical therapist who has specialized knowledge of neurologic physical therapy, they can look for someone with this designation of an NCS. And there's actually a really useful tool that's out there online through the American Physical Therapy Association, and it is choosePT.com/findaPT.

So, if even if you just Google choose PT, find a PT, you'll find that website, and within that you just enter in your zip code, and then you can even filter your search so that you can say, "I want to find someone with specific specialization in neurology", and that's available freely to everyone through the American Physical Therapy Association to help you find someone who is a specialist. But then of course, you need to go through that same process of is it a right match? Are we aligned in our goals, in our approach? Do we have that rapport?

Larry Gifford: Are there certain questions people should be asking when they meet with you?

Dr. Cristina Colon-Samenza: Yeah, I mean, you should feel free to ask the questions of what is your experience in working with Parkinson's disease? Do you have a predominating framework, or approach to treating people with Parkinson's disease? So, understanding their knowledge, their experience would be really useful for you to understand the context from which they are practicing from.

Larry Gifford: Okay. Jessica, what helps benefit people the most at a speech therapy appointment?

Dr. Jessica Galgano: Well, I think really going in, and thinking to yourself, "Okay, these are individuals here to help me. Here to help me identify where my strengths are, where my weaknesses are, and as they establish a plan of care for me, I am huge...", to feel like they are a huge part of the team. I think, Larry, you mentioned it a second ago, Christine, you spoke to this as well. To go in expecting people to fix it for you is not always the best way to approach rehabilitation. So, I think it's that motivation, that desire to want to feel better, to want to improve.

Dr. Rachel Dolhun: And if I can just underscore that you said earlier, Larry, it's about being an active participant. So, with a lot of this, it's you get out what you put in. So, if you're given exercise, I'll say I'm in physical therapy, and I'll say, "Oops, I didn't do my exercises." And they say, "Well, that's fine, but you're not going to get better." So, you get out what you put in, and if it's doing exercises, and you need help from your care team at home to help motivate you to do the exercises. But the important thing is, is putting in the work on your part to get out what your care team is putting in as well.

Larry Gifford: And you can't just be like the dentist where you brush your teeth the day of the appointment. You got to do it every day.

Dr. Cristina Colon-Samenza: Yes, absolutely. Can I just add a little bit more to this topic of conversation though? So, yes, I would agree with everyone. Obviously active participation is key, but I also want to highlight that apathy, or problems with motivation is a symptom of Parkinson's disease. So, right there lies the catch 22 right? So, you might want to improve your speech, or improve your walking, and you might have the information from your speech therapist, or your physical therapist. But then putting all of that together is a challenge because of a symptom of the disease, which is problems with motivation. Something that I have found is really useful is not only just prescribing the exercise, but building an accountability for that exercise.

And that can come in many different formats. It can be like, "Okay, I want you to practice for 10 minutes every day, this really large amplitude, large steps, really aggressive walking." And we create either through an app, or just pen, and paper, or a paper calendar, I want you to check it off each day when you do it, and maybe write some notes on the days that you did do it, and you didn't do it so that we can discuss how last week went when you come back in for the following week. So, there really needs to be an environment of accountability to help people follow through on those plans, and achieve their goals.

Dr. Jessica Galgano: To piggyback on that, Christine, is to really is to have also some faith in the providers that you see because those who are doing these intensive therapies really evidenced based for people with Parkinson's, and those at atypical Parkinsonisms is that the intensive therapies, the nature of the programs themselves when they are administered correctly, will strengthen those motivational circuits that we know can become impaired as Parkinson's progresses. So, therapy itself will aim to motivate you even more. It snowballs in the right direction once you get started, and you fully put yourself in there, you allow your care partners to be a part of that journey. You've got your therapist coaching, and motivating you along the way. It will get easier to feel that motivation to want to participate more, and more as you go on. So, I think it's that initial getting into the office, seeing that provider, establishing that relationship, and then trusting that together you with the team a partnership, you will strengthen that motivation to be able to succeed, and live successfully with Parkinson's over time.

Larry Gifford: Christie and Prentis, what's been your experience with therapists? Different therapies, PTs, OTs speech?

Christie Brooks: My speech therapist, she knows speech, not sure she knows me.

Larry Gifford: Ah, that's an interesting, Jessica, and Cristina, how do you build trust, and how do you get to know your patients?

