

Health Disparities and Parkinson's: Understanding the Issue Thursday, August 6, 2020

Moderator: David Leventhal

Panelist: Dr. Nabila Dahodwala, University of Pennsylvania

Panelist: Jonathan Jackson, PhD, Massachusetts General Hospital

Panelist: Dr. Nicte Mejia, Massachusetts General Hospital

Panelist: Dr. Claudia Martinez, Muhammad Ali Parkinson Center

Panelist: Dr. Altaf Saadi, Massachusetts General Hospital

Note: This is not a perfect transcript. There are errors in grammar, spelling, and punctuation. Our goal is to turn this around to our webinar viewers as quickly as possible; so, we do some minor clean up from the service that provides these to us, but we do not present them as perfect.

David Leventhal

Thanks so much, Mel. And just to start off, it's really a great honor to be among such a theme panelists and to be engaged in this fundamentally important conversation. The issues that we're talking about today have been developing over centuries. So I want to acknowledge that in our conversation today, this is the tiny tip of the iceberg of a lot of the challenges, systemic, systemic challenges that we face. But it's so important to all of us on this call, all of our attendees and panelists that we have this conversation and continue to have this conversation and look deeply into ourselves to figure out how we move forward. As, as a community, I also want to take a moment just to acknowledge that I am here in Brooklyn, and I want to acknowledge the, that this is the traditional ancestral home of the not Bay people, including the Nyack and Canarsie.

They are the traditional owners and sovereign custodians of the land in which I am situated now. And I extend my respects to their ancestors and elders past and present. As we, as we began this important conversation around equity and disparities in the Parkinson's world where we're today, we know that we see people at events and classes and clinics and support groups and programs that do not fully represent the diversity of our nation. And I think for a long time, we have noticed this. We wonder why, but we have moved on. We are now recognizing that this absence is not an accident, right? It's not something that just is something out there that happens. It is not by chance. It is the result of deeply rooted, systemic health and cultural inequalities and inequities and disparities. And we are not satisfied with just noticing this anymore.

We want to understand it. We want to learn from it, and we want to change it. So that's why we're here. And I am so grateful to all of our attendees for joining this conversation. And as somebody who leads a dance classes for people with Parkinson's around the U S I witnessed inspiring participation from thousands of people living with Parkinson's, but a notable lack of racial and cultural diversity in those programs for an art form, like dance that lives among and celebrates all cultures, all people and all bodies. It is particularly disheartening and upsetting to know that there are so many people who are not yet in the room with us. So I'm here along with all of you to learn, to acknowledge our past failures, to acknowledge the privilege that we have had and in many cases, and to do better, to do much better just some, some data to start 265 black people die prematurely in the U S every day, who would not die if there were no racial disparities in mortality.

That to me is a staggering number. I also want to raise one other number. There's a four-year gap in life expectancy between white Americans and black Americans. That's four years. We often hear conversations around access to care that a lot of our challenges are about people from traditionally marginalized or press groups, not having access to care and the importance of increasing access. But studies show that it's not just about reduced access. It's actually reduced quality of care that results in a poor prognosis or report in 2003, by the Institute of medicine, found that in every class of medical treatments, black, Brown, and indigenous people receive poor quality care across the board. So it's not just a question of accessing healthcare. It's a question of what happens in that space. The conclusion of a study did not necessarily believe that American physicians or in our case program, administrators explicitly discriminate.

I think there's an acknowledgement that doctors try to do their best whoever's in the room, but what David R. Williams, the eminent public health researcher and scholar notes, and what they see is an implicit bias and implicit bias among healthcare providers among program administrators among the general population, over 70% of Americans, including physicians have a described anti-black bias. And as Williams notes, the first step is admitting that quote, I am a prejudice person because I am a normal human being raised by the society in which I ever lived. So this is very much a part of, sort of our culture of inequity before we launch into our guests' responses. I want to start with a poll. So I'm going to invite our friends from the foundation to just post this poll here and just rate your level of understanding of health disparities in Parkinson's in particular, give you a moment to, all right.

So here are the results. I think a lot of us are on this call because we're here to learn. So it's, it's wonderful that that the majority of us have, have some too low or very little levels of understanding, and that's why we're here. So that's to be celebrated, some of us have a self-reported, fairly high or very high-level understanding. Great. Thank you so much for sharing

that. It's really important for us as panelists to know where we're starting. And so we can frame our, our conversation around those lines....

Here's the second poll. The majority of people on this call are people who work with people with Parkinson's are here to learn about disparities and inequities as, as they exist in sort of the work context. Second that 38% of us are people living with Parkinson's. And we also have people who are care partners and people who have general interest in this. So whoever you are thank you for joining us. I do want to mention that in addition to having some questions that I'm going to be sharing with our guests today you will also have a chance to post questions in chat. So we will, we'll get to those at the end. So along the way, if you have a question that comes up, please feel free to share it with us. We will leave some time at the end of our conversation to do that.

Alright, so I'm going to start with a question for Jonathan Jackson. And as you heard, the beginning, Jonathan is a founder and executive director of the community access recruitment and engagement research center at mass general hospital in Boston. And you've become a well-known MTA representative communities, color and dozens of affiliated organizations, particularly in the area of research. So I'd like to start Jonathan with this question of sort of how you define the term health disparities, what that means to you and your professional practice and how you would share that explanation with us.

Jonathon Jackson

Sure. Well, starting off with a big question and one that is not without controversy. So I'm going to answer this question from my own perspective with full recognition that others on this panel may choose to define this term differently. So for me, what is really critical at this point in time is differentiating health disparities from health inequities. And I think within the Parkinson's disease space right now we, we have we're still conflating the two quite a bit. So inequities really refer to some of the systemic barriers some interpersonal barriers to, to access to diagnosis, to care, to treatment, to research. And you know, we, we have to acknowledge that right now within the Parkinson's field, our understanding of disparities, which are perhaps defined as more essential differences between groups in terms of rates rate of progression and ultimate outcomes related to Parkinson's disease. So right now, within the Parkinson's space, we wrap all of that up in this sort of define it as a disparity. We know that if your skin kind of looks like this, you may have a higher or lower rate of Parkinson's. We know that if your gender identity is this, you may have a higher or lower rate of Parkinson's. But ultimately right now within the field we don't have a really strong understanding of the inequities that may contribute to those reported statistics right now. So I would say that in terms of our understanding of actual disparities in Parkinson's disease right now we have very little understanding of that term independent from health inequities.

