



PD Movers Webinar Series

The Role of Faith-Based Leaders in Health Promotion and Outreach in the Black and African American Community

Davis Phinney Foundation

Note: This is not a flawless, word-for-word transcription, but it's close.

Kayla Ferguson (Grants Program Manager, Davis Phinney Foundation)

Thanks again for joining. This is the third and final webinar in our PD Movers Raising Awareness and Hope in the Black and African American Parkinson's Community Series. And today's webinar is called The Role of Faith-Based Leaders in Health Promotion and Outreach in the Black and African American Community. My name is Kayla Ferguson and I'm the grant manager at the Davis Spinney Foundation. And today I'm joined by a handful of great panelists as well as Dr. Hiral Shah, who's an assistant professor of neurology at Columbia University Medical Center in the division of Multi-Specialty Neurology. And she'll be leading the discussion with our panel of experts. And in just a moment, I'm going to let Dr. Shah talk about this amazing resource as well as introduce the series that we've done today and herself in a little bit more detail. But before that, I'm just going to go through a quick few housekeeping items that you're likely already aware of, but it never hurts to have a refresher.

For this webinar, it's best to be in the gallery view, that way you can see all of the speakers and the facilitator as we're moving around the room. You might have also noticed that we have the closed captioning on, and you can click that at the bottom of the screen and hide that if you don't want to see these captions throughout the conversation. Also, the chat. As always, we at most Zoom rooms love people to use the chat, and so do we. So, feel free to let us know where you're logging in from. You're your name of course. And then you can choose who's seeing your chat with the blue box at the bottom. You can choose everyone, or panelists or individual people feel free to put whatever questions and answers or questions in the chat, and we'll do our best to answer them as we get going towards the end of this webinar as well.

Claudia, on our team who I don't think is on screen right now, she's going to be keeping track of this chat and we might not get to all of the questions that people ask, but we'll do our best to follow up with any that we don't address in the follow up for this webinar. Which brings me to my last point is that this is being recorded. And this will be sent to your inbox to watch the replay or send along to anyone who might also want to watch it in about a week after this webinar wraps up. And I guess my last note is that this is a webinar so you cannot be seen or heard, and the only way for us to hear from you is through the chat. So, I think that's it. I'm going to pass it over now to Dr. Shah. I'd love for you to introduce yourself in a little bit more detail and then give us some context for this amazing series and these amazing panelists before I do some bigger introductions of everyone who's here.



Hiral Shah, MD (Assistant Professor of Neurology, Columbia University Medical Center):

Thanks, Kayla. So, I'm Hiral Shah. I'm a neurologist and movement disorder specialist and the medical director of the Parkinson's Foundation Center of Excellence at Columbia University. As Kayla said I've been one of the leaders in developing the PD movers and wanted to thank Davis Phinney for really giving us the space and time to share this amazing resource and many of its applications. Just to kind of give you all a little bit of background, if you hadn't joined us before, a reminder of what the PD movers is. So, it is a book and a compilation of narratives of 10 remarkable individuals who are living with Parkinson's Disease and their care partners who identify as black or African American. And this compilation of narratives is told in the first person and accompanied by vibrant illustrations underscoring the importance of representation. And we've traced these individuals and care partners in their journey of Parkinson's disease, when their symptoms began, how they were diagnosed, and how they're coping and thriving with this disease, including some of the treatment approaches that they're applying throughout.

This is the thread of the importance of faith and as well as the empowering messages so that people that are living with this disease can have the best quality of life and access to resources that they deserve. By way of a little bit of background, as Kayla said, this is the third in a series of webinars. So, the first was really just talking about PD movers as a tool for building trust awareness as well as empowerment of Parkinson's disease in the African American and black community. During this first webinar, we discussed the importance of gaining trust in the community and some of the work that I did with Miss Anita Parker, who's on as a panelist on today's webinar to build trust in the community. As we prepared for this book, it took several years of building trust before we came to the point where the community felt open and welcoming, and comfortable so that we could share the knowledge and information we wanted.

We talked about the book as not only a tool, and an educational resource, but as a model of how to engage with otherwise under-engaged communities that individuals and organizations could then utilize to tackle problems in other areas of health that face healthcare disparities. We spoke about the importance of including the community from the beginning, from conceptualization through implementation, and our use of the community-based participatory research model. And finally, we spoke to the impact of the book, how it was sparking conversations, creating connections, and opening doors, and the fact that it was so impactful in this way and so highly acceptable because of the approach that we took including an uplifting the voice of the individual and care partner. So, the second webinar was great as well. In this, we focused on the power of the story. Richard Huckabee and Kermit Smith, two participants in the PD movers shared their narratives and how their life was changed when they were diagnosed with Parkinson's disease.