Dr. Jessica Galgano: Well, I think every therapist is a little bit different. And I think it depends on the setting where you seek therapy, if you're going to an big outpatient center where it's difficult to see your therapist for a longer period of time, or for multiple weeks versus in a private practice where you, or a different setting where you might be able to really see your practitioner for at least an hour a time almost every day per week for many weeks on hand. And I think through those relationships, because I do a lot of those intensive therapies where I'm seeing people at least an hour a day, four, or five days a week for the first month.

And through that process, it's just such a joyful, wonderful way for me to get to know people, to know their goals, what's important to them, what scares them, and what things that I can do grounded in the evidence, but also taking into care the holistic needs of the patient to be able to provide them with the best outcomes. So, I think it's the time that I spend with people, the in-depth interviews, and assessment process that really helps me get to know physical, emotional, mental aspects of what's going on with them as they live with Parkinson's. So, I think it's the time, and it's the nature of me explaining my background, what's important to me when I am treating someone else, or someone. And it's really all about what's important to them, their families, the communities that they participate within day-to-day.

Larry Gifford: Rachel, there is a shortage of movement disorder specialists right now. We tell everybody to go see movement disorder specialist, and there's not enough to go around. Why is that an issue, and what's being done to address it?

Dr. Rachel Dolhun: There's many reasons this is an issue. Some of it is just generally less people becoming doctors, or less people becoming neurologists, and then fewer people becoming movement specialists. And that's happening for a variety of reasons. There are programs including one we lead at the Michael J. Fox Foundation to train more movement disorder specialists. So, we have the Edmund J. Safra Fellowship in Movement Disorders, which every year funds medical centers around the world to train more movement specialists. And so that's expanding access to care, and also because they're trained as researchers at the same time, it's continuing that forward research momentum. So, there are some things that are happening. Telemedicine has been another help to a lot of people with expanding access to movement specialists in many ways. There's also a growing population of people with Parkinson's. And so even the numbers that we have as the number of people living with Parkinson's continues to increase, that shortage will continue to increase.

So, as we've acknowledged multiple times, we want everyone to see a movement specialist if that's a possibility, but we know that it's not possible for everyone. And I do want people to know that you can still get good care, may take a little bit more on your part. You may have to do a little bit more homework like we've talked about with your therapist asking your neurologist, what's your experience in Parkinson's? How many people with Parkinson's do you see? Do you have extra education? Have you taken a course, or do you go to annual conferences where you learn more about this, et cetera. And then there are movement specialists, as I said, that might be accessible through telemedicine. So, look into that. I have a lot of people too who say, "I spend half my time in this place, and then I spend half my time in another place."

Maybe there's a movement specialist in that other place. Or maybe you visit your grandkids once a year, and they're in a location where there is a movement specialist, and you can build in a visit once a year to a movement specialist along with that visit. And then last but not least, there are ways you can access the expertise, and knowledge of movement specialists through things like this. So, there are plenty of webinars, online resources, et cetera, where you can access movement specialists, maybe not personal to you, but in a broader way where you can get some of that expertise as well.

Larry Gifford: Cristina, you work hard to improve access for care for underrepresented groups. Can you tell us more about that work?

Dr. Cristina Colon-Samenza: Yeah, thank you for that question. So, yes, and directly related to this access issue, we have just recently wrapped up a study where we were creating a completely virtual intervention to create support, not only peer support, social support of people living with Parkinson's disease, but also provide specific support for exercise, and physical activity for Hispanics, or Latinos that are living with Parkinson's disease. So, as everyone's been saying, this community, and social support has been so important for so many people's lives, and unfortunately, that same level of community does not exist currently for some of our underserved populations.

So, we created an intervention to create that community virtually. We brought people from all over the United States, including its territories like Puerto Rico, who are bilingual, who prefers Spanish as their first language. And we had a twelve-week intervention where we had everyone exercising together, meeting together, getting that support, and we found some initial indications of this being positive for reducing depression, increasing physical activity, increasing social support. So, we are really excited that, yes, this telehealth, or this remote access seems to be able to bring us together even when we can't be together in person.

Larry Gifford: That's great. Thank you for doing that work.

Dr. Cristina Colon-Samenza: Yes, you are welcome.

Larry Gifford: Prentis, and Christie, any appointment tips you've picked up that help make things smoother, or more effective?

Prentis Brooks: What we do before every appointment that's part of Christie's care team is we sit down, and we talk about what are the one, or two key points that we want to discuss with each one of her doctors. And so that way we go into those appointments with that information. And Christie always asks me, is there any questions that you have too as well? Another good thing is that you don't want to overwhelm your doctor with so many questions. So, what we do is we also utilize the patient portal in between appointments for things that come up so that those can be answered real time, or within a day, or two. And that's been very, very helpful, especially where Christie is right now in her journey with NDS.

