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: 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.

Larry Gifford: Hi, welcome to the Michael J. Fox Foundation Parkinson's Podcast. I'm Larry Gifford. This month marks the third anniversary of my PD diagnosis. I'm proud to be a member of the Michael J. Fox Foundation Patient Council, the host of Parkinson's IQ + You events. And two years ago, I started a podcast called When Life Gives You Parkinson's to share my family's journey and to give a platform for others to share their PD experience. That second part, sharing other people's stories is paramount. We all have received Parkinson's diagnosis, but we're all dealt a different hand. The sentiment is captured perfectly in a favorite adage that I hear in the hallways of the Michael J. Fox Foundation whenever I'm there. If you've met one person with Parkinson's, you've met one person with Parkinson's. What we want to talk about today on the podcast is where are we in regards to being as diverse and inclusive within our Parkinson's communities, from being able to access neurologists in order to get a diagnosis, to including black, indigenous, Hispanic, Asian, and other people of color in Parkinson's research.

As we begin, I want to set the stage just a little bit. I am 48 years old, and I am a white guy. And even though it's a Parkinson's podcast and we're talking about race, it can be some tricky waters to navigate. I am in no ways an expert in research or diversity and inclusion, but I'm learning, and I'm learning every day. I realize racism has led to centuries of pain and lifetimes of hurt and I honor that. The anti-racism and Black Lives Matter rallies and protests this summer have launched thousands of brave conversations as people around the world look at racism, really see it and hear it and begin to understand it. If you're like me, then you're asking tough questions this summer, like, "How am I going to change? How are we going to change? What are we going to do? What should I do? And how do we heal?"

For our purposes today, we're asking what role diversity and inclusion has in Parkinson's from lived experience to research. I know I do not have all the answers. I don't necessarily have all the proper language and awareness that I wish I had, and I'm hoping I don't say anything that's insensitive and is not the most current acceptable term. For me, I'll be driving this conversation from a listening and learning space rooted in curiosity.

Now, if I'm doing the listening, who's doing the talking? Well, that is a great question. And I am pleased to invite three panelists to join me today. Bernadette Siddiqi is the associate director of research partnerships for the Michael J. Fox Foundation. Jonathan Jackson is a PhD and founding director of Community Access, Recruitment, and Engagement, also called CARE, the research center at the Massachusetts General Hospital. He's also the principal investigator of the FIRE-UP PD study. FIRE-UP means Fostering Inclusivity in Research Engagement for underrepresented populations in Parkinson's disease. That study is funded by the Michael J. Fox Foundation. And Maria De Leon, MD, movement disorder specialist, Michael J. Fox Foundation Patient Council Member, and a research advocate. Thank you for your time, your expertise, and welcome to the podcast.

Bernadette Siddiqi: Thank you.

Jonathan Jackson: Thanks for having us. Happy to be here.

Larry Gifford: Now, I believe we can all agree that Parkinson's is a global disease that affects everyone differently. The very causes of Parkinson's and its individualized progressions mean scientists need to partner with a wide variety of patients to understand the disease and develop better treatments. However, until recently, Parkinson's research has largely been focused on a subset of patients, mostly male, mostly of European ancestry. Jonathan, why is that?

Jonathan Jackson: Oh boy. That's sort of the big question. So why is it that historically we have focused on one kind of person to understand Parkinson's disease? And that's just because they're the easiest to find. If you sort of think about the way we define our supply chains in terms of trying to source information for research recruitment, it's whoever's available. It's sort of that just in time, no inventory model that we've heard about in other sectors. But for our sectors, that's all white men. And it's not just white men. It's actually relatively wealthy white men with U.S. kind of median incomes usually over $100,000 annually. So it's not all white men. It's a subset of the most privileged people that are able to have access to this research. And there's a lot of reasons why that is, but I'm just glad that we're finally calling attention to this issue and recognizing that by having more inclusive research samples, we might learn something more useful about Parkinson's disease and its treatment and maybe even its prevention.

Larry Gifford: Bernadette, how has the perception affected research participation and the care and treatment, the people of color receive?

