

Michael J. Fox:

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The Michael J. Fox Foundation:

Navigating Parkinson's disease can be challenging, but we're here to help. Welcome to The Michael J. Fox Foundation Podcast. Tune in, as we discuss what you should know today about Parkinson's Research, living well with the disease, and the foundation's mission to speed a cure. Free resources, like this podcast, are always available at [michaeljfox.org](http://michaeljfox.org).

Larry Gifford:

Hi, welcome to The Michael J. Fox Foundation Parkinson's Podcast. This is part two of the PD Avengers Takeover. I'm Larry Gifford, a proud member of The Michael J. Fox Foundation Patient Council, Co-Founder of PDavengers.com, and Host of another podcast you might've heard of called When Life Gives You Parkinson's. Tim Hague and Soania Mathur are also here from PD Avengers. Hello, my friends.

Soania Mathur:

Hi, Larry. As you mentioned, I'm Soania Mathur. I'm Co-Founder of the PD Avengers, as well as Co-Chair of the Michael J. Fox Patient Council.

Tim Hague Sr.:

Hello, Larry and Soania. I'm Tim Hague, Sr. I am Co-Founder and Secretary and Treasurer of the PD Avengers. I'm the Executive Director of U-Turn Parkinson's and author of the book, Perseverance.

Larry Gifford:

And the winner of season one of Amazing race of Canada.

Tim Hague Sr.:

Amazing race of Canada.

Soania Mathur:

Have to mention that one, for sure, but what we're working on together as the PD Avengers and the PD Avengers is really a nonprofit patient-led organization working with The Michael J. Fox Foundation and over 50 Parkinson's organizations worldwide to build a global alliance to end Parkinson's disease.

Tim Hague Sr.:

We also have more than 3,700 individuals from 70 countries worldwide, who signed up to be PD Avengers.

Larry Gifford:

And we talk about the PD Avengers, and the people are like, "I've heard this over and over to there's so many organizations, how do we know what they are?" Which is why we're here today because we want to introduce you to some of the other organizations.

Soania Mathur:

I mean, you're absolutely right, Larry. We can never have enough people helping people with Parkinson's live a better life and search for a way to end this disease. I mean, if you think about it, Parkinson's was identified more than 200 years ago. And since then we've done a lot. Humanity has put men on the moon. We've eradicated polio. We've changed HIV from a death sentence to a chronic illness. We've mapped the human genome and discovered thousands of galaxies among the stars. And yet the gold-standard treatment for Parkinson's disease is a 50-year-old medication.

Larry Gifford:

It's older than we are.

Soania Mathur:

Speak for yourself, Larry.

Tim Hague Sr.:

That's right, Soania. We're tired of waiting. We need to be a loud, uncomfortable, ever-present voice to demanding change in how the disease is seen and treated.

Larry Gifford:

The PD Avengers was inspired by a great book called Ending Parkinson's disease. If you haven't read it yet, you should get it. It's awesome. It's authors the rock stars of Parkinson's doctors; Ray Dorsey, Michael Okun, Bas Bloem, and Todd Sherer. And what we do is different than every other organization. We think global, act local. We align ourselves with organizations that are ready, willing, and able to collaborate with other PD organizations around the world.

Soania Mathur:

And collaboration is why we're here today. The Michael J. Fox Foundation has been very generous in allowing Larry, Tim, and I, to introduce you to some of our partner organizations across North America and in Europe.

Tim Hague Sr.:

You don't have to have Parkinson's to want to help end it. Family members, medical professionals, therapists, friends. We need everyone to join us at [PDavengers.com](http://PDavengers.com).

Larry Gifford:

[PDavengers.com](http://PDavengers.com). Come on, sign up right now. Let's get to know some of these Parkinson's organizations who are partners of the PD Avengers. Each organization represents one or more of our three pillars; research, wellness, and advocacy.

Soania Mathur:

We covered the research pillar on our last episode, episode one. And basically, we believe that patients are integral in every aspect of research in the search for better treatments and ending this disease.

Tim Hague Sr.:

Today. We want to talk about wellness. We believe every person with Parkinson's should have equitable access to information, medication, and therapies.

Larry Gifford:

And in regards to advocacy. We believe we must build a loud, uncomfortable, ever-present voice demanding, change in how the disease, and seen and treated. We look at the advocacy later in today's podcast, but we're going to start with Tim and wellness.

Tim Hague Sr.:

Thank you, Larry. And I want to welcome Jenna Deidel to the program today. She's the director of programs and outreach for the Davis Phinney Foundation.

Jenna Deidel:

Yeah, thanks for having me. I'm so honored.

Tim Hague Sr.:

Well, it is my pleasure. You know I've long been a fan of Davis Phinney Foundation. I love that you guys over there, Davis and Connie, Polly, all of you. You do such a great job. And it's our pleasure to introduce you to maybe people who don't know you yet. And if anybody doesn't know the Davis Phinney Foundation, they need to, because you do great work. And we're so very grateful to The Michael J. Fox Foundation for giving us this platform to take over the podcast today, to do that.

