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Speaker 2: Navigating Parkinson's disease can be challenging, but we are 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.

Denise Coley: Welcome to another episode of The Michael J. Fox Foundation Parkinson's podcast. I'm your host, Denise Coley. I'm a Parkinson's policy, health equity and awareness advocate. A co-founder of the organization, Special Interest Group Black Diaspora, and a member of The Michael J. Fox Foundation's Patient Council. Today we're going to talk about navigating racial bias and stigma in Parkinson's disease, and how it affects people of color in the Parkinson's community. This is a critically important topic affecting health outcomes, and our guests are here to offer their perspective and experiences from their own Parkinson's journey. It is important to note at the outset that just as every person living with Parkinson's disease has their own unique symptoms and journey, people of color living with the disease also have many different perspectives on navigating racial bias and stigma. Now let's introduce who I'll be talking with.

Wanda Kim was diagnosed in 2012 at the age of 52. She's a Parkinson's advocate, a cyclist, a skilled fundraiser and member of The Michael J. Fox Foundation's Patient Council. Wanda is a Korean American and has lived with her husband in the UK and France since before she received her diagnosis. Israel Robledo was diagnosed in 2007 at age 42. He is a special education teacher, a writer and Parkinson's advocate. He has represented people living with Parkinson's from the Hispanic community with government officials and our research advisory boards. He also is a member of The Michael J. Fox Foundation's Patient Council. He and his wife live in Midland, Texas. Dr. Hiral Shah is a neurologist, a movement disorder specialist at Columbia University Irving Medical Center. Her work is helping to eliminate health disparities and offer support and resources to people affected by Parkinson's and underrepresented communities.

Dr. Shah, along with her colleagues, Dr. Lori Quinn and Ms. Anita Parker, a licensed social worker that serves as a community outreach director of St. Luke AME Church, a group of Black and African Americans individuals with Parkinson's and their chiro partners. They joined together to develop an educational guide for Parkinson's. This group of movers develop the PD Movers - We Keep Moving, illustrated Storybook that was designed specifically for the Black and African-Americans Parkinson community. This is a project that I proudly contribute to as well and is available on The Michael J. Fox Foundation website. Dr. Shah, it might be helpful to start the conversation with a bit of a definitional foundation. Can you explain what is generally meant when we say stigma and racial bias in Parkinson's disease?

Hiral Shah, MD:

Thank you so much Denise for inviting me and allowing me to contribute to this really important topic. So yes, I think some definitions are important to set the stage. So first of all, when we're talking about stigma, stigma refers to negative attitudes, beliefs, or behaviors that are directed at an individual or a group based on certain characteristics or conditions. So in this case, when we're thinking about stigma related to Parkinson's disease, it might actually show up in two different flavors. First, enacted stigma. So these are actual experiences of discrimination, prejudice or exclusion that individuals might face because they have Parkinson's disease. So for example, someone with Parkinson's might face discrimination at work where they would be passed over for a promotion because their perception is that they can't handle the responsibilities of their job due to their illness. A second flavor might be felt stigma. So that's an internalized shame or sense of low self-esteem that's affected due to society's perception of the condition. So an example of this might be that someone with Parkinson's might avoid a social situation because they feel ashamed of their visible tremors or their physical difficulties with movement.

Racial bias, which often works hand in hand with stigma, refers to unfair treatment or prejudiced attitudes towards individuals based on their race or ethnicity. And it can be explicit, very conscious prejudice or implicit, things that are due to stereotypes or unrecognized attitudes. And racial bias in terms of healthcare can manifest with a resulting unequal access to healthcare services, disparities in diagnosis, treatment and care or misunderstandings and stereotypes about a patient's symptom based on their race. And I've thought about some of the different manifestations, and we could get into these in more detail later in our conversation, but a couple of nuggets might be that because of stigma and racial bias, we do observe delays in diagnosis and access to treatment, where people from ethnic minorities or communities of color are not offered advanced treatment or are less likely to be treated for certain conditions. These are issues that we find are concerning and I think it requires us being aware of them and bringing light to the potential challenges individuals may face, especially when they're dealing with Parkinson's disease.