David Leventhal

Thank you. Thank you for helping us delineate some of those terms and understanding where we need more information. I'm actually going to jump over to a Dr. Nabila because you've done some research on about Parkinson's in in communities, in the black community and in, in Chinese American population. And I'm curious in that study that you did and subsequent follow-up, or how, how you see disparities playing out in communities, how communities are expressing some of those, those disparities to you as a clinician researcher.

Dr. Nabila Dahodwala

Okay. Thank you. Well, first I wanted to thank you for inviting me to be a part of the panel and putting together this webinar, which I think is a really very important topic and especially timely right now. So I think this question of defining disparities is really important. I think people use the word differently, and it should, you should be clear when you're using the word, what you're trying to say. And some people will, as Jonathan said, use disparities to really refer to differences in rates of disease or different ways that we measure outcomes related to how sick you are or what rates of people dying. But also there are which, and I would agree like clear inequities and care where people despite having similar disease risk or would have a similar responsiveness to treatment are not getting the same care. And so in my work, I have probably done work that spanned that whole range of how you would define differences, racial differences, ethnic differences, any group differences, however, when it defines the group all the way to inequities and really try to, to disentangle what you mentioned, David earlier, what we're observing in practice, what we see at support groups that we see in clinic.

And part of that was just getting an understanding of people's people from different backgrounds, knowledge about Parkinson's disease, and a word that we use in research for this is health literacy, where what I like to call it as Parkinson's disease literacy, what is awareness or knowledge about Parkinson's disease symptoms? And, and a lot of that for me, came from just my interaction with a lot of patients and, and hearing their stories about how they got into my office. Like what were, what was their recognition of symptoms? What brought them to care? And for me, that was just a place to start, not necessarily the problem, but I just was without a lot of data to go with. It was just based on my own experience, a place to start to get together some knowledge. And we did focus groups just in the Philadelphia community and senior centers, where there were largely homogenous groups of people based on the community or neighborhood they lived.

And the main theme that emerged where the overall knowledge about Parkinson's is low across the community, not just like in, for a specific group, and that's not surprising, Parkinson's is relatively rare related to other disorders. You see like high blood pressure or stroke. So I think it really requires more of a community support for a person who's starting to exhibit symptoms of

Parkinson's to get into care, like, to expect one person to say, Oh, I must have Parkinson's disease. I'm going to go see a doctor is a lot. So I think that was one of the lessons I learned is that true improved diagnostic rates, or to get more people into care. It can't be an approach that tries to change individual's knowledge about Parkinson's disease. I think that's a lot to ask. And then we dug a little bit deeper to learn about what people thought if they were, if, if you saw someone with symptoms of Parkinson's disease, what it may be and what you might do.

And that's where some, there were a little bit of differences coming out between groups and not surprisingly. And this is like sometimes when I see the results and talk about them, I'm like, it's not, it's not something you wouldn't have guessed anyway, but sometimes it takes actually going, like going and asking someone and reporting it so that people take like, are their awareness is brought to it. So not surprisingly language was a big issue. If you do not speak English, you don't know who's going to take care of you. What doctor do you go to see? How do you know what that, where that provider is? That's going to take care of you. So even if you're starting to struggle, if you're starting to fall, or you notice a tremor, many people did not know where to go. They didn't know who would be able to take care of them.

Another barrier that we discovered was the, there was, there was also not there was, I don't know what the best word to use it, but there were some maybe I would say mistrust or distrust in that, that there wouldn't be necessarily something that, that would help you feel better. Like why go see a doctor who they might just do an experiment on me or run tests on me, but they're not actually going to help me. They're not going to help. What's bothering me. So there's this, this feeling that that the medical system would fail them, that it wouldn't give them the help that they needed. And part of it, you know, I see things from like dr. View as well. You know, we have treatments for Parkinson's C's, we can make you better, but it was understanding that it's not just about, Parkinson's sees there's a much more socially complex issues going on in people's lives that as a medical system, we really fail them. And I think trying to get at ways to address social issues along with medical issues is really important. So those are some of the things we learned. Sorry, if I've talked a lot.

David Leventhal

Thank you. I actually wanted, that's such important information. I want to continue that idea of perhaps putting it under the umbrella of trust and relationship building between, between the medical world and people living with Parkinson's because it is such, it's, it's more than just the item, the information, and can treat you, but how do we develop relationships that are based on trust? And, and strengthen those relationships. I'm going to turn it to Dr. Claudia Martinez and to see whether clarity you've seen similar issues in the community that you're working most closely with from them Hammad Ali Parkinson's center in Phoenix, or these is what an ambulance

talking about, resonant for you in terms of issues of trust, and really understanding the whole picture of how people are interfacing with, with medical care.

Dr. Claudia Martinez

Yes. Well, again, thank you so much for having me and for giving me the opportunity to represent the community that I'm passionate about working with the Hispanic Parkinson's community. And I totally agree with, with dr. Nabila, what the barriers that she described are similar barriers that we have encountered in when working with the Hispanic community. And I could add some more actually, but even like when, for example, dr. Nabila mentioned language that's, you know, it's still a big barrier for the Spanish speaking community as well, but I think even we need to understand a little bit further than that, because many times, what I see is that organizations make a huge effort, for example, into translating materials and making them available in the language of this population that we want to help and reach out to. And that's great, but, but we need to make sure that, to understand that it's not enough because many times people think our organization's saying, okay, this is it. Or does this what we need to do. And then everything is going to be much better. And it's just a first step because to me, it's what really impacts people is what you were describing as that trust is built around understanding not only their language, but understanding their culture, understanding the, you know, the environment that they live in, understanding where they come from.

So that that's something that goes beyond language. And that really helps trust to give you a clear example. When I started, I think something that was really helpful was to be able to develop a program that understood that needed to go beyond providing translated services. So I, I, I told the people that I, that I work with that dead was important, but that was just a start because I couldn't translate services. I could translate materials, but I, I couldn't translate services because that wouldn't work or translate programs. So what I told them, it's like, we need to understand the culture and started by myself, even though I'm a Latina, I was born in Colombia, raised there until I was three, four years old. I moved to the United States. I was very mindful that the Latino culture is very diverse. And many times we tend to put everybody from, let's say, the African American community, the Latino community, Asian communities, as this big umbrella that supposed to give us like an understanding of all of this people.

And it's not like that. I mean, there is a lot of diversity that you need to be mindful of in order to be a respectful and in order to build that trust. So I'm a Colombian and I came to work in a Latino community in Phoenix that is built mostly by people from Mexico, from Mexican descent, as well as from central America. And I knew very little about them. So the fact that I'm Latina, I didn't immediately think that, you know, I know everything that I need to know about this community, but it's that moving forward into getting to know that culture and going, you know, giving yourself the time to kind of play with that community, go to that community

because we many times think about cultural competency and that's great, but something that's something that you've learned behind your screen at the office, and that will give you a first understanding.