Jenna Deidel:

Awesome.

Tim Hague Sr.:

So tell us if you will, the Foundation, the Davis Phinney Foundation was founded back in 2004.

Jenna Deidel:

Mm-hmm (affirmative).

Tim Hague Sr.:

For those who don't know who is Davis and what was the intent of establishing the foundation?

Jenna Deidel:

Yeah. So anyone who doesn't know Davis hopefully should get to know Davis is a really wonderful person. So Davis Phinney was, he actually still holds the title today as the winningest American cyclist and most awarded. So I think he has 328 cycling wins. And as someone, one of the only team members at the foundation, who's not much of a cyclist, that's particularly impressive to me. And he's still rides his bike rides, rides his e-bike religiously, but he was diagnosed at the age of 40 after, like so many people's stories, years and years of knowing something wasn't right. Finally, got that Parkinson's diagnosis. So he's been living with Parkinson's for over 20 years and really he had a very, had a really public presence as a cyclist. He'd started to work in commentary and really was known as a personality, especially, here in Colorado and in Boulder.

Jenna Deidel:

And so, so many people urged him early after his diagnosis to start something, start an organization, a foundation or something, just to bring more attention to Parkinson's. And he was actually pretty reticent to do that. That wasn't really one of his goals at that time in his life. But after enough urging by the right people, he decided it was the right choice to try to help himself and others living with Parkinson's and started the foundation, which really, when it first started, was primarily focused on fundraising. It didn't look like it does today with a focus on education and inspiration and all of that. But as Davis was living with Parkinson's himself and Connie learning how to be an amazing care partner, so much of their own experience, they realized other people needed access to, they knew they had access to information.

Jenna Deidel:

Also, Davis, this was 20 years ago. So people were still prescribing rest for people living with Parkinson's and certainly, Davis, that was not going to ever be his MO. So he didn't take that prescription and knew he felt better because of it. And so really came alongside all of the pioneers at the time who were demanding more and wanting to understand more about what could you do to live well with Parkinson's, especially if you are such a young person, but at any age, being diagnosed that you might live with it for a long time.

Jenna Deidel:

And what does that look like? And so through their own experience, got more inspired to say, "Actually, maybe we should step up and be a little more vocal, a little more involved, grow the staff and create a foundation." And so, now here we are 17 years later, and that's really what the foundation still is. The mission has not changed in 17 years. We help people with Parkinson's live well today. And that today really drives everything we do. It demands urgency, which I think is so well aligned with PD Avengers' vision, there's urgency. There's a real urgency because it's about people living right now and we get one chance at that.

Tim Hague Sr.:

Davis has been incredible to watch and to represent what I often call the other side of the PD coin of wellness, of exercise, of taking care of oneself, and setting such a fine example for all of us. And I know that that was his life's mission, cycling and all that he was involved in, but to have him in a leadership position within Parkinson's and set that kind of example is incredible. So I think about the future and I wonder, how does your organization define success now? What's it look like for Davis Phinney Foundation to say they've been successful with the Parkinson's community and how will you know when your mission's been accomplished?

Jenna Deidel:

We asked this to Davis. We said, "Well, what does it look like? You started this, what does that mean to you? What does it look like? What does it mean when we've succeeded at scale on our mission?" And he said, "Well, everyone is living well with Parkinson's." So we said "Everyone." He said "Everyone." And so I think to us, that's really what it comes down to. And that doesn't just mean the people right now, who are getting diagnosed and are being brought in. To me, that also translates to all of the many, many people we know that are underdiagnosed. And then beyond that, the many, many people who, even, with the diagnosis are not going to get connected to the care, the community, the engagement that is needed for them to live well. Translating that bigger, lofty goal of success of how are we expanding the

people who we're helping to live well, really in the last 18 months, we've invested a lot more resources into sort of equity access, inclusion work.

Jenna Deidel:

We've started. We put together a board, an advisory board, and body to help us with that work. We've started health disparities webinars series that actually Soania has helped us out a bit with. And David Leventhal from Dance for PD has been a collaborator on and many other people in our community. Just to start that conversation, but really, in the big picture, I think in the next couple of years, what this turns into is partly with our established, like the programs we're quite well-known for, our every victory counts manual, our victory summit events, our online education, really taking a lens of access to some of that work.

Jenna Deidel:

In a way, maybe even more so than we've done in the past. And thinking about, especially, in this last year and a half where we've, the virtual world has allowed us to reach more people and also made it really, really apparent who's not being reached and who doesn't have that access as we go more and more digital as a country and as a sector, what does that mean? And how do we address that those issues of access, also issues of access in terms of health literacy and awareness and things like that. And then it also means focusing on a new initiative that we just started piloting this year called Our Healthy Parkinson's Communities Initiative, which again is really born out of our desire to expand who it is that we're serving. And also do that in a way that's authentic to us, to grow and evolve our work, to be more inclusive and help more people.