Denise Coley:

Dr. Shah, thank you so very much for those wonderful definitions. Would you share your observations of the impact of racial biases and stigma as seen by the providers within the healthcare community and how it affects communities of color, for example, under engagement, delayed diagnosis, specific health disparities and under-representation in research?

Hiral Shah, MD:

Absolutely. So let's start with delays in diagnosis. So for example, people with early symptoms of Parkinson's, they may delay seeking medical care because of fear of being stigmatized or labeled, and they may be also in denial itself because of the symptoms they're experiencing. The other issue is with diagnosis. There is unfortunately still a little bit of this pervasive belief that Parkinson's disease is a disease of the older White man. Prior to 2020 when Melissa Armstrong and her colleagues published some new pictures of what the image or face of Parkinson's is, there was a teaching in medical schools, which I think led to this pervasive belief that it's a disease of the old White man, but we now recognize that unfortunately, Parkinson's is an equal opportunity offender. It affects women, men, young and old, and people of all ethnic groups. But if providers are not

aware of Parkinson's and its prevalence amongst ethnic minorities or communities of color, they may not recognize the symptoms and signs, and this can contribute to delays in diagnosis.

You mentioned healthcare disparities. So racial bias and treatment, which I touched on briefly. There have been studies that reveal that unfortunately, African-American and Black individuals as well as Hispanics are less likely to be referred for advanced treatments such as deep brain stimulation, six times less likely. They're also less likely to be referred to physical therapy. They're less likely to be treated for depression. So even when the same providers are taking care of patients with Parkinson's, there's something that leads them to treat people differently, which leads and compounds healthcare disparities. You mentioned research and awareness, so these biases can extend into clinical research. Historically, people from minoritized groups have been underrepresented in Parkinson's disease research. Less than 6% of clinical trials even report on the ethnicity and race of participants. And so the participation is really quite dismal. And if we're not including all members of the community in research, then those findings are less generalizable.

I think there are many reasons why there's this lack of participation. I think that research itself needs to be more inclusive in its design and consider the perspectives of groups from different backgrounds and different lived experiences. We have to do a better job as clinicians and researchers, making communities aware of how we're doing research differently than was done in the past, and how efforts are really being taken to overcome and build trust given fact that many communities were very sadly and unfortunately exploited, Tuskegee being one example of a research study where individuals, African-American men with syphilis were not offered effective treatment despite the fact that it existed and monitored over decades to observe the natural course of the disease. And I think many people think that these are historical issues, but they're alive and contemporary issues still today. These concerns remain active in the communities that I've been working with, and I know you've been doing this work as well.

Many communities simply don't recognize what the signs and symptoms are of Parkinson's disease and mistake them for normal aging. I think in communities of color, there's also a different expectation regarding one's health that when there's many other comorbid conditions, whether that be arthritis, diabetes, orthopedic issues, I think often people in communities of color that don't have that same access to healthcare resources and information will dismiss or overlook some of these signs, assuming it's "normal aging." And then when they finally come to the attention of a healthcare provider, they're much more advanced in their symptoms and their stage of disease.

Denise Coley:

And trust is a major factor that we'll be hearing throughout the conversation. Wanda, we know that delayed diagnosis and misdiagnosis is one of the way biases can show up during a Parkinson's journey, as mentioned by Dr. Shah. Sometimes healthcare providers rely too heavily on the old description, old illustration to guide a Parkinson's diagnosis. How does this Parkinson's disease stereotype play a role in your Parkinson's diagnosis?

Wanda Kim, JD:

Well, I was thinking back on this and actually what my own background is that my father has Parkinson's. So at the back of my mind, I've always been a little bit concerned whenever I had a lack of balance or whenever I felt a little bit unsteady because I have to say, I think I had symptoms for several years before I was finally diagnosed. I think I've symptoms since my mid-forties and I wasn't diagnosed until 52, but I've also suffered from terrible knees throughout my life. I had my first knee operation when I was 10 years old. And so I'd been going to a number of physios to work on my gait, my balance, my knees. And one of these physios said to me, have you ever thought about going to a neurologist? And I asked her why. And she said, there's something about your gait. I don't think it's actually mechanical.