Bernadette Siddiqi: Yeah, so perception of a disease and whether your community can be impacted by disease has an impact on whether you will seek a diagnosis or look for doctors to find the right treatments. For example, a study conducted by the Veterans Affair, the VA, found that on average black patients in their network were diagnosed with Parkinson's disease seven years later than the white patients in their clinic. And so, what that says is that there's barriers that are keeping communities of color or underserved communities from receiving a diagnosis on time or when their symptoms start to set in. And frankly, if we're seeing people wait seven years to get the right diagnosis, then that means that there are people who don't have the financial resources or the time to actually continue to pursue that diagnosis. So that suggests that we may actually be under-counting or people may actually never receive a Parkinson's diagnosis.

And then further down the line, you have questions about who is accessing the right care. So again, research showing that there's disparities in the treatment that people are receiving based on their backgrounds. So to your question about research participation, it's kind of a domino effect. Of course, if you're not being diagnosed, and if you're not going to doctors to talk about treatments, you're not going to be having these conversations about research participation and being introduced to opportunities to participate.

Larry Gifford: Wow. That's a lot, Bernadette. It's hard to put all that in my brain and make sense of it all. But it seems like we've got a lot of work to do to move forward in this area.

Bernadette Siddiqi: Absolutely, absolutely.

Larry Gifford: So Jonathan, what do we know about the increased or decreased risk of Parkinson's diagnosis as it relates to one's race?

Jonathan Jackson: Oh boy. I think the answer, at least the best answer that I could come up with, is less than we think. So if you can actually look, there have been retrospective studies of how common Parkinson's disease is going back to the fifties, the thirties, even some really early ones from the looking at something that's Parkinson's like from the late 1800s. But what we initially thought was there wasn't so much of a racial difference as much as there was this North, South gradient. So back in the fifties and sixties, and even on up through the eighties, people just thought that people who lived in more Northern climates were more likely to get Parkinson's that have more southerly climates, something similar to what we have actually established with, say, multiple sclerosis.

More recent research has started to cast some doubt on what we know about the intersection of Parkinson's and race. I think between the 1980s through the 2010s, there was kind of this clear indication that Parkinson's disease really was a disease of white men. We didn't think that women got it as much as men. We didn't think that any other race or ethnicity got as much as men, but then you have to go back to some of the things that that Bernadette is suggesting.

There are these weird biases baked into the data. So for a lot of this, you have to have a diagnosis of Parkinson's disease, which will usually come from a movement disorder specialist. Well, if you think about how insurance in the United States works, first of all, you have to have some kind of complaints and then you have to go see your primary care doctor, and then you might get referred to a neurologist, and then you might get referred to a neuropsychologist, and then eventually you might see a movement disorder specialist who can give you that formal diagnosis. So that requires time, that requires access, that requires money, that requires somebody to maybe drive you to appointments. And we know that wealthy white men are the kinds of individuals who are most likely to be able to see this process through.

That, in addition to the fact that there are these strange epidemiological biases that haven't seemed to penetrate Parkinson's research, so thinking about different kinds of selection and attrition biases, thinking about survival biases, different things that might make it less likely for a group to get that diagnosis or, and to be counted in these tallies, for other reasons besides not having Parkinson's disease as much, all of that leads us kind of straight to a big question mark. So the research says that Parkinson's disease seems to affect white men more than other groups, but I'm actually highly skeptical of the quality of that data at this point in time.

Larry Gifford: Well, and I think the other fact is that if everybody believed it was a white man's disease, it's less likely that your general practitioner is going to look at you as a Hispanic woman and go, "Yeah, this is probably Parkinson's disease."

Jonathan Jackson: Exactly. Yeah.

Larry Gifford: The recent Fox Insight COVID-19 survey results validate previously reported effects on the pandemic of people living with chronic disease, especially people of color. Now, the study found nonwhite race and lower income were independently associated with difficulty obtaining Parkinson's medications. And those with lower household income were less likely to attend appointments through telemedicine. Maria, hello.

Maria De Leon: Hello.

Larry Gifford: You’re a movement disorder specialist and a person living with Parkinson's disease. As a movement disorder specialist, what kind of barriers do you see for people of color who have Parkinson's?

Maria De Leon: I agree with Bernadette and Jackson with all the different disparities. The biggest disparity I think has to do with economics more than racial issues at times because not having the money or insurance to go see a physician, or the time to have a nanny, or to have a sitter, especially in communities like the Hispanic communities, where you have multigenerational households and you're taking care of grandma and also your children, is very hard, particularly for a woman, to leave in the middle of the day to go to seek a physician, much less to participate in research.