Tim Hague Sr.:

Well, I'm really excited about that. You know that I'm a hands-on kind of guy, being a nurse for 20 years and-

Jenna Deidel:

Mm-hmm (affirmative).

Tim Hague Sr.:

... your boss and I have talked about this type of work over the years, many, many times.

Jenna Deidel:

Many times.

Tim Hague Sr.:

I'm really excited to hear Davis Phinney taking a lead in this and really addressing that other side of the PD coin.

Jenna Deidel:

Yeah.

Tim Hague Sr.:

I mean, I'm super excited about any steps we take towards research and finding cures.

Jenna Deidel:

Mm-hmm (affirmative).

Tim Hague Sr.:

I'm way more excited about finding out how to live well with this disease right now-

Jenna Deidel:

Yeah.

Tim Hague Sr.:

... because I'm living with it.

Jenna Deidel:

You are. And so many people are, and it's incredibly, it's much more difficult than it should be.

Tim Hague Sr.:

Well, what's the number one ways that people can participate or interact with the foundation? If you want people to get involved with you, what's the one thing you'd say do this?

Jenna Deidel:

I mean, there's a lot of great ways if I had to choose one, I think just getting onto our email list and signing up for the things that are interesting to you. So we do a ton of live webinars. We do live virtual events. We also put out a ton of blogs. We have a great Facebook group and we have people living with Parkinson's, care partners, and other community members interacting with us in every situation in that place. So really, I think every, every avenue that we create, we try to make a really a two-way street feedback loop. So if you email us, you should get a response. If you call us, you'll get a real human being. If you comment on our Facebook page, someone will respond. That's really at the heart of everything we do. Really authentically, any questions that you have, any feedback you have, if we're missing the point on something, we always want to hear about it and so every avenue is really great.

Jenna Deidel:

And then we also have a huge cohort of, like I said, those super volunteers. So our ambassadors and also the folks that are stepping up to lead and participate in what we're calling Community Action Committees, which are coalitions of individuals in different states, neighborhoods, cities, whatever that is. If you're also inclined, you kind of want to do more, you want to become a PD Avenger participant in the world, there's a ton of opportunities for volunteerism and we have some that are really great fits for some people.

Jenna Deidel:

If you are that kind of person looking for a way to do more and to join in that cause, please reach out to us. We love to match people with the right opportunities. So even if you're just like, "I know I want to do something and I don't know what it is," you can send us that exact message and we'll try to match you. And even if it's not with us, it could be with a totally other organization, but that village is what's going to move us forward. Really happy to have that.

Tim Hague Sr.:

And of course, if a Every Victory Counts or The Victory Summit comes to town, you definitely got to be there, especially if either Soania or Larry or I are speaking at it.

Jenna Deidel:

Of course, yeah. And in the meantime, while we're not getting together so much, you can probably also find some great recordings of Tim speaking and maybe Soania speaking as well.

Tim Hague Sr.:

Well, my last question for you is, since this is a PD Avenger takeover of The Michael J. Fox Podcast, we need to know why Davis Phinney Foundation decided to join the PD Avengers.

Jenna Deidel:

Yeah, of course. Well, I think the faces that I'm looking at right now, Soania, Tim and Larry, it's hard to say. If you're going to do something, we know it's going to be something special. Even if we're not sure what it is, we're going to say "Yes, please. Thank you for inviting us." That's a big part of it and that's really true across our sector. There's a lot of really incredible leaders. When you get to know the people who are doing this work and also living with Parkinson's, it's important to listen, and it's important to have a seat at that table.

Jenna Deidel:

I think the other piece of this was really recognizing that this would be an opportunity for the Davis Phinney Foundation to do a lot of listening and a lot of learning, especially on a global scale. Living in Colorado and then also operating primarily in the US and a little bit in Canada, we know we don't have that global perspective all the time. We can get quite focused on just our current situations. And so it's incredibly helpful to have voices from across the world and in various different living situations and medical systems and things like that to get out of the bubble or the rut and really make sure that we understand what's going on. It's incredibly helpful to be able to sit in on that and participate as well, but also do quite a bit of listening.

Jenna Deidel:

I think we're so, again, as I've already mentioned, so well-aligned with really the Parkinson's voice being incredibly important and also people living with Parkinson's cannot be the only ones to fight this fight. There needs to be a lot of allyship to come into this. To the extent that the Davis Phinney Foundation can join in to this group led by people with Parkinson's, but provide some of that allyship and that coalition building, we're happy to try to help with that alongside all of our peers who have joined in. So really appreciative that you guys have included us.

Tim Hague Sr.:

That's great. Well, Jenna, we certainly thank you for coming and joining us today on this PD Avenger takeover at The Michael J. Fox Foundation's Podcast. I want to just encourage you to keep on doing what you're doing. Your voice is so very important, not only in North America, but around the world. We're excited to partner with you as PD Avengers and to help people live well today in all that we do.