But then after that, you need to be a cultural respect and you need to build what I call her. I like to call cultural empathy. And that's when you're willing to put yourself in the shoes of that community, you're trying, you know, you're willing to go and attend an event in that community center, see how they interact the music. They listen to the food, they enjoy how they communicate. And B can, you know, genuine in your interest and of learning and being mindful of your ignorance, but your desire to, you know, build that, that understanding. And I think that's what probably helps a lot in, or has helped me in building this trust and, and being able to kind of work around them. Any barriers that we've encountered.

David Leventhal

Thank you so much. Dr. Saadi, I want to start, can kind of continue on from this idea of cultural empathy of really understanding people where they are, because you, as the, as a neurologist and associate director of the asylum clinic at mass general hospital you you've been committed to community engaged in policy relevant research that improves outcomes for people from traditionally marginalized populations. And I wonder within your work, how you are asking colleagues other medical providers to really build these relationships of trust. This also comes out of a question I see in the chat of sort of, how do we, how do we nurture this? How do we create trust between medical or community partners and, and, and population, many of them are coming in without English as their primary language and perhaps coming in with different cultural understandings about healthcare and medical care? So how, how do we bring all this together to start developing relationship of trust? Claudia gave us some ideas. I'm curious in your practice, how you've seen that work.

Dr. Saadi

So thank you. And for the invitation to be here and for this wonderful conversation already. The few things that I was thinking about I guess I start off from the place that patients are not going to have trusted me and that I have to earn that trust. And I think that's sort of my starting point. So my work and to see if you contact in terms of the asylum clinic. So these are individuals who have fled persecution in their home countries, could be from across the world. And we conduct either medical or psychological evaluations or help them with their assignment application. There have been studies and a lot of them have been subject to physical violence have been exposed to violence in different ways. And there was an interesting study that had looked at sort of asylum seekers and survivors of torture, and they had sampled thick something short of 500 people. And they had found that around a third of them had a doctor that was sort of involved in their care who was either sort of supervising or involved in some way in terms of their exposure

to violence. So either supervising the torture that they injured, or they went to the hospital and sort of, there was no acknowledgement of this experience, this very traumatic experience that they had by the medical professional.

And so I remember reading that and sort of, it really has shifted my view of how I how I think about my role, your role as a doctor, and sort of starting from the place that people are not going to have trust. And then I'm going to have to earn their trust over time. I think from the research had the thing that I was thinking about is that we really need to be thinking about doing research that is partnered with community-based organizations, right? So we can't start with the assumption that people are going to trust me because I'm a doctor or people are going to trust me because I come from so-and-so hospital or from this, you know MGH or any other name, right. That I have that there are going to be people that folks might trust more.

So whether that is the leaders in their church or leaders in their school, or it could be a host of other people in their community that they might trust more. And so that for me, pushes me to think about how do we partner with those individuals to advance the work that we're doing and the research that we're doing, and to make sure that so did the entire spectrum of programmatic activities, whether it's just programs or whether it's research has really partnered with the community in every way. And I'll just give you an example of one project that I had been involved with in LA before I moved back to Boston. And it was a trial worth the walk. And it was a randomized weightless control trial involving senior adults with a history of hypertension who were recruited from senior centers. And the focus was to try to increase walking and stroke knowledge. And this was among Latino, Korean, Chinese, and black seniors, and they were involved through the whole process. So even in terms of thinking about the study designed, right, that folks, when you, when the research team went to the different community centers, people said, look, we don't want to have this trial. Let's either some people get this intervention and other people don't. And they really people insisted on the waitlist control aspect of it because they felt like no one should not get a potentially beneficial program. And that was very much that the community wanted they the paper that I had wrote written out of that project, that focused on how mistrust of researchers influence the outcomes of the trial and was very much informed by our community advisory board that we had for the project where I presented the numbers. And I said, look, this is what the numbers are showing. Like, what, what are the things from your perspective that I need to make sure to include when I write this up for an academic or scientific audience? So I think the point there is sort of multiple, but one that we need to go through trusted intermediaries and not assume that we are those people and to be open to involvement of community organizations across the entire spectrum of care you know, beyond just recruitment via sort of through the whole thing. So those are some of my initial thoughts.

David Leventhal

Thank you. Dr. Mejia, also from mass general hospital, you are the working within neurology, but, but in diversity and community outreach as well. And I'm curious if you if you have successful interventions or approaches in mind that, that have really tried to address the issue of, of trust access and, and, and disparity, what are, what are some projects that you think really lay the ground for, for progress?

Dr. Mejia

Thank you. Thank you. Just like everyone. I'm, I'm thrilled to be here. I think it's a big commitment of, of your organization to be having this conversation as the starting point for many more things to come. I want to take a step back and think of dr. Jackson's comment, because I think that really matters in this discussion. What we're talking about here is inequity. And what we're talking about here is how we decide to shape or not shape or systems to treat our patients whether it's diagnosing someone on time or giving them the very best, you know, medications and surgical options and physical therapy options to the end of helping them achieve good outcomes. There are all these different steps where barriers can come into play to create, or, or, or even worse than inequities. So, you know, several of the speakers here have talked about language, and I'll use that as an example, to answer your question.

So, you know, you have to take a step back and think that in the United States, as of the census, and this is a decade ago, there were 65 million Americans who needed to, or prefer to speak a language other than English 65 million Americans. And that all felt there's certainly an intersection with people who immigrated to this country like myself, who, who grew up in Latin America before coming here and primarily speaks English Spanish. And even though I'm fluent in English, a provider who speaks Spanish, certainly I, I have this, you know, this attraction and greater connection to it's not just that, right? If you think about people, for example, who, who speak American sign language people across native American groups who, you know, also have different languages represented. So 65 million Americans among them, if you take people in their sixties or people in their seventies, you have two or 3% of them who will have Parkinson's disease and, or system is not set up in a way all through the different steps to help them achieve an early diagnosis and the best possible care.

So I worked and I'm at Harvard medical school, Harvard medical school has a variety of teaching hospitals early on in my career. I joined in addition to working at the large academic hospital, that mass general is I worked part time at a federally funded community health center. And there, I thought, you know, there's a large population that speaks Spanish. I speak Spanish, I'm a movement disorder specialist. I've been doing all this research around inequities and in things like deep brain stimulation, receipt you know, working to make things happen. And soon I

realized it's not so easy because the hospital did not have a neurosurgeon. And having someone think of deep brain stimulation required them to go to a larger hospital that maybe my patients didn't trust, or their insurance didn't cover or wasn't really set up appropriately to provide linguistic services.