So I booked myself in to see a neurologist, and that was in about March of 2012. And we went through a gamut of tests, MRIs, nerve tests, all kinds of scans, all kinds of blood tests, nothing was coming up. And finally at the end he said, well, let's just do a DAT scan to just rule out everything. What the DAT scan showed in my case was that I had severely depleted amounts of dopamine in my brain, and it was at that stage that I was referred to a neurologist who actually focused on Parkinson's and he's my neurologist to this day. And so my diagnostic journey started in March, and it wasn't until mid-July of that year after a slew of tests that I finally got to a Parkinson's doctor. And it wasn't because of lack of healthcare availability. It was truly because I was told every step along the way, you're too young, you're a woman. I kept saying, I think my dad has Parkinson's, but that didn't seem to sway anyone.

So yes, I do believe that the picture of the old White male overrode a lot of the data that was there. I did not have a visible tremor, but as my Parkinson's doctor has told me, not all Parkinson's presents with the visible tremor as we all know. So it definitely caused me to have a later diagnosis than I might have.

Denise Coley:

How do we recognize bias? What should we look for? How can it show up subtly and easily be mis-justified or misinterpreted?

Israel Robledo:

For me, as far back as I can remember, I'm one of nine kids. My dad would always say, if somebody went out of town, he would ask, how were you treated? And I never understood that until it came to pass that my oldest brother said, the reason dad asked that is because he wants to know if you are respected in the position that you are in and the conversations, the way you were treated, because in our community, you couldn't go past a certain street because you were not accepted within that population. Unless you are going to work and unless you are going to school, you are not allowed to go there.

So when we talk about medical care within our Hispanic population, it was left. You don't go there because you don't trust that they're going to do the best that they can for you. And like I said, I'm number eight of nine, so I never quite understood that until my older brother said, this is what he means. And I thought, oh, okay. Now I understand. It hasn't been that long ago that this was prevalent back in the seventies, 1970s. So if you could understand how a Hispanic family in Cleveland, Texas has dealt with bias, it was pretty rapid and it was scary from the stories that I've heard.

Wanda Kim, JD:

I've lived outside the United States for most of my, well since I was in my early twenties. So I'm not going to tell you how old I am now, but this is a long time. I will say that I haven't experienced much overt racial bias in terms of unfair treatment. I will say that there are stereotypes that people have. In my previous work life, I was in finance, I would enter a meeting room and they were primarily men, and they all just assumed I was going to be quite quiet and submissive and agree to everything because I'm a Korean American. Little did they know that that's really, that's not my character at all. So there were some stereotypes. I think in terms of medical treatment the doctors, particularly in the United Kingdom, I found, and I found this as a difference with the United States, they were quite surprised, almost all of them were quite surprised when I asked questions.

They were quite surprised when I brought up information that I gleaned from other sources from the internet, from the Michael J. Fox Foundation website, from own research. I don't think that they were offended, but they were surprised and they weren't really used to any kind of challenge. I learned how to modulate my tone so that we would have a good conversation. But I think there may have been a bit of a stereotypical response. And also, I'm not quite sure how much of it is because I'm a woman. I think that that also is at play here.

Denise Coley:

I have a few examples. The first is when a person comes in suffering from Hypomimia, which is called face masking, not all healthcare providers realize that all people, genders, ages, cultures are affected by Parkinson's disease, therefore they might think you're suffering from something else. If the person suffers from Hypomimia, a mask face, the bias might cause them to be interpreted as an angry person or disconnected or not listening. The perceptions can cause delayed diagnosis, a later stage diagnosis or the possibility of the other comorbidities might come the focus or not understanding, not having implementation of social prescriptions such as simply working on diet, hydration, exercise, mindfulness and meditation and staying connected are utilized as the way to slow progression along with medication. Do you have any comments or similar experiences?

Hiral Shah, MD:

Yeah, Denise, just to add to that, as a physician and provider, when you ask how do you recognize bias? I just want to point out that I'm very aware that I'm not always aware of my bias. So I think that's why we really need to try to be mindful, be present, be in the moment. And to me, bias is when we are treating a group of people or individuals a certain way and we may not recognize it. And so I think I try very much to try, as you said, meet people where they are, try to be curious and understand what is this person's and family's goals and main concerns and priorities, rather than bringing my assumptions of what they must want this or they must want that, I found that it's much better if we start by asking, how can we make this a productive consultation for you?