Jenna Deidel:

Thank you all so much. We really appreciate being included, and it was wonderful to talk to you today.

Tim Hague Sr.:

Thank you.

Larry Gifford:

Thanks Jenna.

Tim Hague Sr.:

As we continue down the wellness path, I want to introduce you to the Brian Grant Foundation, Katrina Kahl, the executive director, this foundation is all in on wellness and has been a leader in this field.

Katrina Kahl:

Yeah. Yeah. Thanks for recognizing that we've been working with the wellness community for Parkinson's since our founding back in 2010.

Tim Hague Sr.:

What role do you see the Brian Grant foundation playing in the lives of people with Parkinson's as it relates to wellness and wellness for me is all those six phases of wellness. You don't have to touch on all of them, of course, but you know, physical wellness, occupational wellness, intellectual, spiritual, social, emotional.

Katrina Kahl:

We aim to support people in believing that they can live well with Parkinson's. Our hope is that we're inspiring people to believe in wellness for Parkinson's. And we do that a lot through the journey of our founder. We do that a lot by sharing the stories of other people with Parkinson's like yourself, who are living well with Parkinson's and what that looks like for you and how you're doing that. And I think once we are hopeful that people are inspired to believe in living well with Parkinson's, then they can come to us and learn about what that looks like. And for us, a big component of that is exercise. Clearly, it's one of the best therapies for Parkinson's. So we do promote exercise fairly heavily, but we also look at things like diet, nutrition. We also look at things like mental health, emotional health. We do try to look for the evidence-based therapies that you can do outside the four walls of the clinic.

Tim Hague Sr.:

Well, what are some of the ways that people with Parkinson's can participate or interact with the Brian Grant Foundation in pursuing wellness?

Katrina Kahl:

Well I'd say head over to [briangrant.org](http://briangrant.org). We have a lot of information on our website living well with Parkinson's. We have a lot of resources, exercise videos, cooking videos, recipes. We do mindfulness courses. We have webcasts. All kinds of different online resources to help people incorporate wellness into their lives, whatever it is that they're trying to do.

Tim Hague Sr.:

Now how'd you guys get started with the nutrition?



Katrina Kahl:

A lot of this came from Brian and his journey with Parkinson's and prior to that his journey through the NBA. So exercise, diet, those pieces of being an athlete are very, very important part of being an athlete. And so when he was diagnosed Parkinson's he wanted to know what he could do, starting with exercise, and then talking about diet. So a lot of it has come from Brian's own experience. It takes a lot to study diet and its effect on the brain. So we really wanted to be able to say, "What do we know? And how do we distill that in a way for people that they can actually incorporate meaningful changes to their diet, to live well with Parkinson's."

Tim Hague Sr.:

And I always say to people, they'll ask me what's a good diet. And I'm like, "Well, one way you don't pack on all know this extra, right?" And anytime that we can lose weight, if we're overweight, anytime that we can be a little more fit, anytime we can throw away the cigarettes or a little bit of sugar, science has shown us that those things are facts of life are good for all of us, whether we have Parkinson's or not.

Katrina Kahl:

Small changes make a big difference in diet. And that's one thing we try to stress a lot is you don't have to throw out everything you've always loved to eat and instead incorporate a lot of food you've never heard it.

Tim Hague Sr.:

Why did the Brian Grant foundation, why did you Brian decide to partner with the PD Avengers?

Katrina Kahl:

We decided to partner with the PD Avengers, because you guys are awesome.

Tim Hague Sr.:

I love that.

Katrina Kahl:

We heard Soania, Tim and Larry and we were like, "Yeah, sign us up." Oh and then after we heard about the dream team starting this out, we absolutely believe that change comes from the people who are affected by Parkinson's. That it really does take a movement led by the people who are affected with Parkinson's to change the course of this disease and Doctors Okun, Bloem, Sherer, and Dorsey outlined a plan for us that couldn't be more clear. And so now our job is to pick up the ball and keep running with it. And I think the best way for that to happen is through a community of people that's led by people with Parkinson's. So we're excited to be a part of the PD Avengers. And we're really grateful to you guys for getting it started.

Larry Gifford:

You know what I love about the Brian Grant foundation is Brian Grant. If you haven't seen his video on our YouTube channel you've got to check it out. But he's great A. But he's all into the PD Avengers and he's making these karate moves and he's excited for it.

Tim Hague Sr.:

Katrina also told me, Brian Grant Foundation wants to hear from more people with Parkinson's. Your stories, struggles, successes, and ideas. Email them at [info@briangrant.org](mailto:info@briangrant.org).

Larry Gifford:

That's pretty cool that they're wanting to hear from PWP about what's going on. I like that.

Soania Mathur:

Hey Tim, I think you've got one more organization talking about wellness as well don't you?

Tim Hague Sr.:

That's right Soania. A lot of folks listening that probably heard of the APDA. Well in Europe, they have the EPDA.