Some of the biases, as Bernadette was saying, is that the studies, epidemiological studies, they've done have been primarily on Medicare patients. Of course, Medicare patients here tend to be mostly white. And so that puts a bias. Studying as a movement disorder, of course, you're learning that this is a primarily elderly white male disease, but my experience has been otherwise. And of course, that started my interest in trying to learn and improve epidemiological studies and improve care for all people with Parkinson's.

Growing up in Mexico, of course you never heard of Parkinson's. Now it's as common as it is in the US. I, myself, was in my late 30s when I was diagnosed, which was kind of an unusual thing, even for myself as a movement disorder specialist. My grandmother had Parkinson's, but she developed it later in life. And so for me to be in my 30s and having an illness was definitely something eye-opener, and having those barriers. Going to a physician and saying, "You're Hispanic, you're a woman, you're in your 30s. Why would you have Parkinson's?" And I'm like, "I'm a Parkinson's specialist. I think I have Parkinson's." And they're like, "But it doesn't happen. Why would you want to have Parkinson's?" It's not that I want to have Parkinson's-

Larry Gifford: Why would you want to?

Maria De Leon: ... but the signs say that I'm having Parkinson's. It took me three years of specialists three years to get officially diagnosed because everyone kept saying, "You're a woman, you're Hispanic, and you're young."

Larry Gifford: Bernadette, I want to know, how does underdiagnosis and suboptimal care for communities of color in clinic affect the research side?

Bernadette Siddiqi: Right. So medical research is about learning a disease so you can find treatments. And so, we know that the best way to learn about a disease is to study people who have the disease. However, if you have underdiagnoses, you're missing groups of people or communities that you won't be able to understand and study how the disease affects them, what the symptoms may be more relevant or prevalent in that community, and how to treat that. So one, missing a large portion or a significant portion of people who have the disease is going to make it difficult to define and understand how to treat the disease.

And then second, if we are studying populations in research, which right now we are, who come from a very similar background, it's very difficult for us to kind of question the hypotheses that we're generating. So I'll give you an analogy, Larry. If I were to only see brown cats in my life, then I went to you, Larry, and said, "All cats are brown. That's it. There's only brown cats in this world." And you'd come to me and say, "Well, that's not true. I've seen cats of all different colors, all stripes. That's just not correct."

So if we keep studying people who have very similar backgrounds, genetic, environmental, we're making assumptions about Parkinson's disease that may not be correct. And it may be driving the development of treatments that honestly may not be effective at all for anyone, or only effective for a very limited population. So it really is important for people to be diagnosed and get treatment and have these discussions with their doctors in order to find themselves involved in research and helping us to define what this disease looks like to find better treatments.

Larry Gifford: Well, and Jonathan, you're doing just that with the FIRE-UP study. We're all fired up now after hearing all these stories. What is the FIRE-UP PD study?

Jonathan Jackson: Yeah. So it's a full link for the study. The title is really long, but it's very descriptive. So it's Fostering Inclusivity in Research Engagement for Underrepresented Populations in Parkinson's Disease. So we just call it FIRE-UP or FIRE-UP PD. And the FIRE-UP study is really focused on trying to understand to what extent these factors, all of these factors that we've been talking about, to what extent they really play a role in getting somebody into a Parkinson's research study.

So if you've heard anything about trying to recruit underrepresented populations, and for this study we were actually pretty broad, so it wasn't just racial and ethnic minorities, we were also thinking about women. And we also included individuals with relatively low incomes and relatively few years of education in the study as well. So we were really thinking very broadly about who is underrepresented in Parkinson's disease research. I think, again, if you look at the rates of participation for most Parkinson's disease studies, we're looking at rates of 90% white, we're looking at rates of over 50% have master's or advanced degrees or doctoral degrees. We're looking at 40% to 50% with incomes over $100,000. This is not representative. We know that Parkinson's exists in people who don't look like Michael J. Fox, for example.

So in the study, we decided to try to highlight what those barriers might be, and we provided sites with a very clear direction, which is we know that there are disparities in how you are recruiting to research. Go out, find out what those barriers are, figure out a specific population, and, "Here's a little bit of money to actually solve the problem," and that's actually the key. And what was interesting about this study is that we actually gave sites dedicated funding to overcome these barriers. Most research sites sort of have thoughts and prayers. They have aspirations to be more diverse, but they're not able to do so.