Larry Gifford: Rachel, Cristina, and Jessica, how do you stay in the loop with the other providers on a person's care team?

Dr. Rachel Dolhun: That can be a tough one. And I hear this a lot from people. I have so many doctors, why can't they just talk to each other, and they should, or, I have so many providers, not just doctors, but I have so many providers, why can't they just talk to, and they should. But the reality is there are a lot of challenges around that communication. So, that's where, again, you can be your own best advocate. So, one way I tell people, if possible, try to see your providers in the same location. If you're by a major medical center, try to see everybody in that same location, or at least locations where you know that they use the same medical record system because then everything's in one system. And so it's much easier for people to, at the very least, even if they're not talking, refer to other notes, and be up-to-date on what happened, or what if I send somebody to Cristina's PT, then I can look at her note, and see what was done, what she recommends, et cetera.

So, that's the first thing. The second thing is a lot of doctors will print out, or give you a visit summary describing, or summarizing what they did, or what changes they made, and why those changes were made, and what your next steps will be. Ask for a printout of that, or make your own really detailed notes like with Prentis talking about being in the visit, and maybe one of your roles as a care partner is taking notes. So, just make sure that you're keeping a good list, whether it's a printout, or your own notes, and then keep them all in the same place, and take that to every appointment. So, then you can say, if your gut doctor is saying, "Well, what did your Parkinson's doctor say?" You can flip to that page, and say, "Here's what they said at our last visit." So, you can facilitate some of that communication through these other ways.

And then the last thing is sometimes, especially if you're getting conflicting advice, or you're confused, or you're saying, "I'm not sure, should I still be on that medicine from my cardiologist? You're saying my blood pressure is low, but I'm not sure." Say, "Can you talk to my cardiologist? Would you call my cardiologist?" Sometimes you need to just ask the direct question, and I would bet they won't say no, but you need to ask them, and encourage them to talk, and say, "You all talk please, and then come back to me, and tell me what I should do with that medication."

Larry Gifford: Or you can always see your pharmacist who talk about the interactions with pills. I do want to take a moment to call out the foundation's landmark study, the Parkinson's Progressive Markers Initiative, also known as PPMI. It's recruiting volunteers, people from all backgrounds with, and without Parkinson's can help move research forward. Join the study that's changing everything by clicking the link in the resource list. Rachel, if someone wants to get involved in research, what kind of providers should they connect with?

Dr. Rachel Dolhun: Well, they don't have to see any specific provider. So, that's thing one you can find out about research on your own. So, the Michael J. Fox Foundation has a tool that holds all ongoing trials called foxtrialfinder.org, and you can go there, and see what trials are available in your area. But the second place is, like I said, any provider, you might just need to ask the question. So, we actually talked with some community doctors, and they said their most common reason for referring somebody to research is when somebody asks, but not that many people are asking. So, you simply need to ask the question. And if they say, "I'm not sure", say, "Can you help me do that research? Or is there a place I can look", whether it's Fox Trial Finder, or there's another one called clinicaltrials.gov. But there are many ways that you can find out what research is available, and that you can get involved. You sometimes might even need to bring an opportunity to them, and say, "Hey, what do you think about this for me?" And help open that discussion so they can help you work through it.

Larry Gifford: Coordinating all this morass, and getting all the therapists to talk to your doctors can feel like a full-time job. But I'm wondering, Christie, and Prentis, how do you stay organized between the appointments?

Prentis Brooks: We have a calendar that is a, it's a virtual calendar I should say, and it also is a family calendar so that our two adult kids can also see what's going on. And so we keep that calendar up to date every week. Christie, and I, we talk about it at the beginning every week, to look at what appointments are coming up, and how do we need to get prepared for those. And then once an appointment after we meet with a doctor, and we schedule a new one, then we put that on there automatically all the time. So, it's constantly updated, and that's the best way we've been able to manage that with everything. And so it's a moving target.

We try, and do the best that we can. Occasionally at an appointment we'll fall through the cracks. I would also encourage everyone to opt into with your healthcare provider for getting communications from them as far as reminders of appointments. And we had that situation happen last week that we both weren't aware of an appointment, and it was because of the email, or the text reminders like, "Oh, we've got this appointment coming up this week that we need to go to." So, that's another way to manage that is to opt into those communication options that your healthcare provider, or your doctor provides for you.