And the obstacles and opportunities that presented their moving words showed us the importance of maintaining hope and optimism and the role of faith in that journey. And the other conversation I wanted to highlight, which we weren't able to get to in our second webinar, was a conversation with Randy Pearson, the illustrator of the book. He had a really moving discussion with myself and other members of the Davis Phinney team about why he chose to participate in this project and how it changed things for him. He himself was a caregiver during this journey, and I think that he was able to bring the narratives to life using these vibrant images and illustrations that almost are another character in this storybook of PD movers. So that brings us to the session today where we're going to be talking about the role of faith leaders and faith-based organizations in building awareness and empowerment in the African American and black community. And I'm so thrilled that you'll get to hear from our wonderful panelists today. So, I'll let Kayla take it from here and introduce our team.

Kayla Ferguson:

Yeah, awesome. Thank you for that context. I think that's really helpful to set the stage for the conversation going into today. And yeah, I'm just going to take a few minutes and let everyone know who's on the screen. So, when they're answering our questions, you have some context for their expertise and the work that they do. When I say your name, if you can maybe give a little wave. I know we have your name already on your screen, but feel free to wave so people know who I'm talking about. I'm not going in any particular order on the screen, so that'll be helpful. So, Wendy Lewis, she is the Chief Executive Officer at the Parkinson Council. And since her tenure, the Parkinson Council has reinvested over five and a half million dollars into the greater Philadelphia region for research comprehensive care and quality of life initiatives.

And she also is one of the Davis Phinney grant recipients for the Diversity PD initiative that you'll likely hear more about today. In addition, there's Fredericka Waugh and she is the faith-based Faith-based liaison with the Parkinson Council and the Diversity PD initiative. She's responsible for collaborations between the Parkinson Council and Faith-based Institutions. Fredericka retired in May 2020 from the Alzheimer's Association, Delaware Valley chapter where she worked as the Associate Director of Diversity Inclusion. And currently, Fredericka is the program coordinator and lifestyle change coach for the CDC Diabetic Prevention Program, to prevent type two diabetes. That was a lot of words there, so hopefully I didn't say it too fast because she has so much, so much experience. Next is Sandra Coplin. If you want to give a wave Sandra is 66 years old and she is living with Parkinson's and one of the PD movers. And she also has stage three chronic kidney disease. She was diagnosed with Parkinson's several years ago and is a proud member, as I said, of the PD movers and contributed to the PD mover's book, which tells their stories. Sandra credits Faith in her family as the motivation that keeps her moving through any trial that she encounters.

And next, we have Anita Parker. She is the director of community outreach at St. Luke AME church. She's also a licensed social worker with over 30 years of experience working in

multicultural communities with individuals and families. Additionally, she is a member of the PD movers as well and has served on several community boards that address health disparities and social justice issues that impact communities of color. And last but not least, we have Dr. Nia Mensah. She's an associate professor at LIU, Brooklyn's DPT program where she is an in-house fitness for but where she, where there is an in-house fitness for PD program. Her passion is working with adults and children with brain-based disorders, and she is a member of Mount Neboh Baptist Church where Dr. Johnny M. Green Jr. Is the senior pastor. Nia has worked with Teachers College and CUIMC health initiatives for people with Parkinson's over the past three years as she is passionate about reducing health disparities in the black and brown communities locally and abroad. And then of course we also have Dr. S Shah, who is our kind of facilitator for today, and she did a great job introducing herself. So, I don't think I need to redo that introduction. But with that very, very quick those very, very quick bios that we also have on our website, by the way, in case you want to reread them and know better. I will pass it over to Dr. Shah for, to get this conversation going.

Hiral Shah:

Great. And so just as Kayla pointed out, I think you know that we have a very diverse, experienced group of women, I should point out, that are directing this panel today. And I wanted to start as we always should with our person on the panel who's living with Parkinson's disease. I always think it's so critical that the voice of the individuals that are dealing with this illness be put front and center. And so, Ms. Coplin, if you don't mind sharing with the group, you know, how does faith play a role in your life? I know that we've discussed this extensively, but if you could share with this par the participants today and I think Ms. Coplin, you're muted.

Sandra Coplin (Member and Contributor, PD Movers):

I'm so sorry about that, everyone. Yeah. So, I was raised by a single mother who raised my sister and I to be God-fearing to people. And I've carried that through my life. I was a member of the church in the Bronx. I live in Connecticut now, but I was a member of the church in the Bronx during all my school years. And after that, when I moved to Manhattan, I was attending St. Paul's church. I've never been a member of any committees and so forth, but that strong background of faith and belief is what has started, from back in the early days and taken me through to this current time. It has led me to be strong, do some very difficult deaths of children and the family diagnosis of cancer with children and the family.