When we said, okay, let's try to get you out to a neurosurgeon quickly. It came up well you need neuropsychologic testing. And whereas that neuropsychologist who speaks the language, who that, or patient speaks and how are they going to get appropriate neuropsych testing to go through the board committee review? So I think a challenge, if you, if you break it down through the different parts, arriving to a diagnosis, arriving to a treatment, there's all sorts of challenges and barriers that really promote or exacerbate inequities. So thinking about interventions, I think the two main points I'd like to give one is that as a Parkinson's community, we really need to think and change the diversity in our teams. And I'm not just saying neurologist, I am saying neuropsychologist, I am saying nurses, I'm saying social workers, physical therapists. I know in the chat, there was a question about dance classes and how can they be, you know, more aligned to people across, you know, who's teaching that class.

What language is that class being offered in? Right. So across the continuum we need a greater diversity, racial, ethnic, linguistic gender related, so that patients have a different experience when it comes to clinical research, the same thing happens. We've done research around the inequities in clinical trials, and we've noticed that principal investigators who speak languages other than English, tend to be more mindful about translating all their clinical research forms into other languages and, and, and recruiting people across languages. So again, I think you know, I think it's important to take a step back and think of, of what Jonathan Jackson was saying early on, what are the systems in place and where can we intervene effectively? There is a neuropsychologist at mass general, Jackie ketose she's Latina, and she created something called Munos. And, and, and, and finally, I'm answering your question, which is what are some, some sexual interventions? So moon doesn't is a multicultural neuropsychology clinical service where there is neuropsychologic testing offered in Spanish and other languages and where there is training of neuropsychologist who speak Spanish and other languages. And I think that we need more of those types of interventions to, to really move the needle.

David Leventhal

Thank you so much for that comprehensive answer. And for stepping back, I think it's an important, important to always approach that sort of question about current interventions from, from more background, from more understanding of how we get there, why we need it. And actually, I want to step backwards. I want to go a little bit back to the conversation around trust, and I want to go back to Jonathan for this one, because one of the challenges we have is sort of, how do we get people to take that first step into doctor's offices or physical therapist offices,

wherever we're talking about or dance class even to begin that trust, right there have been, you've mentioned some of those ideas already around making sure that our teams really reflect the communities that we are working with. But I'm wondering if there are some, some more ways that we can really try to try to create that sense of trust to get people in the door, because there, there is, there's a lot that we can do, but if we don't know that people are out there and we can't connect with them, there's, there's very little.

Jonathon Jackson

Yeah, I, I think that's, that's certainly true. This is a tough question. And the reason why it's tough is it's probably not for the reason that you think the reason why it's tough is because I have learned that when it comes to trying to bring in folks who have not been part of the workflow in the system that you've already got going trust is not where you begin. You begin with empowerment, you begin with partnership. You begin with, by determining a clear return of value for the audience, for the individual, for the community, for the neighborhood that you're reaching out to. And what you have to do is you have to build a workflow from there. So there are so many questions coming into the chats about, you know, how do I get more diversity here, or how do I get folks there?

The number one thing that you have to do is stop, take a breath, and you have to realize that the question that you're asking is not one question it's like 19 questions. Because the, the truth of the matter is that everybody who has any trouble with diversity or recruitment and the gnome hypothesis is that you do have trouble with this. So that's the assumption, everybody that has trouble with this has trouble for different reasons. It could be because nobody's aware of your program. It could be because no one can get to your program. It could, because people think your program is useless. It could be because they think the program is great. But if for some reason it's just not for that. You know, there's a question that came in that was really making me think about you know, that says, do you ever think the focus on language and ethnicity could compromise getting the best position?

Now that is a question that has a lot of assumptions embedded in there. The, the, the assumption is that you know, number one, that there is a best position out there that there's a number one position you know, ranked number one in the world who, you know, gives the best quality care to every single person, no matter where they're coming from, not true. The best physician is the one who can understand. You can understand what's important to you and can connect you to services, to medications, to treatment and can build a plan with you. That takes into consideration all of the contextual needs and desires that you have. And there is not one person. There is not one institution anywhere in the world. That's going to get that right for everybody. So when we talk about the focus on cultural competence, when we talk about the focus on language, that vicinity, it is not separate from your knowledge as a practicing neurologist.

It's, it's integrated with that. And so if you are trying to build trust, if you are trying to reach out to some of these communities, the first thing that you got to understand is what are the barriers? You know, if you look at the extent literature in Parkinson's disease which I've done, I've done, I've recently wrapped up a study that looked at a lot of these problems extensively. Maybe we'll get to that later. But the bottom line is that the, the barriers are well-documented, but it's impossible to know which barriers you're facing and how those barriers interact without a careful examination and analysis of what's going on within your center. So you need to, you need to understand where's the bottleneck within your group, because maybe you've got people coming in the door. Maybe you've got people in your clinic, and you're just not seeing them, because the way that you ask questions about participating in a research or reaching out to you know, serve on patient family advisory councils, or referring people to dance classes, maybe you only refer people who ask.

And there are a lot of people who don't know how to ask. So, you know, we have to understand what those barriers are and what you're hearing from all the panelists is AEs is a variety of solutions that have worked really well in the context where that person is in or where that group is. And so, in some cases you simply just need translation. You know, and, and that's not just translating to a language other than English some night time, that's, that's translating movement disorder, specialist speak to a person living with Parkinson's speak it's still English, but you have to translate it in a way that that resonates and connects with that person. Other times you're going to have to do with what dr. Martinez has done, which has built an entirely new workflow that serves the needs and the goals of individuals in context with a, with a diabetic system, with their families.

And, you know, it would be irresponsible for any of us to say, this is the best solution for you. The only way that we can understand what the best solution for you is for is by understanding the deeper context. And, you know, if you are not prepared to take that step for yourself in reaching out to some of these communities that are connected to you. And so in terms of reaching out to a more diverse and available patient set in terms of just reaching out to more women if you don't have women you know, that you're seeing that are living with Parkinson's disease you know, that's, that has to be the first step. So, you know, when we are giving advice, you know, the Mo the first thing that I really need to caution is you need to understand the barriers, because when you go to the community and you can say, we want you to be involved, you really don't want to run to the situation where you're saying with one hand, come join me, be with this. And with the other hand, you're saying, Hey, hang on. Your insurance. Is that right? You know, we keep bankers' hours you know, you got to bring a study partner with you. You know, you, you certainly have to pay, you know, between 40 and \$50 for parking every time you can, you're coming in near us. So we don't want to send those mixed messages. So we really have to do the internal work first, recognize what those barriers are, approach, trusted community members and

offer a partnership, offer incentives, make sure that it works and it's valuable for them, and we're not doing this just because we want to see more Brown faces and recognizing, you know, you know, what the value is there. So, you know, again, my response is all over the place because the answers are all over the place. There is no there's not going to be any one size fits all solution.