Josefa Domingos:

Hi everyone. So my name is Josefa Domingos. I'm a physiotherapist, but also a board member of the European Parkinson's Disease Association.

Tim Hague Sr.:

I'm really excited about the things that EPDA is doing in Europe. What role do you see the EPDA playing in the lives of people with Parkinson's as related to wellness?

Josefa Domingos:

Yeah. So when it comes to wellbeing, the EPDA plays an important role by providing information, resources and also supporting and promoting the member initiatives and events throughout Europe. So they have more than 30 members and if each one organizes events and information that gets across to everyone. So I think it's uniting Europe in that sense. Additionally, to that we also run our own projects, which seek to inspire and support people to live a full life with Parkinson. So for example, we have a section on our website that's called About Parkinson and Living Well, that provides high quality information about all the aspects of living with the condition to help people with Parkinson's, their families and caregivers. So we also have information that comes from the Parkinson Life magazine as everyone knows. A program that we call the EPA exercise costs and also the Keep On Moving videos, which people can access through our website and also on YouTube.

Josefa Domingos:

Additionally, to that, we also, as an umbrella organization, EPDA continues to support Parkinson's sporting events organized by national or local associations throughout Europe. But now we are actually aiming to do a larger and more ambitious international event. So on a scale that I would say we've never seen before, so we are looking to organize an international Parkinson sporting event, like the Olympics Parkinson.

Tim Hague Sr.:

Right?

Josefa Domingos:

So this is an exciting event that we are actually doing our feasibility study now to understand what exactly people would like to see in such an event.

Tim Hague Sr.:

Right. So these are like full on Olympic games.

Josefa Domingos:

Exactly. For people with Parkinson. Definitely.

Tim Hague Sr.:

Awesome.

Josefa Domingos:

I think it's time that we see so much exercise and so much sports been adapted for Parkinson that just putting it together it's I think more than the awareness of Parkinson's as well. It will help inspire and promote physical exercise as a lifestyle intervention now.

Tim Hague Sr.:

Okay. Can I start now?

Josefa Domingos:

Okay. Okay. Yes, you can. It will be our first registration.

Tim Hague Sr.:

Well that'll be good.

Josefa Domingos:

Now you just have to choose your modality. Which exercise...

Tim Hague Sr.:

I'm not sure. Running is depressing anymore, maybe I'll cycle.

Josefa Domingos:

Okay. No, but it will incorporate all sorts of, I would say touch upon different aspects of wellbeing. So even for example, arts and creativity like...

Tim Hague Sr.:

Perfect.

Josefa Domingos:

Supporting emotional wellbeing, I think is also important. Just having activities that can resonate with everyone.

Tim Hague Sr.:

Well, Josefa my last question for you, why has the EPDA decided to partner with the PD Avengers?

Josefa Domingos:

Oh, that's an easy one. So the EPDA vision and the mission, I would say totally in line with the PD Avengers. A call to action for change in how Parkinson's is seen and treated. So it was very easy to combine into to get into that message. Since the EPDA was founded in 1992, we have always tried to engage and unite the Parkinson community to work together for that common goal of improving people's lives and wellbeing. And this was actually the reason why we initiated the whole Parkinson Day in 1997 and also promoted the United for Parkinson Global campaign.

Josefa Domingos:

And also promoted the United for Parkinson global campaign in 2017 and 2018. So it's really that effort to get people together. So, ultimately, the PD Avenger's mission to unite the 50 million voices with the goal of ending Parkinson's definitely resonates with our spirit. And we believe that the Parkinson community should act as one for the common good, right?

Larry Gifford:

All right. So, Tim, what are your favorite wellness tips for people? Because I know you're the big wellness guy. You've got the U-Turn Parkinson's. You're constantly telling me to get out there and exercise. What are your tips?

Tim Hague Sr.:

What are my tips? My tips are consistency, Larry. Number one, you got to be active every day. The goal is to be active every day... doing something, and not super hard exercise... every-day activity... 20 to 30 minutes getting out and just being active every day. Whether that's walking your dog, going for a walk yourself or just cycling, or if you run, or whatever you love doing. I know you're on your Theracycle often. That's great. I don't know what Soania does every day though. What does Soania do?

Soania:

Life.

Tim Hague Sr.:

That's not the same.

Soania Mathur:

I do a variety of stuff. I do yoga. I do weight training and walking. That sort of thing.

Larry Gifford:

I get out there three times a day for a 20 minute walk with the dog. It's great.

Tim Hague Sr.:

That's fantastic. So, that's my number one tip, is consistency. Try to keep yourself in a routine that you are able to do regularly and that isn't so onerous that you dread getting up and doing it every day.

Larry Gifford:

And we need people to be well so they can be great advocates.

Tim Hague Sr.:

That's right.

Larry Gifford:

This is our third pillar, advocacy. And we're going to welcome John Lehr, the President and CEO of Parkinson's Foundation. John, welcome to the PD Avengers Takeover of the Michael J. Fox Parkinson's Podcast.