Larry Gifford: Do you have advice on if the family member with Parkinson's isn't on board with the extra support, if they still want to be independent for everything, how you can get them to take that extra help, or therapy?

Prentis Brooks: That's a good question. That's not a situation with us. We do know some friends of ours that that's a challenge, and it's really the care partner is the one that's really driving that, and constantly encouraging them to take these options as far as care that's really helpful for them.

Dr. Cristina Colon-Samenza: I think, Larry, that one would come back to showing the value. If the individual living with Parkinson's disease can find the value, and align what's important for them with the service that's being provided, I don't think there would likely be as much resistance. So, I think it's approaching it with lots of time, and space to say what matters most to you, and I want to attune these services, or this help. So, it's in alignment with what's most important to you, right? This is for you, it's about you talk to me about how we can work together instead of having this opposition, which I think is what I hear you talking about.

Dr. Rachel Dolhun: The talk about is the key, right? So, I think oftentimes we assume they just don't want to do for X, Y, Z reason, but maybe there's something else there. Maybe they don't like the physical therapist, or maybe the appointment time is at a time when they want to watch their show, or whatever it is. But if we don't ask, we don't really know. And so it's about asking, being open, being curious, approaching people in a gentle way, and from a place of love, and genuine support, and having their best interest in mind, and saying, "Hey, just talk to me, and tell me what it is, why it is that you don't want to", and maybe we'll agree that we table that for now. Maybe there might be a way to work it, and if we both agree that this is what's best right now.

Larry Gifford: So, building a care team is not easy. I think this is what we've come to a conclusion with. It can be frustrating, it takes time, but when it clicks even just a little bit, it changes everything. We want you to walk away from today, not overwhelmed with one idea, or one next step to explore. So, we're going to move on to Q&A now. The first question is, somebody's husband has Lewy body Dementia. Are there additional members that he needs add to his care team?

Dr. Rachel Dolhun: Of course, as with anything, whether it's Lewy body Dementia, or Parkinson's, the care team is very personalized to what symptoms you have, and what's most bothersome to you. So, start there. Are there symptoms that are not being adequately addressed right now? And you don't have to know who the care team member might be that could help with that, but you do have to feel empowered to bring that up to your doctor, and say, "These are the things that we're struggling with. Are there other ways, whether it's different medications, or treatments, or other care providers who can help?" So, you'll want to think about physical therapy, occupational speech therapy like we've talked about. But again, if there are other symptoms, or things that are not fully addressed, especially in something like Lewy body dementia where the medications may not fully address all of the symptoms, that's where other members of the care team do become that much more important.

And then the other two things I'll say is in something like Lewy body dementia where memory, and thinking changes are some of the most prominent, you can talk with your doctor about whether it might be helpful to see a doctor who specializes in memory, and thinking. Now, that may not be necessary depending on the doctor that you're seeing, and whether you feel like you have a good relationship, and they have good expertise to offer there. But sometimes people will consider that additional physician as part of their care team. And then the second thing is, like we've talked about with Prentis throughout, but maybe we haven't underscored enough, is making sure that as a care partner you are getting support too, and you have your own care team. So, in everything that we've been talking about, and in all of the visits, it's natural, and it's right that we're focusing on the person who has Parkinson's, or the person who has Lewy body dementia, but we don't want to leave out the care partner, or make them feel invisible, or like an unrecognized member of the team.

And sometimes that means that you have to advocate for yourself. So, you need to introduce yourself, or reintroduce yourself as the person's care partner, and why you're there, and what your goal is. And you need to ask for the support you need, too. Again, you don't need to know what support that is, so don't let that stop you from asking. But if there's any place you're struggling, or feeling like you could use extra help, bring that up, and don't feel embarrassed, or like there's not time to bring that up. Make that part of your top couple of concerns to bring to the doctor in the visit.

Larry Gifford: Here's a related question. How does the care team need to change over time as Parkinson's progresses?

Dr. Rachel Dolhun: Prentis, and Christie, you certainly have experience with this, so it'd be good to hear from you all as well. But as Parkinson's changes, of course, symptoms change. So, symptoms may increase, new symptoms may develop, other symptoms may kind of fall down on the list of priorities, or list of most bothersome ones. And so it's about being in tune with how Parkinson's is changing, and then what we might need to change to address that. So, if walking becomes more of a problem, or if falls start to happen, then again, we may want to bring in physical therapy, hopefully we've had them already, but maybe we need to bring them in again, or maybe we need to bring them in for the first time. Or if speech changes, or you're having drooling, or swallowing problems, again, we'd then want to bring in speech therapy. If mood changes become more prominent.