But you know, if people could be more specific and detailed about a barrier that they're trying to overcome, the barrier, can't be, we don't have diversity. That's not a barrier. That's several, if you could be more detailed than, you know, we, I think, you know, could potentially offer much more concrete advice about how to build empowerment, how to build, trust, how to build connection and partnership and all of the things that I think we want, that we are well intended in terms of what we wanted to do, but, you know, are ultimately falling short.

David Leventhal

The workflows though, still the approaches themselves are so localized, really, they're very specific. They have to, they have to be, yeah. With that in mind, what can the Davis Phinney foundation or other national organizations do with that knowledge, right? That can move these changes forward, start to remove some of the barriers that are there, but in a way that understands and respects the very local dynamics and ecosystems that are present. And I'm going to throw that question to a, to an umbrella in terms of sort of what, you know, what can we, what can organizations do that are focused nationally and focused on sort of policy change and big picture issues? How can we support that kind of local change and bury removal or, or at least strategic analysis that needs to happen on the very local level?

Dr. Dahodwala

I think, I mean, I think what, like an easy answer would be to invest in local communities and really strengthen the systems that are in place there. I think things that would cross communities though, is I think having a stronger, I mean, as we're seeing right now with COVID a stronger public health infrastructure to really kind of, that would cross diseases. It doesn't have to be specific for Parkinson's disease, but really a stronger community health setting for people to receive the services they need. And they might not all be medical services. Like one thing that we spent some time talking about is language, but we haven't talked as much about race and the inherent racial inequities that are present throughout our society, not just in healthcare, but lead to poor health outcomes with, with biases that we have within just ourselves as individuals, but that are like systemic our healthcare system.

I mean, our healthcare system works really well for a group of people, but there are a lot of people that it does not work well for. And to really change that system, I think, needs to be done at a health policy level. So I think advocating for changes in how we deliver care, how having a little bit, I think, really more interaction between the medical and social services. I think we can't

have them so separate because so much of the racial inequities are tied to socioeconomic status. And we can't ignore poverty and unemployment and lack of childcare and how all of that coalesces and more into how people are able to see their doctor or take their medicine or pay their copays. So I think, and there's, there's even more, I think there's another whole big surge on telehealth right now with, again, with COVID-19.

And I think that is an opportunity to improve access, especially for people who may be geographically or remote or more rural. But again, we have to think about how that can work for every community. And I, I mean, I haven't seen the data yet, but I'm sure it'll come out that there's going to be again, an inequities who, who can access care through telehealth. So I think that would be another Avenue that the foundation could advocate for more resources investments in communities and the public health infrastructure personalizing the care as Jonathan was saying that really every intervention or every approach needs to be personalized for the context that we're dealing with. And if we can really, if everyone, I think puts their effort into it, I think we can change the way our current system is built.

David Leventhal

Thank you. I actually want to continue on from that issue of, of kind of you know, really individualizing care. And I want to approach this with Dr. Mejia. Because often I think when we're looking at making change or local level or making change in a clinic where we are looking at data that talks about groups of people and generalizes, those groups of people, but when it comes down to it, we all know that quality care really comes from seeing people as individuals with their individual stories or individual challenges for really busy overworked medical professionals. How do we, how do we carve out space for, for that kind of individualized care and individualized empathy around each individual story, particularly Parkinson's, which I think is such a, it's a holistic picture, right? It affects every aspect of someone's life. And so the response to that has to be understanding how all of those pieces fit together. How do we do that when you have, you know, 20 minutes to see somebody in an office and you're rushed and you're, there's a lot going on, how do we, how do we balance all of that?

Dr. Mejia

Your question has two parts to it. I, I don't want to leave the system sparked out because as much as the individual interaction matters, the system plays a big role. And so I'll share a story with you. One of my patients recently had to go into a nursing home for respite care. We've known each other well, we've developed a good relationship over time. We thought things would be smooth and quickly realized a couple of days into their stay and their family far away. The reason that they were in respite care that the facility was not set up to meet their dietary needs. They had a special vegetarian diet that because of religion, because of religion, they had a special diet. And by day three, she said, I can't keep eating lettuce every day. So in those conversations

we had had over years, we had developed a relationship where I knew that matter, but the system wasn't set up to support that need.

So, so I, I, I am for size the system, again, because as a foundation, you have the power to change the system and you have the power to advocate for changes that decrease the barriers because in a way again, even though the individual interactions matter, this is stomach changes, probably carry more weight. With regards to your question specifically, though, there are certainly ways that we train that we teach in medical school and that we learn as clinicians to listen and listen intensely, right? And there's, you know, sociologists who've written about, well, how do you engage with a patient? So you're asking what really matters so that you're double checking, that people are understanding what you're asking and that you're exploring any middle grounds that may be, have to be reached at some point in my own practice. A couple of decades ago, I met an internist at a federally qualified community health center who shared with me that instead of starting their encounters, like we usually do with the chief complaint and going to the history, they actually started their encounters recognizing there was a chief complaint.

I know you're here to see if you have Parkinson's disease, but then moved on to the social history. And that's what I do in my practice. I start by taking a step back and asking the patient and their circle their loved ones who are there with them to walk me through their life. You know, where were you born? Where did you grow up? Because I think like other speakers have said, we make so many assumptions that sometimes are wrong. Right? Who, who is, who lives at home? Who, who is, who do you love? Who's there to support you. Who's your right hand. I ask about education, religion, everything we got to know each other as the starting point of our relationship that will develop a, for many years.

David Leventhal

Great. Thank you. Dr. Saadi. We're talking about building that relationship around an individual's story. How do you feel something I meant to ask earlier, but I'm going to bring it in now because Nabila had mentioned as well, is this issue of racism and implicit bias, right? Which is, which is embedded in, in the system, but it's really embedded in individuals within healthcare, within communities. How do we go about challenging that implicit bias and, and which is a big question and how do we, you know, what are the best ways that we can, that we can inform, educate corral people into really acknowledging their implicit bias? It's, it's hidden because it's, they may not even know it's there. So a few questions. Do you see this happening in the work? And then how do we change that?