John Lehr:

Thank you very much. It's a pleasure to be here.

Larry Gifford:

Tell us the mission of the Parkinson's Foundation and what makes the organization unique.

John Lehr:

So the Parkinson's Foundation... We were first established actually in 1957 and in 2016, we brought together two legacy organizations to form the Parkinson's organizations. So we've been around for a long time. And our mission really is to make sure that people who have Parkinson's live well today. That they have access to the very best healthcare that's available, and that they have the highest quality of life. While at the same time, we are investing significant monies into research to understand the underlying causes of Parkinson's disease, the basic biology of Parkinson's disease. And also investing in clinical research to discern trends among patients and to advance therapies and treatments for people with PD.

Larry Gifford:

Well, I remember in Kyoto, the Parkinson Foundation unveiled a great study about women and Parkinson's, and is really sort of a leader in sort of exploring that area that's become very hot these days. How do you pick those projects?

John Lehr:

That's a really great question. So the way we pick them is, we rely on people from the Parkinson's community to tell us what the most important issues are to them. We have what we call our People with Parkinson's Advisory Council. It's made up of 15 individuals, most who are living with Parkinson's, but some people who are caregivers of people with Parkinson's. And so, obviously at the foundation through our board and our leadership team, we have broad initiatives.

John Lehr:

We have three mission pillars: care, research, and education and empowerment. Within those three pillars, there's a number of things we look to do. But we are always going to the Parkinson's community, to our advocates and saying, hey, look, we think we should do this. We think we should do that. Do you agree with that? Do you think that's the right emphasis? So, for example, we are conducting a research study on mental health right now, just to look at referrals for mental health among people with Parkinson's. That was an idea that we thought was good. And we went to our PPAC council, and they

said, yes, that's absolutely what you should be doing. You should be spending much more time on mental health issues. So we heard that and we committed the resources and we outlined a plan. And so right now, we're in the execution of that plan.

Larry Gifford:

What are some of the ways that people with Parkinson's or the caregivers can participate or interact with the organization?

John Lehr:

So we launched a Care Partner Summit a couple of years ago. We did it live, in person. Obviously with COVID, we've gone offline, virtual. We have a lot of resources available to people who are care partners of people with Parkinson's, but we used that Care Partner Summit to really hone our skills and learn best practices. What's working. What's not working. And again, it's listening to the community, listening to the people who are in the care-partner role every day, to make sure that when we put together materials and resources and disseminate those materials and resources, including through our helpline, which is 1-800-4PD-INFO, that we're giving the very best information to people who are in the care-partner role.

Larry Gifford:

There's so much with wellness and advocacy and research that's going on. How do you know if you're being successful in what you're doing?

John Lehr:

So as part of our guiding principles, we're a national, in fact, international organization. We have 47 centers of excellence. Most of those are in the United States. We have a number in Canada and then a number of them around the world. So we have a Parkinson's outcomes project that takes patient data from people in our centers of excellence. That's been a 10-year study where we can look at and see our interventions leading to better outcomes for people with Parkinson's. Are referrals to the necessary services being made for people with Parkinson's? So measurability is one of our guiding principles. And we look very carefully at all the outcomes related to all the programs that we put on. And where we're not seeing outcomes, we ask the tough questions and we think about new directions. We are all about the greatest impact for the greatest number of people living with Parkinson's. That's really the motto of the Parkinson's Foundation. And a corollary to that is, there are 10 million individuals, by current estimates, of people living with Parkinson's.

Larry Gifford:

All right. So here comes the tough question. How did you get parkinson.org? Everybody wants that one.

John Lehr:

Well, I think that's the advantage of being one of the first organizations in the Parkinson's space. We were actually able to get... one of the Legacy in Organizations was parkinson.org. Interestingly, the other Parkinson's organization in New York was PDF, which we thought Adobe would be interested in buying from us, but they haven't stepped up to the plate yet.

Larry Gifford:

So, obviously, this is the PD Avengers' Takeover of the Michael J. Fox Foundation Parkinson's Podcast. Why did the Parkinson's Foundation decide to partner with the PD Avengers?

John Lehr:

Well, first of all, you guys are doing great work and we want to always support people in the Parkinson's community... support people who are doing great work. Again, going back to our four guiding principles. One of our guiding principles is collaboration. Parkinson's Foundation is now about a \$50 million a year, five zero million dollar a year, operation. And then when you think about the size of the population of people living with PD... us, Fox, a number of the other large organizations, it's not enough.

John Lehr:

I mean, we did an economic burden study, in collaboration with the Michael J. Fox Foundation, that found that in the United States alone, the costs, both direct and indirect, for people living with Parkinson's disease is \$52 billion. So then you think about the charitable donations, and you realize that, as great as all of us are in trying to work this problem, we need many people at the table working it, collaborating. It's a big issue. And so we welcome anybody who's interested in getting into the space to help with our people living with Parkinson's.