Maybe it's revisiting mental health therapy, or even a psychiatrist. And something, too, just on this note is people will often say, how do I know when to go somewhere else? If I start with my Parkinson's doctor, how do I know when to go somewhere else? So, a lot of times your Parkinson's doctor's able to manage a lot of, if not all, of what comes with Parkinson's, at least at the beginning. But then say you have anxiety, and we've tried multiple medications, and we really just can't get control of it, and it's still really bothersome. We might say, "Let's have you see a psychiatrist for help." And same goes for something like constipation. We will do a lot, and there's a lot of tools, and tricks that we have to help with these things, but if it gets to a point where what we're doing isn't working, and you're still having a really bothersome symptom, then that might be when we bring somebody else on. So, the bottom line of how your team evolves, it's going to be very personalized, but it's going to be in response to how Parkinson's is evolving.

Dr. Jessica Galgano: I also think it's very important to talk with your therapist, talk with your doctors, because as Parkinson's progresses, and things come up here, and there, you don't know if the current therapists who you're already seeing deal with that in some way. And I think many times in speech pathology, for example, people forget, we also do a lot of counseling within the scope of communication, swallowing, executive function changes. We also do a lot of work with executive function, and really working on those cognitive communication skills that can be more impacted later on in the course of the development of Parkinson's, which sometimes we don't even see in the early part. So, talking with your therapist, talking with your doctors about new things that come up to see if there are evidence-based approaches that they use to target those things now that you're experiencing them in ways that you didn't have to earlier on.

Christie Brooks: Yeah, [inaudible 00:49:27] I had uti, and [inaudible 00:49:28] urologist.

Larry Gifford: So, you added an urologist later in the game?

Christie Brooks: Right.

Larry Gifford: Got a urologist. And [inaudible 00:49:45]

Prentis Brooks: She also had a...

Dr. Jessica Galgano: So, many [inaudible 00:49:48]

Prentis Brooks: She also had an event with her heart, and so had to add a cardiologist to as well. And unfortunately we've not had the challenge of them not communicating with each other. And so like say our quarterback is a moving disorder specialist, but she gets updates from all of them, especially as we have appointments with them throughout the year, too.

Larry Gifford: One more question. This might be for Cristina. I care for my 82-year-old mother that does not speak English well. She has trouble explaining her symptoms. How can I get a better understanding of how to help her?

Dr. Cristina Colon-Samenza: Okay, so I'm not sure I'm understanding the question exactly. Is it that the primary language of this individual's mother, and the primary language of the adult child are different?

Larry Gifford: Different?

Dr. Cristina Colon-Samenza: Yes. That's a really good question. I don't know that I have the answer to that.

Larry Gifford: Flashcards?

Dr. Cristina Colon-Samenza: Yeah, that's a challenging one. I mean, in the clinical environment we have language lines, and translators, and things like this to help us when someone's preferred language is different from the preferred language of the provider. But within the home environment, I don't know that I have a good answer for that. And actually I'm wondering if Jessica, you might have some tips on that?

Dr. Jessica Galgano: Well, I also have some questions. I think it depends on exactly what is happening. If for example, the person with Parkinson's who's home, and speaks one language is home with their loved one who doesn't speak the same language, but you can hear the voice, you can hear the speech, the speech sounds clear, you could use something as simple as Google Translate, which is really effective these days at helping to translate other languages into the language that you understand. If there is more than just the actual language barrier, and it's more about the fact that you might not hear the individual with Parkinson's, or speech clarity sounds reduced. You might encourage them to use that speech with greater loudness.

So, we're always thinking about amplitude of movement with Parkinson's. So, you'll say, "Okay, mom, I want you to say, try to say it again nice, and loudly", so they will feel that loud, and they'll just get up to those more typical volumes. Then you'll be able, or Google Translate, we'll be able to hear, translate, and understand those words so you can best communicate. So, I think we're kind of talking about two different things here. The physical ability to hear, and understand the motor movements of voice, and speech production versus the ability to understand linguistics like the language being used, vocabulary sentence structure to be able to communicate.

Larry Gifford: I wish we could go on forever, but we are at time, so Jessica, thank you. Christie, and Prentis, thank you. Rachel, Cristina, thank you. And thank you for being part of our community, and joining us today. And thanks to our panelists, all your expertise, we hope you found today's discussion very helpful. Thank you, and have a great day.

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