So we ran the study for about a year, and that included time to pick sites and time for them to get up and running and implement their particular workarounds for these barriers. And in some cases, that meant that the researchers for, really, the first time, were going to the community. They were going to the patients and they were looking to partner with them and say, "We've got these really hard questions in Parkinson's disease. Do you want to come and help us figure it out? Do you want to come and help us understand what Parkinson's can look like in your community?" They saw a fantastic response in the community.

What we saw was a really increased rate of diversity. So we weren't just getting racial and ethnic minorities, especially in the intervention sites who were actually able to do something. Control sites, they had to kind of continue their normal recruitment practices, but they had this increased awareness of the value of diversity. And what we found is that for those intervention sites, they increased recruitment, not just for our study itself, but also recruiting to an online study run in part by the Michael J. Fox Foundation, which is Fox Insight. What was really cool is that it turns out that even within these movement disorder clinics, as lily white as we like to think that they are, what turns out is that the workflow that they had developed was simply not designed to reach out to those individuals.

So what we found is that there are multiple barriers that all intersect and overlapped in crazy ways to make it hard to attract and recruit and retain underrepresented individuals to research. I think another way of putting it is that the way that we do Parkinson's research right now is really, really designed for one type of person, and I think that moving forward, we need to be much more thoughtful about the time and the design and what we are asking participants to do. Otherwise, we're going to continue to see, again, just that brown cat type of person in our research studies.

Larry Gifford: Now, I see Maria here nodding. Maria, you want to chime in here?

Maria De Leon: Yeah. Well, I have several points with ... Thank you. Yes, I'm really glad of the work you're doing with FIRE-UP. One of the barriers that I see often is that when we try to include other non-English speaking communities, we simply translate the material without taking notice of the culture or the cultural significance or the wording. And so, many, many times I've looked at this translated documents and they make absolutely no sense.

Larry Gifford: Thank you for bringing that to light, Maria. That's a really important point and something that Jonathan and his cohorts can consider as they craft FIRE-UP 2.0. But the FIRE-UP PD survey results will be released later this year in a paper, and Jonathan, I'm wondering what you think the headline is going to be.

Jonathan Jackson: Oh gosh. What I think is great about the FIRE-UP PD study is that there really is something for everyone. For folks who are a fan of these online studies and thinking about things like the digital divide, we show that it is possible, at least in part, to potentially overcome that. And then for folks like me who are very, very granular and kind of mechanism-oriented. This study is great because it starts to unlock what some of those mechanisms are. So we take a really granular look at different parts of a Parkinson's research design and we ask people if there's a lumbar puncture, if there's a DaTscan, if there's a need for a study partner. Does that increase or decrease, or is it kind of the same in terms of your willingness to participate in a research study? We ask that alongside measures of trust and engagement using validated scales.

And so what I think is most exciting for me about this study is that now we start to have these precision mechanisms for designing the perfect kind of study in the right community at the right time to ensure not only that a community is well-represented, but that they're also interested in the research. So I think there's a lot of really great directions that this work can go next and I'm just happy to be a part of it and happy to be supported by the Foundation.

Larry Gifford: How does that impact the cost of research?

Jonathan Jackson: Ah. So it turns out that if you think about the cost of research, the number one cost, the number one, I guess, cost inefficiency in research is inefficient recruitment. We know that most research studies, especially clinical trials, they'll cost anywhere from a few hundred thousand to a few billion dollars to get that drug up and running. And it turns out that you can't get anybody enrolled, you can't keep anybody in the study, no one knows who you are. You have these really basic problems that any marketing student could solve.

But it turns out that what we found in FIRE-UP PD is, we gave $45 thousand for six to eight months for intervention sites. We gave $10,000 to control sites. Everybody in our study, all eight sites, intervention and control, improved their diverse enrollment and engagement. They improved in terms of relationships with the community. People formed groups. The study ended five months ago, they're still meeting on a regular basis even now in the time of the coronavirus.

So proportionally, it doesn't have to cost much to make these different changes, but historically clinical research as a field is relatively conservative. We do what our mentor taught us and our mentor does whatever they were taught. And so it's totally possible to make these structural changes at very little cost, or if you consider the cost overruns, at substantial cost savings. But you have a much more generalizable population that allows you to ask much more detailed and specific questions about Parkinson's disease itself. So it really is win-win-

Larry Gifford: That’s awesome .

Jonathan Jackson: ... and it's really just a matter of changing our mindset.

Larry Gifford: Another roadblock for some communities of color is trust or mistrust, whether it's a mistrust of healthcare providers or too trusting of cultural beliefs around aging and disease. Maria, have you experienced trust as an issue, either as an MDS or as a person with Parkinson's?