How can we make sure we use this time together wisely? Because I know I do have my internal checklist of things that I want to make sure I ask and check in on, but if I haven't addressed the number one priority of the patient sitting in front of me then I haven't done my job. So I would just encourage the providers and healthcare professionals that are listening to remember that it's never a criticism. I think we all have our biases based on each of ours lived experiences.

And all we can do is try to be mindful of that and be present with the patients that are with us, because I know that all of us have the same goal of trying to provide the best care that we can.

Israel Robledo: I'm thinking back to some even with, I'm not saying within the Hispanic community, but a lot of other communities, many times language comes into play. And that is something that when you say bias, sometimes it's so overt because a person may be worth millions of dollars, but if they can't speak the language, there is a literal block there in front of them, you can't get past it. And that's where you see people say, oh, let's find somebody who can help us get through this. And I see Dr. Shah doing that, but a lot of people will just look at somebody and turn their back and say, I don't know what you want. I don't understand what you need for us to do. So I think that's, oh gosh, I hadn't thought about that. But I think that's, let's say Haitian community or any community where English is a second language, it can be quite prevalent of a bias.

Wanda Kim, JD: Well, Israel, if I can pick up on that, because certainly I live in France and I have been to doctors there and my French is truly atrocious. I can make clear what it is I'm feeling and what it is I need, but I sound like a two-year-old, and I can see them trying to treat me like an adult and failing because I sound like a two-year-old. So I have learned to bring a real French speaker with me each time, and that is an impediment. It's, one cannot speak directly with a healthcare provider. And also I think that with the best will in the world, it's difficult for them to see me as an individual when they're not actually interacting with me, they're interacting with my interpreter. I think it's a very, very good point. And something that when I go to a non-English speaking country, I certainly feel.

Denise Coley: I think that's something that comes up a lot with people who have a second language. And one of the things that came up recently is cultural sensitivity, and there was, I think AARP actually did an article about these are the things to go and look for when you're looking for a doctor that you want to have cultural sensitivity for. So I think that is something on the horizon. I'd like to give another example and get your thoughts on it. When I go to the pharmacy and if I happen to have tremors that day and they're giving my medication, the pharmacist will come up to me say, you can't drink and take this medication. So I say, I don't drink. So this goes on for three beats. And then I say, I have Parkinson's. After one last look, I get the medication, so now I have my medication sent to me at home. So that's one instance that is not in the medical office, but going to a pharmacy. When I think of bias, those are some of the things that trip you up.

And then just last example I have. Just to make sure that I have success in a hospital or a ER room, I make sure that I take my hospital care guidelines with me. I meet with the hospital pharmacist to make sure that the medication's available. I meet with the surgeon, I meet with the doctor, I meet with the anesthesia department, and I also have my husband go with me and make sure that there's medicine in the bottle in case they don't have something in the pharmacy. And let them know that I've done my homework, I know what is necessary so that it will make it a more compatible visit. But I've also found that, and sometimes in medical offices, it helps to have that same research that we're

here toe to toe and we just want to get the best out of the visit. Any comments on similar experiences or thoughts?

Israel Robledo: I want to say I'm totally shocked, but I think that's part of the reason we're having this conversation is because to say there's something that you see that's not me, but in your mind that is not a good thing from their perspective. It's like talking down to you because you're shaking. You should be shaking because that's just not normal and go to that, oh, you're drinking. But no, it's very interesting because I only see that with advocating for clinical trials as well. People need to be in the right frame of mind sometimes because it's like, oh, you can participate, but they're like, well, I don't know what to expect. How am I going to get through this? And so it's beyond, I think what a lot of people understand that we see it so many times.