Larry Gifford:

So when are we going to be able to sign John Lehr up as a PD Avenger?

John Lehr:

We'll take care of that right after this call.

Larry Gifford:

Great. Great.

Soania Mathur:

Well, thank you very much, John, first of all, for doing the work you do. I'm just wondering. What gives you hope? What gives you hope about what's going on in the PD field right now?

John Lehr:

Thank you for that question. I really appreciate that. What gives me hope is just... look, this is a tough disease. This is what I always say to people, right? Parkinson's is so much more than a movement disorder. It's really a whole body disease. And the complexity of a disease that affects the brain is considerable. But what I'm excited about is the fact that there are so many brilliant scientists and clinicians working on this alongside of us. And, if you look at the number of publications 40 or 50 years ago on Parkinson's, they were relatively low and just the explosion of research that's taking place now. I think there are many different avenues of discovery that we can go down. In our own foundation, we are focusing on genetics.

John Lehr:

Our PD GENERation initiative is really saying, all right, look, we understand that there's a certain percentage, relatively small, of individuals who have a genetic cause of Parkinson's. So let's identify those people because there may be therapies that can be targeted toward those genetic mutations that

might be extrapolated to the larger population. So we're involved in trying to recruit 15,000 individuals with Parkinson's to the PD GENERation study. That should yield enough people with the two main mutations, GBA and LRRK 2, to enroll in potential clinical trials that may be upcoming. So that's one avenue but there's an avenue for alpha-synuclein. There's an avenue for immunization. There's an avenue for circuitry. There are so many different lines of inquiry that really brilliant scientists around the world are pursuing. And one of the things that I'm most encouraged by, just in the last couple of years, is Parkinson's Foundation has always been an investor in the basic biology of the disease.

John Lehr:

And I think with ASAP coming on board and, and putting even more money, really just putting a huge amount of money into this space to understand the basic biology... I think all of us working together in collaboration with the NIH and other great national organizations, I think we're making progress. I never want to over promise and under deliver. It's a complicated disease. And we just always have to keep that in mind. But one foot in front of the other. One research study after the other and we'll get there eventually.

Larry Gifford:

Thank you so much for your time, John, and for all that your organization does. And we look forward to putting your picture on the gallery wall in just a couple of minutes.

John Lehr:

All right. Well, thank you so much and thank you for all the great work that you're doing.

Larry Gifford:

All right. So, now, I do have a couple more advocacy-related organizations that I want to introduce folks to. The PD Avengers believe in the think-global, act-local approach to advocacy. And one of our member organizations that really embodies that is Parkinson Canada. The organization advocates on issues that matter to the Parkinson's community in Canada. Dr. Karen Lee is the CEO, and she tells us why it's important for the Parkinson's community to be heard.

Dr. Karen Lee:

It's so important to raise the voice of people living with Parkinson's in many ways, right? One, from listening and hearing what people need. We got to do that in different ways. We can do that through programming, services, advocacy. At the same time, collectively together, we are stronger.

Larry Gifford:

Dr. Lee believes that Parkinson's organizations can work together to amplify their impact.

Dr. Karen Lee:

There are many ways to, shall I say, participate, interact with people living with Parkinson's and Parkinson Canada. Right? We have peer support groups. We have peer support groups, we have wellness programs that we are starting to launch virtually we're going to we have during COVID, there's Super Walks, there's Pedaling for Parkinson's. There are many different ways to encourage people to go to our website, which is Parkinsons.ca, and hopefully there is something there that really speaks to you. At the same time, we're actively looking at different ways from listening to the community how we can



better support people living with Parkinson's. So over the next year, I'm excited about the potential launches of a mobile app that really helps in wellness, taking care of yourself, as well as some exciting pieces that I think people are really excited. It's still under wraps, but for me, it's an exciting time for people living with Parkinson's here in Canada specifically. We have been taking the time to listen. The Parkinson Advisory Council is so important for us, it's important to me, to get the voice of the person living with Parkinson's integrated into all we do. The ideas are coming from the community and we're here to see what we can make possible.

Larry Gifford:

And as you guys probably know, Parkinson's Canada has been a huge advocate of the other podcast that I do called When Life Gives you Parkinson's, you can find it on iTunes or wherever you download your podcasts, but they've just been so supportive of what we're doing too. It's exciting. They're so fun to work with.

Soania Mathur:

Yeah, they're absolutely fantastic. They've been so supportive from the beginning and that's what we really cherish, is those organization relationships that we seem to be building.

Tim Hague Sr.:

That's right, Larry. Parkinson's Canada has been a leader in Canada for many, many years, and they are a fantastic group to work with. Love Karen, John, many of the folks there that we have that we collaborate with regularly.

Larry Gifford:

And you can check out Parkinson's Canada online at [Parkinson.ca](http://Parkinson.ca). They got one of those good URLs too.

Tim Hague Sr.:

Yeah.