Maria De Leon: Yes, very much so. And I don't know if it's something that is ingrained in us as a culture because of where we come from, and then propagating with myths and stories. "He went to the hospital and horrible things were done to them, and bad things happen. Doctors didn't listen," and so on.

But even as a physician, being Hispanic, I of course attracted the Hispanic population. And it was always very interesting that once they found out that I could speak the language, of course the rapport increased. But then they wanted me to take care of them for everything, not just their neurological illnesses. But I was like, "I'm your neurologist. I'm your Movement Disorder Specialist." But they're like, "Yeah, but I can talk to you and you listen and you understand what I'm saying." And so then, "Can you manage my diabetes? Can you manage ..."

And so it's that trust, that finding someone that they can open up to and relate. Because even things in Mexico, I remember, my grandmother as I said, had Parkinson's and I diagnosed her. Back when she developed symptoms, my grandfather would go to the doctor himself and say, "This is the symptoms my wife has is having. Treat her." So he had never laid eyes on her to know what was going on. So she was being treated for all kinds of things. And I took one look at her and say, "Grandma, you have Parkinson,' so let's get you treated."

So it's that kind of thing sometimes in our communities that they think, well, they're older and so things are supposed to happen, so they're not thinking very well. They're not walking very well. They're falling, they're just age-related. So, one of the biggest issues for me is to try to increase awareness that this is not normal aging process, that there needs to be evaluation and that can improve with early diagnosis and treatment. So they don't just have to suffer in silence and be delegated to the back of the room. And, "That's grandma," or, "There's mom. She just has some issues."

So finding the right person. And I think because, at least in the Hispanic community, and then I think it has to do with also socioeconomics. Many people would just go to the clinic when they have a problem. If it's nothing urgent and acute, they're not going to go. If it's not going to cause them to die, then they're not going to go to the doctor. They're not going to go and make an appointment, sit there and wait because they have to work, to make ends meet. So that's part of the whole process.

And so having somebody they can relate to that even is not Hispanic or from the culture or background they are, but somebody that tries to understand and listen to them and say, who understand their plight, then I think that that builds a rapport. And it takes some time to ... Not just the first time, "Hey, we're best buddies so I'm going to tell you my whole life, and this is what's going on." So it really ... And with the way medicine is now, 15 minutes and that's it. And so that even the neurology tends to be a little longer, but still it takes time and rapport to be able to build that trust

Larry Gifford: Bernadette, you're Dominican and Pakistani heritage, and your great-aunt had Parkinson's when you were growing up. What did you know about Parkinson's as a kid?

Bernadette Siddiqi: Yeah, I knew very little. And honestly it wasn't until I started working at the Fox Foundation four years ago, that it actually clicked for me that she had Parkinson's. It was in reading about the symptoms that I was like, "Oh yeah," that's what I saw my great-aunt had. And so for me, it's this realization about education and awareness of Parkinson's disease is quite limited. And it shouldn't require someone working at the Fox Foundation or Jonathan having a PhD or Maria being a Movement Disorder Specialist. Those shouldn't be the requirements for people to have information about Parkinson's disease to get a diagnosis and to find the right treatments.

And so, shockingly, even having someone in my family, I had very little awareness of this disease. And it's clearly a point that as a community, we need to change and raise more awareness for this disease in communities. Particularly communities that are disadvantaged and don't have access to this information readily.

Larry Gifford: Jonathan, there seems to be issues on how researchers recruit, discrepancies of treatment, distrust of doctors, cultural beliefs, stigma around disease. These are not easy problems to solve. Where do we begin?

Jonathan Jackson: No, they're not easy problems to solve. And I think that is both exciting, because there's a whole field of work to do. And there's many, many people who are very excited about this, because sometimes I think the limiting factor is that people feel that the solution is simple. There aren't these minorities in research, well, let's open up our closet full of minorities and let's get them in the door. And then it turns out that it doesn't quite work that way. It's complex and I think the one thing that it really does, it shows the power of systemic and structural racism and discrimination.

I think in short, what we're really starting to recognize is that racism exists at the level of structures and systems. It's not any one person's fault, nobody means to do it. But nonetheless, it does tend to disproportionately affect these folks that have lower societal standing, lower societal privilege. And so that means for the first time, that we have this mandate that's very clear, very operationalized, very detailed, of how we can start to dismantle those systems.