Dr. Saadi

That is a very, very big question. And I will take a small part of that and sort of start by sharing sort of a personal story in terms of my own attractions in the healthcare space. That sort of

influenced my thinking about a lot of this. I think that and I'll give two examples, sort of one clinically and Northern one personally. I think about being in medical training and I was shadowing a doctor and we were waiting for an interpreter for a patient to show up. And she said, this is a woman who had lived here for several years. And the doctor made a comment about, Oh, I can't believe we're just having, you know, I'm going to be running late for clinic, or she's been in the country for, I forget, you know, how long at that point he was like, she's been in the country here for decades and she can't bother to learn English.

And you know, he was making this comment sort of just to the side. He, when he actually saw the patient, he was very nice to her. But I think it sort of, for me, it was like, well, he's having these thoughts of it in the back of the back of his head that he may be verbalizing, or he may not be verbalizing a lot of times people don't verbalize these thoughts and that without a doubt this sort of have an impact on the care with that particular individual. So whether that is that encounter is, has more judgment in it or that it might be shorter or there've been studies that show that even when started breaking back bad news physicians might be less likely to offer a comforting hand or to touch the shoulder of the patient.

And again, it sort of might manifest in ways that might be more subtle than that, that comment that that doctor made to me. And I think the point that I sort of want to make to that, and I will send sort of share the personal story that I wanted to share. But is that when we think about sort of whether it's implicit bias or sort of all types of biases that we really need to be thinking about it in every encounter that we have, that it can't be an afterthought and the can't be sort of this one hour session that we're going to have, that's going to be about disparities. It can't be in our medical training where, you know, you have one class or one lecture on it. It really needs to be incorporated to thinking about everything, every encounter just sort of every at every point, and we need to be thinking about how could bias be playing a role, how could structural issues be playing a role.

And then the personal example that I want to bring up was one that I had with my father. When I was in medical school, he was diagnosed with cancer. And I remember going to whistle to a lot of appointments with him, and we're a family of immigrants, but my father is fluent in English, as I am studied has a PhD that he studied in the UK, but we would show up to these appointments and there would always be an interpreter there. They would wait, the doctor wouldn't even start talking to us and he would see either me or my father and would just like not saying, he'd be like, Oh, I'm waiting for the interpreter. And we would constantly be like, you know, we don't need an interpreter. I'm fluent. My father's fluent. And I bring up that example as a point to say that sometimes these biases that people, or how it manifest may not necessarily be out of ill intent.

Right. But that the, when this happened and this happened across multiple providers, they were actually trying to be culturally competent, right. That they were that in their understanding, they were like, Oh, this is what we have heard. Or maybe someone shows up with a headscarf or who looks like my dad and sort of making those assumptions. And so the other point I sort of want to make is that, yes, we are talking about some of these general issues that affect communities at large, but at the end of the day, we need to be treating each person as an individual and sort of checking ourselves in terms of what assumptions we bring to the table. And we are always bringing assumptions to the table.

David Leventhal

Thank you so much. I'm going to finish my questions with Claudia. And I want to think we've talked a lot about kind of the, the system's response to inequities and, and to trust and many of these issues that relate to the challenges of, of disparity and care. I want to focus before we turn over to questions from attendees on this question of what individuals in the Parkinson's community can do to address this issue, right? We've talked about why medical professionals, other health, healthcare professionals can do program directors almost on that kind of professional side. What can the community do as, as individuals to bring awareness of these, these issues and to make things better from their perspective, because I know you work with a huge community base, primarily focused on the Hispanic community, but there are many other people will come into the Muhammad Ali Parkinson's center. How can we all play a role in lifting these barriers and, and providing better care for everybody?

Dr. Martinez

Well, that's a, that's a big question again, but, but a very interesting one. And also I would like to go back to what Jonathan said, cause I think it's really important that when we try to address you know, these issues that we give the opportunity to the people themselves, the either PWPs care partners, community members to have a role and to play a role, not only at being passive recipients, but instead being invited as partners. I think you use that that word Jonathan and many times we think that, you know, we care so much, and our intentions are, are really, really good, but we are, we are trained many times to be providers, right? And we need to bring and give, and people are there just to receive a ride because we'd been the train training, what are the best practices and what you know that they need, but, but definitely needs to be rethink the other way around.

And as Jonathan said, that's part of starting building trust. You don't start by building trust. You start by, you know, asking the people, you know, I want to listen, I'm interested and being also transparent on where's your grill, real motivation, because that will show up sooner or later, is that you want to just recruit people for your study or you know, make sure that your program has a great numbers or you're truly interested in, in addressing the barriers that this person or this

community is facing. So that's, I think that's a very important point that you brought David, because definitely we need to have the patient's care partners and community members at the table. And, and what in, in my experience, that's been very powerful because like empowerment is the other word that Jonathan used. And that is very important because this, this this community members, these people who are facing inequities many times having had the chance to be heard, and many times they've been approached, as I said before, with solutions or with ideas or with programs, but no one has asked them, you know, what it's, what would you like to see?

What does, what made to be, you know shaped so that it fits your needs. And another important part of that is bringing, you know, into the table. What it's, what, what I like to call like perceived value. Because many times we would like to think that we have this great problem that have been, you know, research supported, and they have all these great results in different communities and that, but that people don't respond to them. And it's not because they're bad. It's because maybe as Jonathan said, that's not what they need, or maybe it's over at a time they can't come, or maybe there is not shy childcare. And this person prefers to be the grandma for their grandchildren, then attend an exercise class. So with all of dad's said again, then I'm white. What we've done for example is, is make sure that that we ask that we ask people, okay, so let's talk.

And what do you think will be a good way to start this program on many times what I do is I ask them, you know, I'm thinking about doing this, I'm thinking about, you know, that we need this. Do you agree what we built already? That, that conversation with patients care partners and also community members, and for those of you who are asking how to start times if you don't have starting point are ready, going out to the community and find out those organizations that are already providing successful services community, you want to outreach, even if it's not healthcare related, could be a good way to start and see what the, what dynamics they have built. But in our, in our particular case, for example a great example that I can give is people that are part of our choir.

We have a choir for Hispanics with Parkinson's disease, and they are the best spokespersons that we can have. And I tell them that all the time I tell them, okay, okay, let's talk, you know, let's start real here. If we go out into community and, and we announced there's going to be Claudia, dr. Claudia Martinez talking about Parkinson's disease versus the quieter voices. Anita is, is going to have a performance for the community. Who do you think that's going to get more drawing and more people are going to go to? And of course, it's the choir scores they're going to like to listen to music and dance. And while they're doing that, then the choir members have become, you know, empowered enough to be able to take the mic and say, I am so on. So, and I've been, I was diagnosed with Parkinson's and then I would, I, my family didn't even know what that disease was.