Wanda Kim, JD: Denise, I was nodding when you were talking about the reaction to your tremors, and Dr. Shah when you were talking before about felt stigma. I felt myself nodding there. I was diagnosed in 2012, right about the same time that I was retiring from my job. So I didn't really have the concern about continuing to work and trying to hide my Parkinson's. I was always quite open about my Parkinson's, but then again, I didn't have the same situation as others who were concerned about what it would mean in their workplace. Having said that, I was continuing to work in other capacities. I was advising various startup companies. I was helping other companies raise money. And so I was still in the financial world meeting with old and new contacts, and I found that I would always make sure I got to the meetings first, whether it be in a restaurant or in a meeting room, and that I'd be sitting.

And so when they came in, I wouldn't get up, as a woman you don't always have to get up. And I really use that privilege because I was very awkward when I tried to stand and especially if I was meeting someone for lunch, I would say, oh, I've got this. I'm just going to do a few emails now. So see yourself out. I paid for a lot of lunches because I was just so concerned about showing my tremors, and I'm thinking, why was I so concerned? Because people would see my sticks and I would say to them, oh, I have Parkinson's, but I didn't actually want to show that it was affecting me, even though I was happy to say it, I wasn't really ready for the looks of concern. I wasn't ready for the, well, it was a felt stigma. I felt this was not something a lot of people knew me pre-Parkinson's and I didn't want them to think less of me.

Denise Coley: Yeah, I agree with that because I was falling, but I didn't know that I had Parkinson's until after I left the job. So there are all these big things that can happen with symptoms that makes you not part of the club anymore and a oddity. And so it makes it a little bit more rough sailing. And Israel, I saw that you went to say something.

Israel Robledo: Yes, I was going to say, yeah, I agree with Dr. Shah that the felt stigma is very real because if just looking at a person's face or their physical reaction when you say Parkinson's, when you tripping or your balance is off or whatever, and they're like, they literally just turn away from me because they don't want to know anything. And if they do want to know, you feel like you have to explain the

whole process and for what percentage of those people you explain that to really care, because a lot of times it's like, oh, you don't look good. Oh, look, you're nervous. It's not a tremor. Oh, you're shaking a lot because what's going on? So they put it back on you like you're doing something wrong.

Hiral Shah, MD:

I've heard these types of stories a lot too, and I think that a couple of things come to mind. One is that often the observers, people think something seems off, but they don't know what it is. And so then they make a lot of assumptions, and sometimes they even think it's something much worse or unfortunately with the negative connotation, whether it be drugs or alcohol, or sometimes they just don't know. And I think I've had so many patients who even after they're diagnosed that decision to share their diagnosis, they often don't share. They're very selective about who they tell and how they tell. Because just as you all expressed, they don't want someone to say, well, now how are you doing? They don't want to hear that from someone who now knows that they have Parkinson's. So I think these felt stigma, it's something that we don't talk enough about, about the experience of that.

And then I think then the racial issue on top of it, when you all were speaking, it reminded me of patients that have expressed to me, particularly those women that are from communities of color, I find that they've complained that something is wrong and they felt dismissed, or they felt that their symptoms weren't given the right validity or credibility, that no one believed them, and that you have to get someone to believe that something is going on. And I wonder whether, as Wanda pointed out, because she didn't have a tremor, it's when you don't have a tremor that's very visible, it's harder for someone to appreciate that something is off. I'm not feeling right.

Denise Coley:

Dr. Shah, what is the root of these biases? Are healthcare providers aware that Parkinson's affects all ages, genders, and cultures?

Hiral Shah, MD:

Yeah, so just to take the second half of your question first, I think that we're working really hard to change that image and perception and the face of Parkinson's disease to make people aware that it is a condition that can affect the young and the old, even in the prime of your life when you're working, that it can be a condition that starts then. So I think discussions like this one, but a lot of the work that other researchers are doing is to create more awareness and create heightened awareness of the fact that Parkinson's affects all ethnicities and races. And I think people really see an urgent need to do a better job of including all members of the community in research, so that that type of information gets out to the research community so that it's better recognized. And gosh, if I knew what the root of the biases in these healthcare settings was, that would probably be the million dollars question.