And so that to me is very, very exciting because it's the big work, it needs to be done. And I think for now, with tools like FIRE-UP PD, with the support of the Michael J. Fox Foundation, we can really start to go after that in a very principled way.

Larry Gifford: All right, Bernadette. You're heading up a task force for MJFF on this. When did the discussion around diversity and inclusion begin at the foundation?

Bernadette Siddiqi: So we've been discussing this topic for a very long time at the Foundation. Our mission is to accelerate the search for treatments for Parkinson's. And we're aware that in order to be successful at that mission, we need to study a diversity of people with this disease. And so for several years, we've been thinking about how is it that we're going to engage these underrepresented communities in Parkinson's research.

So I'll say back in 2016, we began funding research around understanding attitudes towards research among the Hispanic community. And then as Jonathan shared, in 2018, we began funding and initiating the FIRE-UP PD study.

And it was really in the last year or so, as I think many organization are doing now.

Larry Gifford: What is the Michael J. Fox Foundation already doing as it relates to diversity in the future?

Bernadette Siddiqi: We have the Global Genetics Parkinson's Disease study, which has teams in five nations of Africa, five teams in East Asia and a team in India, looking at the genetics of these communities. We know that we studied a lot of genetics, as you said before, Larry, in European populations, but there might be changes in the genetics of people with Parkinson's in these countries that can help us advance the search for new treatments. So that's one initiative.

Another initiative that we've had a lot of influence on for the last five years or so, has been around training future movement disorder specialists. So each year we fund several centers who train the future movement disorder specialists in the US and also internationally. And this year, actually working quite closely with Maria, we added a criteria to have these centers explain to us how they're going to train these future doctors to think about diversity and inclusion in their clinical care and research.

Another initiative that we're working on is called CLEAR PD, as you can tell, we like our acronyms. And that's really a training program for research staff to help train them on how to recruit diverse populations. So to be more inclusive about the way they engage people in Parkinson's research. So this is a training program that we'll be developing, and then we can really share that program out with the broad research community. So it's not that these research practices just remain housed at the Michael J. Fox Foundation, but they're shared and being implemented across Parkinson's research studies.

Larry Gifford: Well, that's great.

Bernadette Siddiqi: Two last things. One is around making sure that who applies to us for funding is also diverse. So there's a lot of research showing that diverse teams outperform homogeneous teams. And so we are stating in our funding application that we value diverse teams and their diverse ideas. And so we welcome research proposals from these diverse teams, because we feel that the solutions to this complicated problem of Parkinson's will come from diverse teams.

Lastly, as we talked about in this conversation today, there's a lot that I think a lot of communities could benefit from hearing from people like themselves who have Parkinson's disease. I think I could have benefited from seeing more people like myself growing up, who spoke about Parkinson's disease and share their stories. And so the Foundation has started a blog called Racial Bias and the Parkinson's Journey to share these stories with our community, so that there is awareness that there are people of color and other disadvantaged groups that live with Parkinson's, and that their journey may also be difficult because of the racist systems that may make it difficult for them to receive a proper diagnosis and treatment and participate in research. So using, again, our platform to signal to the research and patient community that these are issues that are affecting our community, and we can work together to really try to tackle them and find solutions.

Larry Gifford: Well, I love that you're using story, because story is so powerful. I mean, it's how the cultural beliefs started and became what they are today. And so by telling new stories with a different angle, you can change those cultural beliefs over time, which is really powerful.

Bernadette Siddiqi: Exactly. I definitely believe that stories really change hearts and minds. And so the more we can use that medium, I think the more we'll be successful.

Larry Gifford: How can people track the progress of the diversity inclusion initiatives?

Bernadette Siddiqi: So this is work that we do, of course, in the service of the Parkinson's community. We are accountable to our donors who make this work possible for us. So what we'll be using is our platforms, our blogs, our webinars. It is very important for us to be transparent about this work. So our communications plan is to be on our channels reporting back on how this work is doing.

Larry Gifford: That's great. And you're welcome here anytime.