And we, then they tell their story. Then they can say why the acquire is important for them. So that's a way that we've being, bringing them to the table and let them know how important they are for our organization. It's not like I tell them the story that you have to tell is so much more powerful than any flyer that we can provide at a health fair. And, and what you have to say, it's, it's really meaningful, not only for us in order to build an awareness, but also for your treatment and for your wellbeing, because you are also the, the expert in your disease. Your doctor knows a lot, but he doesn't know, you know, how you leave at home or how the medication wears off. Or then what is that you like to do with your grandchildren? What are the times that you want to be on to make you know, your life meaningful? So it's those two areas being really powerful on becoming partners for raising awareness into their own communities, as well as engaging them in becoming more, you know, empowered to talk to their, their own providers has been really beneficial.

And your point is something that's so important. I think going back to that question about the foundation's role and the value of not having all the answers, in fact, meaning not having any answers, but knowing how to ask the right questions and knowing how to listen and building whatever comes next from, from the community who are experts in their own environment, situation and needs.

David Leventhal

So that's actually a really great segue for us to turn the questioning over to our community Davis Phinney, vanishing community, who are very actively suggesting questions and things that they'd like to know more of, which is wonderful. Please keep the questions coming. And I'm going to say this now and later, but if there is a question that you have that does not get addressed in the next 15 minutes or so we please send them to us by email Mel will provide information about that, and we will make sure that there is a response to your question. So we have a limited time to answer as much as we can. Now I'm going to turn it back to Mel. Who's going to help lead navigate through some of the questions that have come through. Thanks, Mel.

Mel Dizon

Yeah, absolutely. I just want to say one of the things that I think you just talked about that I think is super important and in some of the questions are scattering around this, but is the idea of meeting people where they are, and this is what you're doing. And Phoenix, this is what the choir is doing. Like you said, are they going to want to see dr. Claudia Martinez talk? Are they going to want to come to the show? Right. And listen to the music. And those are some things that like another example of that is the wash and learn program. And Baltimore, it's a, they're, they're meeting people at the laundromat because that's where they're spending a lot of their time. And so they're educating kids, they're taking technology. There's a barbershop example of the barbers

getting trained, right. To teach people and notice different things. And so that being where they are and meeting them there is such an important first step.

They're really a couple of great questions here and I'm wondering, well, let me see somebody said with the concept of cultural empathy in mind, what can members of the Parkinson's community do to be inclusive without tokenizing one person of color in their community or within their reach and all efforts while well-intended, this could do more harm than good. I think this is a common question that people in our community face, because they, they are aware of this issue. They're aware that it's a problem and they want to do something about it, but they're worried about that tokenization. Jonathan, do you have something to say,

Jonathon Jackson

Oh boy I think we all have something to say if I'm honest. So as usual, this is one of those questions is actually several questions. And one the first thing that I'll say is the perfect is the enemy of the good, in many situations when it comes not all but many situations when it comes to trying to interact with the community that is different than the community that you often see. So, so don't wait for you to have a perfect representation on your team to have all the resources in place, to have a very detailed plan that is well funded and sustainable for 30 years before you reach out to the community. That's usually what people do, especially people who come from either medicalized spaces or academic spaces. You know, there's a, you know, I think again, a well-intentioned push to not be perfect to, to get things just right.

And to not be offensive in trying to reach out what we do recommend is to be vulnerable is to recognize that you're coming into a space that you don't know a about. And, you know, certainly bring your intention with you, but recognize that there may be an impact that's different than what you're looking for. So there's a bunch of questions that came through of like, how exactly do we do this? It starts with a conversation find somebody you trust, if you don't know anybody from that community that you can trust that you might have to do a cold call and you might get it wrong. But it is still very much worth doing. You know, what's important to do is to take the advice that Nabila said which she was talking about patient encounters and bring that into whatever interactive space that you're, that you're mentioning, do not make assumptions about how the conversation is supposed to go, how the flow is supposed to go.

Don't make an assumption that the end of you know, that somebody should be grateful that you're there. You know, you have to recognize that it needs to be a conversation where they can say no, where they can you say, let me think about it, come back later. They can say, I've had terrible encounters go away and never come back. You need to make sure that the folks that you were approaching have the empowerments and have the partnership and, and sort of have the ability to express whatever it is that they need, or they want. So, you know, if you are trying to

reach out into these spaces and again, there's no one way to do it, but the best way to do it is to do it with vulnerability and with humility and to recognize you know, that's, you know, I, I think that there are a lot of people probably on this webinar who are extremely worried about putting a foot wrong about making it worse, about setting a relationship back.

First of all, get over yourselves a little bit. Those of us who are in marginalized groups, we deal with this a lot. We're sick of it. You know, and, you know, in many cases we are willing to endure a little bit of you saying it and getting it a bit wrong. And because we understand where you're trying to come from. So, you know, that kind of takes me back to where I started. The perfect is the enemy of the good, just try, try your best. And if somebody does criticize you know, try to receive it with grace and recognize that, you know, this is a learning opportunity that somebody yelling at you is actually a gift because, you know, what's, what's much worse is you just getting ignored and people forming a whisper network and saying not to work with you, which happens a lot more than you might think. Gosh, I went on a little bit longer than I wanted, but that's, again, a big question. Just try, be vulnerable, be humble. It's okay. That you're going to make mistakes, but just try to learn from them.

Mel Dizon

Great. Thank you. I think you just relieved. A lot of people say, just do it. You don't have to be perfect. This is from somebody who said PD is misdiagnosed at a high rate. Often. It is the case that neurologist movement disorder specialists take different approaches in diagnosis and treatment. Should there not be standard practices for the more basic repeatable process oriented clinical tasks? Does someone on Dr. Mejia, you look like you're shaking your head.

Dr. Mejia

Hi, I'd love to answer this question. And the reason for this is a few summer cycle. There was an undergraduate student working with me on a project about Parkinson's decease inequities, and as she was new to the field and learning about Parkinson's to see, she says, she said to me, wait a minute. What's wrong with the pictures? Every time I go onto Google, every time I open a textbook, there's always the same picture in that book. It's always that white, older male stooped holding a cane where are all the other pictures?

And when I listened to your question and I think of how we teach medical students about Parkinson's disease, how we treat, teach residents and even movement disorders, fellows about Parkinson's disease. We need to change our imagery. And I know that several of the Parkinson's disease organizations have, have done great things around changing the pictures on the websites. And I think that makes a difference, but, but again, going to the structural about what are the images that we use to teach and what are the images that, that we share with our patients? I can tell you if many of my younger female black, Latino patients who were given diagnosis of

malingering cyclic, genetic multiple sclerosis, a variety of other things, because I think that picture frames us.