I'll try to answer it. I think that there's multiple levels of these biases. I think that there's, at an individual level, I have to speak to my own personal experience. Even myself being the child of immigrants, I'm sure my lived experience gives me certain biases that because of what I've seen and what experiences my family has had, that perhaps that skews my manner of engaging with people or also the types of questions I have or the way that I think. So I think there are individual

biases, probably based on one's own lived experiences, one's upbringing, the type of context in community one was raised in, the type of training one had. I think there are biases that are baked in at the systemic level, unfortunately, whether it be because of insurance access, geographic issues, when we're thinking about in the United States, the urban and rural communities, and the types of ways that we can access and engage, I think we have biases about...

I think I'm from Northwest, Indiana, I grew up. And even that simple fact, people often raise their eyebrows when they see a Brown person from Indiana. They don't know how to make those two things make sense. So I think people just don't know what they don't know. My in-laws live in rural Wisconsin, and people probably have an immediate image of what rural Wisconsin looks like, but yet you don't actually know what it's like to live in that type of environment. So I think people have biases at an individual provider level, at a systemic level. And then there's probably the institutions themselves that have systemic biases because of the structures that we work in. And I think it's a very complex question and we're trying to unravel it and try to break down those barriers the best we can. But hopefully that's why we're having conversations like this one today.

Denise Coley: Wanda, you have a global perspective here. Can you tell us about any differences between how race and ethnicity are defined, and how you're treated as an immigrant living with PD in the UK and France versus what it's like here in the US?

Wanda Kim, JD: It picks up what Dr. Shah was just talking about. Where do some of these biases come from? When I'm asked, how do I identify, I will always say in the United Kingdom, I'm a Korean American, I'm American first, but I'm a Korean American. That is my ethnicity. And I don't say I'm Asian-American anymore. And I don't say that I am Chinese, which is how the British tend to categorize East Asians. And where this really comes out is whenever I fill out an official form, whether it be for the National Health Service, whether it be for a survey, whether it be for a tax form, there are quite often questions about one's ethnicity. And if one puts down Asian, which I would in the United States, that is immediately thought of as South Asian in the United Kingdom. So India, Pakistan, Sri Lanka. And if there is another tick box for Chinese, and I think that that's meant to capture East Asia.

And because I'm not Chinese and I don't fall into the category of how the British seem to consider Asian, I just put other, but then I do try to follow up in each case and try to engage with whatever institution is asking me the question, which is not always very fruitful because I'm not sure how they use this information. And if they're using it in such a way that there's a medical application, for example, everything that I fill out for the NHS. And a lot of that happened over the COVID period when I went from my vaccines, when I had to fill out forms as to what medications I was taking. They wanted a breakdown of one's racial background, and yet I thought they weren't capturing me. So it's concerning. And then I thought, well, what do I fill out when I'm in the United States? And I know that the categories are different.

And then I think, well, if medical professions all over the world have different categories, how are we ever going to generalize when we try to have a consistent database of patients, of symptoms, of whatever? So I'm hopeful that clinical trials at least are a bit more standardized. But it shows why do the British go for Asian and Chinese? I suspect is because that's where the people from their history have come to the United Kingdom. They've come from the old British Empire, which included Hong Kong, which included India. So I can understand how those terms came to be, but they shape the biases now and they shape the tick boxes that we're all supposed to fit into.

Denise Coley: Thank you so very much. And Israel, that was a great lead-in to you. Could you talk about your experiences with clinical research and how it has affected?

Israel Robledo: Yes. It's really interesting because I've always, here in Texas, for example, people say, well, you're Mexican American. Well, I'm American of Mexican descent. My family comes from there. I'm American. So that's where sometimes when you look at with clinical research, it's like, well, are you, oh, this race and it's getting better than this ethnic population. It makes a difference because with research, you're looking at certain patterns, and I don't think that some of those answers are correct when just like Wanda said, okay, you're Hispanic, or you're Mexican-American, or are you American? So it's a very convoluted research question. So if you think about me trying to recruit people for clinical research, if you haven't been treated with respect and treated well, as my dad would say, the likelihood of you going further is nil. So we run into a lot of barriers when it comes to, okay, so we need so many people of this race or this ethnic population.