Bernadette Siddiqi:	Thank you, Larry.
Larry Gifford:	Jonathan, how are you feeling today about future research in Parkinson's being diverse and inclusive?
Jonathan Jackson:	How am I feeling? I think if I could sum it up in one word, it would be overwhelmed. I'm overwhelmed with hope. I am overwhelmed with skepticism, just because it seems as though we have so far to go. So over the course of this chat, we've talked about problems in the epidemiology of even understanding where the disparities are in Parkinson's. We don't know about the accuracy of our tests, even the ones that are...
	Even keeping it limited to English, we don't know about the accuracy of those tests for all groups, much less translating it to others. We've talked about the multiple layers of barriers when it comes to participating in Parkinson's disease research. And I know, I know that we haven't even scratched the surface. So on one hand, that means that I'm never going to be out of work. There's always going to be a job for me, which is great.
Larry Gifford:	Always the optimist.
Jonathan Jackson:	But at the same time, I also want to make sure that we can implement solutions that really help people, that help people get a diagnosis. Like like everyone else on this podcast, I found out last summer that my Great- Uncle Leonard had Parkinson's disease. Nobody mentioned it before. Nobody knew about it. And my grandmother has sort of mentioned it in passing, that it was affecting her brother. And I had no idea it was in my family.
	And I think, like Bernadette said, it shouldn't be required that you somehow be connected to the Michael J. Fox Foundation, or are funded by the Michael J. Fox Foundation, in order to figure out that Parkinson's is in your own backyard. So we got a lot of work to do. I am feeling hopeful and overwhelmed, and I

sincerely hope that there are some people out there who will join me in this quest along the way.

Larry Gifford: Maria, what message would you like to leave for your fellow medical professionals today?

Maria De Leon: The time is right for changing perceptions about Parkinson's treatment, about other neurological diseases, diminishing stigmas and knocking down myths. I think that we've made a huge progress over the last 30 years in neurological science. And I think that we're at the right time with the changes in trying to understand the diversity and trying to improve inclusivity.

I think that Michael J. Fox is doing a terrific job with trying to improve that and other national organizations. But we don't need to forget our physicians, the ones that diagnose and treat the patients. Oftentimes I find that they're kind of a post-thought, like, "Oh, by the way, yes, we need to..." I mean, the population is aging, the number of Parkinson's patients is increasing, and we need people that are going to be managing this population and treating this population. So we cannot forget about the people there at the front, the line, trying to take care.

And so we, as physicians, are trained. We see one, we do one, we teach one. And so we need to be changing the culture of what we see, but that has to do in part of who is around us. In medical school, if there are only a handful of women or there are only a handful of minorities then you really don't have a lot to go on. That's the culture. So trying to improve that culture and the type of patients we see and who we're seeing...

But I think that for Parkinson's I have said for many, many years, for over a decade, that Parkinson's is a huge umbrella. It's like breast cancer. There's not one single type of breast cancer. There's many types of breast cancer. And so I think that now that we're focusing on the different minorities and the diversities and the different populations, we may be able to begin to dissect what makes us different. What is it that is causing this population to have Parkinson's versus that?

And I think, as I said, and I'm going to close with one of my favorite lines that I said before that, as van Gogh said, "There's no blue without yellow and orange." You have to understand the uniqueness of each one, the properties of each one, in order to be able to understand the whole, so that I think that if we begin to dissect those differences, we possibly can find the cure for what ails the whole.

Larry Gifford: A better understanding of Parkinson's disease for some means a better understanding of PD for all. And you can play a part. As Bernadette mentioned, the Michael J. Fox Foundation is seeking to grow its diverse community to share experiences and perspectives from all touched by Parkinson's disease. If interested, please email your story to shareyourstory@michaeljfox.org, along with the best contact information to reach you. We may share your story in a future communication.

Download the Foundation's Navigating Clinical Trials guide to learn the basics of clinical research and the importance of study participants. You'll find the guide in various languages like Spanish, French, Italian, Japanese, and more. The link to the American Spanish guide is on the show notes.

Thank you for listening to the Michael J. Fox Foundation Parkinson's podcast. If you like it, please leave a rating and a review on Apple Podcasts. It really helps raise awareness of the podcast. And please share this episode with your friends and followers on social media.

For everyone at the Michael J. Fox Foundation, who is here until Parkinson's isn't, thank you for listening. I'm Larry Gifford. You can follow me on Facebook, Twitter, and Instagram. It's the same handle @parkinsonspod. Be well, take care of yourself. We'll talk to you next time.

Speaker 1: Did you enjoy this podcast? Share it with a friend or leave a review on iTunes. It helps listeners like you find and support our mission. Learn more about the Michael J. Fox Foundation at michaeljfox.org. Thanks for listening.

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.