Larry Gifford:

[Parkinson.ca](http://Parkinson.ca). Parkinson's UK has been around since 1969, about the same age as Levodopa. The influence Parkinson's UK has had on the world of Parkinson's is quite dynamic. It was the first organization to establish Parkinson's specialists nurses, it helped to fund breakthrough genetic studies around LRRK2 and PINK1, and it created the original PD assessment scale adopted by neurologists around the world. Paul Jackson-Clark is the director of engagement, and he told me that Parkinson's UK is focused on advocating for individuals with Parkinson's.

Paul Jackson-Clark:

There were clearly any number of people in our community who were in more challenging situations. Maybe it's in residential care, maybe they haven't got close family and friends looking out for them immediately. So there's an increasing role for organizations like Parkinson's UK, making sure that we're getting access to the right services to that individual as an individual level is critical, that we're helping people navigate health and social care in the UK to get the best and right services they're entitled to. It's complex stuff often navigating the system, and you throw Parkinson's into the mix and then you maybe throw, I don't know, older age or less support from family and friends, and so it's a big role that we have

to play in helping people there. But also we definitely see our role more internationally, sort of global research push.

Paul Jackson-Clark:

And I think if we look at Parkinson's against perhaps other conditions, I think we'd see lots of evidence where Parkinson's research is more joined up and an important part of that is down to the role that lots of organizations around the world Parkinson's UK, Fox foundation, Canadian Parkinson's Association, Parkinson's Foundation, we've got colleagues in Australia and New Zealand, all over the world, Africa, the list goes on of connected organizations sharing their research priorities and agenda, and we play a really important role in that, both as leader and also as collaborator.

Larry Gifford:

The Parkinson's UK is truly focusing on key issues facing people with Parkinson's by raising the voices of those people.

Paul Jackson-Clark:

Our main overarching theme is about transforming Parkinson's together. The together bit in that is critically important that. The together a bit is really just hope trying to describe the sense of we are a total community. Whether your Parkinson's UK as an organization, whether you're an individual somewhere in the UK, whether you're a group of people, a different community or tribe representing a particular Parkinson's group together, we've got numbers, we're trying to develop and harness all our collective voice. So that's the together bit.

Paul Jackson-Clark:

The transforming bit is both looking at, again, the individual and seeing how we can make sure that each individual is getting the best deal for them, is able to live their life to the full as an individual, but also the transformation bit, it's about transforming society and people's perceptions and understanding of Parkinson's. It's trying to dispel myths about Parkinson's and the condition.

Larry Gifford:

You can learn more about Parkinson's UK and its programs at [Parkinsons.org.uk](http://Parkinsons.org.uk). And there is also Parkinson's Australia and there's also a Parkinson's New Zealand, and we've got Romania and...

Tim Hague Sr.:

Peru, Columbia, Africa.

Larry Gifford:

It's unbelievable. Germany. There's a great presence in Germany now.

Soania Mathur:

Spain.

Larry Gifford:

Everybody's being a PD Avengers, and we need you to be a PD Avenger too. Go to [PDAvengers.com](http://PDAvengers.com), sign up today. When you sign up, you can even send in your picture, get your picture on the gallery, and tell

us about yourself and invite five other people to be PD Avengers too. But when you sign up, really you're just saying, "Yeah, I want to be part of that loud, uncomfortable voice," and you may not have a whole lot of time on your hands to donate your time. That's okay. You have a superpower that we want to take advantage of and maybe that's donating something that you know how to do really well. Maybe you're a designer or maybe you know how to make capes. We could use a good PD Avenger cape.

Tim Hague Sr.:

Maybe an artist or a writer. All kinds of super powers that we need.

Soania Mathur:

Absolutely. I think it's only by working together that we're going to get this done. So please do sign up. We need you.

Larry Gifford:

And we will never ask you to raise money for us. We do not compete with the other organizations with fundraising. They do it better than we do it, and they know how to spend that money more efficiently than we do. And so what we do is we raise voices, we raise urgency and we raise awareness. And if you'd like to be a part of that, we would love to have you on our team.

Larry Gifford:

That is the part two of the PD Avengers takeover of The Michael J. Fox Foundation Parkinson's podcast. And I think the world headquarters of the Parkinson's podcast for MJFF is not too dirty after we've been here. We've cleaned up ourselves pretty well, and Tim scraped his initials into the wall, which was [crosstalk 00:46:59].

Soania Mathur:

Expected.

Tim Hague Sr.:

We do appreciate the MJFF and I wanted to leave them a little token of our appreciation letting them know we were here. But a sincere thanks for them allowing us to come in and take over today as the PD Avengers and introducing all these other organizations to the world. So thank you very much.

Larry Gifford:

And we are united in ending Parkinson's and on behalf of all the people at The Michael J. Fox Foundation who are here until Parkinson's isn't, thank you for listening. On behalf of the PD Avengers, thank you for listening and spreading the word and helping us end Parkinson's forever. Thank you, and we'll talk to you soon.

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