Denise Coley: I'm going to go with the last question, and I'd like everyone to give a short answer to the question. When you're looking at an opportunity to advocate for yourself about Parkinson's, about disparities, about racial bias, what was the key to getting you into that role? So I'll start off with me. To become an advocate. Number one, I decided to educate myself daily regarding Parkinson's disease. Number two, I completed a few Parkinson's disease training courses to be certified to work with researchers. Three, I became a Parkinson's ambassador or volunteer with Parkinson's Foundations. Four, I am an advocate to drive awareness and empower people to be advocates. And number five, I bring awareness and opportunities to drive more inclusion and clinical research, treatment, therapy and medication. Do you have additional comments or tips?

Israel Robledo: Denise, I think you've hit the nail on the head. That's exactly what I did. It was as a matter of, this is who I am as ethnic minority. It was like what you said, I'm going to educate myself on this and then be able to help others along the way. So no, that's exactly what I did.

Wanda Kim, JD: I think you guys are much more organized than I am. I essentially looked at, when I received my diagnosis, I thought, how do I maximize my well-being? So there was a lot of research into how do I just maximize health? Maybe not only Parkinson's specific, but my overall health. I chose to disregard the things I really didn't like, like absolutely no alcohol and exercising a ton, everything in moderation. But then I realized that as I started to look at what different Parkinson's organizations were doing, especially The Michael J. Fox Foundation,

I realized that what I really needed was hope. And not just for myself, but for so many people. The numbers of people getting Parkinson's as we know are growing, and they're growing faster than the population is growing.

And when I see what the researchers are doing, that gave me hope. And when I understood the importance of having that kind of information and seeing the lack of awareness in the places that I live in England and in France, the lack of awareness of the current state of research and some of the great research breakthroughs that we've had, I just feel that that's an unequal treatment too of Parkinson's patients. Because with that lack of knowledge, I think there's a deprivation of hope. And for so many of us and for myself, I see that in order to continue going in the face of what can sometimes be a pretty dreadful disease, we have to have that hope. And I think everything that everyone on this call is doing makes me feel that there is great progress in this area. But I do see that disparity just in the places that I live.

Denise Coley: Dr. Shah, do you have some closing remarks?

Hiral Shah, MD: Well, I guess piggybacking on what Wanda stated about hope, I think that's where I started too. As a clinician in Washington Heights, I think I observed that our clinic population didn't reflect the diversity of the community around us, which Washington Heights is a multicultural community, predominantly Hispanic. And I really wanted to understand why was that? What could we do to better reach our local community? And so as Denise pointed out, we've partnered with Ms. Anita Parker at St. Luke AME Church. And I started just by listening and trying to understand what we could do to better connect to these communities and how we could bring that awareness and education to provide hope, because I think sometimes what we heard was that people were just becoming isolated and withdrawing because they didn't know.

And with knowledge, I do think comes power, and we can empower communities so that they feel like they're a part of this journey. A few things that I heard other people say reminded me of the unfortunate power imbalance that sometimes happens between provider and patient. And that's compounded when you don't speak the language, when you don't have the information. So I think a lot of my work has been about bringing that education, those resources to empower the community so that they can be an agent of change to address these healthcare disparities.

Denise Coley: Fortunately, there is more research underway to help assess and address racial bias within the Parkinson's community, including a few studies and programs supported by the Michael J. Fox Foundation, such as GP2. This study aims to expand understanding global genetics of Parkinson's. The Edmond J. Safra Fellowship in Movement Disorders builds a global network of Parkinson experts to provide high quality care and expand access to movement disorder specialists. The Parkinson's Progression Markers Initiative, commonly known as PPMI, is a Michael J. Fox Foundation landmark study. It gathers information over time to learn more about how brain disease starts and changes, and how to stop it. For more resources on this topic, check out our show notes or go to The Michael J.

Fox Foundation website at michaeljfox.org. So in closing, thank you to our panelists for their courageous conversation.

Wanda Kim, JD: Thank you.

Israel Robledo: Thank you.

Denise Coley: I would like to thank everybody for listening today. We will list resources in the show notes. Please take a few moments to rate and review this podcast. There will be links to do this in the show notes as well. I would like to leave everyone with a quote from Maya Angelou, "Hope and fear cannot occupy the same space. Invite one to stay." I invite hope. Until next time, I am Denise Coley.

Speaker 2: 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.