David Leventhal

Sort of dovetails with our conversation earlier about making sure that that practitioners really represent their communities, the diversity of the communities, and sort of like who has who's representing that group, but also the images, right? The conventions that are put forward. I infer that, that those are really representative as well. So great, great point. Thank you.

Mel Dizon

Yeah, along that point, David somebody asked, what do you suggest providers do to invest in their own learning and the communities they serve? It should not be the responsibility of the client, the patient to educate their provider. Does anybody have an answer for that one?

Dr. Nabila

So, I mean, one thing that you got, you may have already heard about that, that Penn has, is this community health worker program, which has been a really great program to bridge that divide. So that it's started by [inaudible], who's an internal medicine, and she saw this gap in care that there was a very diverse population that was within our community in Philadelphia, but providers have their own individual experience that may not, well, definitely not span the diversity of the people we see and the challenges that many of our patients face CRA are, are cross a lot of different domains, not just in the disease that we might be treating. And so she developed this program that has been community health workers had been out in, you know, and used for centuries. But, you know, has now just, I think, got a little bit more attention and trained people from communities where the PA the patients that were taking care of live to bridge that divide. So providers can, you know, still do, but we're good at in terms of we can still connect with patients. We can still listen to them. I think we need to in general, talk less and listen to what people are telling us and make recommendations for care, but the community health workers can follow up with what's going on, can help with the patient get to their appointments, can help the patient troubleshoot the other problems that they're having. And, and kind of, if there is a cultural divide or a disconnect between the prep provider and patient about where those barriers might be for receiving the best care that health, the community health worker can be, that person who can talk to the provider and the patient help navigate that. So I think that's one possible solution. Obviously, I think providers should always try and, you know, do their best and be as educated as possible about the community that they serve. But it, it can be a lot, I mean, there, there can be very many members from a lot of different communities that we are treating and to necessarily be the expert in all of those would be a lot. And so one solution is to have community members take on part of that role and share it with us.

Dr. Martinez

I would like just to briefly ask the Amie to add that to what dr. Nabila said that we also use that as a model, the community health workers modeling has been really, really beneficial. I mean, as, as you said, that is a model that's been in use for, for many, many centuries. And here in the Hispanic community, we, we call them promo Torres and, and it's really a wonderful way to integrate, you know, the, the knowledge of the community. And we have a promoters program for Parkinson's that has helped us not only build that bridge, but also educate our own many times on for them getting to know all the, not only that the aspects related to Parkinson's, but as we said before, related to the family and the community involvement and promotoras are a wonderful tool, and you don't need to find them that are necessarily related to health, but they're, they're just lay people who are part of their community, where they live in.

And there they have a passion for not only empower, but also the betterment of their own community. So we've found that they're wonderful partners, even if they're just fate base or have to do with any other topics related to their community and they're willing to learn, and they're willing to learn more about, Oh, there's Parkinson's disease and what resources you have, because we're all at now there, another way that we've been successful about approaching is, is also trying to be mindful about, it's not just about our program, but it's also about what they have to offer. So then, okay. So what is that your promoters organization do community health workers are a wonderful resource for us because when we need to keep in mind that when we're serving the communities that need is not only providing services that are related to healthcare, but to many other areas that they might be having barriers or issues with.

Mel Dizon

So keep that in mind. It's also important, right? I think that goes along with and I'm sorry, I can't remember who said it, but we need to go through trusted mediaries this idea that it has to be come from the MDs to go to the person with Parkinson's is a big gap. So if we can use these community health workers then it is going to address everything, not just Parkinson's has somebody asks how common are community health workers on the national scale? Is it, is it something that, you know, every community has and then what are ways that to move in that direction and actually work with the community health partners to get all the information out to the people in the community? I mean, that's too big of a question and we have five minutes left. I don't expect you to answer that, but is it, is it a common,

This is a longer answer, but there are great models. One of them is [inaudible] it's it from the cancer community. So check, check that out.

Mel Dizon

Great. And we, we just to let people know, if you're in case you don't have your chat open, we are going to share all the links, any research that came up during this conversation, any links to programs, we'll make sure that we share all of that with you in a post email. Claudia, did you have something else to say?

Dr. Martinez

Yes. I just sort of really wanted to add the vision and commitment. Obviously, they're based in California, but they have an annual conference that extra lease coming up. Now it's going to be virtual and, and I can share the information because we'd been attending their conference for probably eight years. And it's been a wonderful partnership and it was initially just California and Arizona, but more and more States are sending their representatives to the, their annual conference. So it's a great resource to have. Great.

Mel Dizon

Thank you. I'm just going to do a quick close, and then I'm going to hand it over to David. Cause I know he's got something he'd like to say to, to end everything, but I want to thank all of you in the audience for joining us today. You will get the recording, you'll get a recording for the audio, the video, you'll get a transcript, all of the show notes and all of the chat that we've been talking about today. So you don't miss those questions that should be coming to you probably early next week. So and also stay tuned for information and emails about our upcoming webinars in this series. We really hope to dig more into this topic and address some of the questions that we had today. I want to thank Dance for PD for their partnership again, for today. I want to thank David for being our moderator. Nabila, Jonathan, Nicte, Claudia and Dr. Saadi for being here today. It was so great. I also want to thank Jenna again for making this possible she is our director of programs and outreach super great at spearheading all of this for us. And I will put my email in the chat box. So if you have any questions, feel free to follow up with me and I'll let David close it up.

David Leventhal

I want to echo those thanks and echo the gratitude that Mel expressed to each and every one of you join us as panelists and also to all of you who attended the webinar as participants to learn to listen. And to understand this very complex landscape. I also want to encourage all of the participants to send in questions or ideas that you would like to see us cover in additional webinars in this series. We have a few ideas that I've, I've talked about with Mel and Jenna and other members of the Davis Phinney team, but we're, as I've already said, we are very open to your ideas, your suggestions and questions, things that you would like to know. So please send them our way so that we can include those topics in the series. We will also be sending a follow-up email that has some organizations listed that that provide opportunities to learn more, but also

to donate, to support this important work in communities around the U S I encourage us all to keep having this conversation.

I encourage us all as, as Jonathan said we don't have to get it right the first time we have to, we have to listen. We have to be humble. We have to be able to be vulnerable as Australian Aboriginal activist by the Watson said, if you've come to help me, you are wasting your time, but if you've come because your liberation is bound up with mine, then let us work together. So, when we were all in this together, we're all looking for a more, just fair and equitable society, and we want to work together to make that happen. We, on the foundation side, we'll be working to, to ask the hard questions and to try out some of the incredibly informative and guiding answers that we had today. So, keep us thanks to all of you and I look forward to continuing the conversation and to continuing to learn. Thank you.