So, when it came along from my diagnosis of Parkinson's, it was shocking, but by no means anywhere near what some of the other tragedies have been. And again, this is where faith came in. It has never led me to question why something has happened or why is this seems to be a continual thing that we go through in life. I believe that the trials are just a part of my journey through life, and I handle it the best I can, and I've found that that has been helpful. And I don't foresee where there could be anything more difficult than some of the things that I've dealt with involving children. So, I kind of feel that anything else I can deal with and that all



comes from the strong faith and belief. And like I said, my worship doesn't only come from an institution because since I've moved up here to Connecticut in 2020, I have not yet joined in the church. Partially because in 2020 the covid was the outbreak and so forth. But that didn't bother me at all because my faith is within me and that has helped me through all of this with the Parkinson's and gets me through each day.

Hiral Shah:

Absolutely. Thank you so much for sharing that. What I'm hearing is that faith for you has been a steadying force despite any obstacle that you might face. And I think we all know that we all face challenges and obstacles and there are factors in our life and family that serve to uplift us and give us that inner strength that we all need. And for you, it seems that faith has played a central role in that. Yeah. And I just want to underline that you state stated that you may have had a church in your life before, even though there may not be the institution of the church. Those values and principles remain important to you today.

Sandra Coplin:

Absolutely.

Hiral Shah:

And as a healthcare provider, it reminds me that when I'm considering an individual before me, that's facing an obstacle and a challenge that it behooves me to inquire about whether someone has faith or spirituality in their life and whether that can be something that provides them strength. Because of course many people come to the doctor when they're in a period of difficulty. But one thing that we know Ms. Parker, is that they don't always come to the doctor for a source of support, but they may instead turn to their church, which is a place of information and trust within their community. So, I wonder if you could speak to that and in terms of the role faith plays in your life, but also faith plays to the Parkinson's community.

Anita Parker (Director of Community Outreach at St. Luke A.M.E. Church):

Well, faith for me started way back when, when growing up and I was always in the church. And then my mother died when I was 10 and my aunt had to take five children in a home. She had no children. So again, that faith walk, knowing that family was there, the church, St. Luke AME church, the church I belonged to, still belong to was there to help us as children. And again, going to school, life changes. And again, like mentioned before, struggling sometimes with my faith because that happens. But all in all, going to school, getting my education, and giving back to the community, one thing I learned about faith is that if you receive, you have to walk and share. And that's what, as a social worker I did, you know, all the different fields. So, people come at different levels. I may have met someone when I was in high school, but now they reconnected me in adulthood and they say, you have not changed.

Not letting titles, anything. I'm just a humble servant. And once you realize you're a servant, the community, the faith, you walk, and young kids see how you walk. Some people talk the talk, but don't walk it So I'm always conscious of that. So, dealing with health and faith together, I realized I could make a big difference when I return. I was in Florida, I lived in Florida for a while and I did the one church, one child, I said whole different. And then Yankees coming down here telling us what to do, and that's what I was called. But again, I was accepted. Trust in the faith community is very important. Trust in the church and outside of the church, the community have to see you and accept you. So, working with health issues, the main thing for me, because of my life experience with health.

So, I was able to collaborate my faith and health together and work with people on different levels. Parkinson's disease is another way of connecting with people. I saw it in my church, I saw it in my community. And one of the doctors who I work with in HIV and AIDS with children adolescence, he said, I got something. I want you to try to do this application, and get your church involved with this. I said, okay. I didn't know what topic they were going to do, but when I got there, met Dr. Shah and Dr. Lynn, and I connected. It was a connection there, I guess kind of experience. We connected and we began and I began doing some research and sharing information that's happening in my church and my community and what I saw. So that made me want to stick to what we had.

One of the assistant ministers, Reverend Minsk, and we had a nurse, normal husband who's passed on, died. And when the transition came about, I still felt that this is important. We came into the church, we had focus groups, people at you don't know who you're going to meet, you know, like I, they may not have, but they may know somebody. So again, the numbers kept increasing in our focus groups getting ready to talk about it, they women brought women from housing developments. It was an open and the pandemic came, we didn't stop. And that's the beauty of being seen in the community. You did not leave us. A lot of people said that when he had our first health fair, Nina did Mount Neboh. I just St Luke and people said, you are still here. And they came. And that's important with Parkinson's disease. We got to get the message out here in every venue. We are now doing work in the interfaith groups in five different barrels, talking to the faith leaders. We are being asked to come and through health fairs just come and talk and we are available. So let people know Parkinson disease is very important to us and our community. We must educate.

And that's one of the things I find that working with Parkinson disease and working with the community, educating them, it's very important to making people know what we can do to help others and prevent Parkinson's. You know, help people to live and thrive with it. Because that's important too, because sometimes doctors may say, that's it.

Hiral Shah:

That's right.



Anita Parker:

So again, thank you.

Hiral Shah:

So, Ms. Parker, I think I just wanted to highlight some of the things that you shared in terms of when we work together. I still remember your words that you said that we can't start in the community with Parkinson's disease. They won't come. We have to start with brain health. And I think that I was very recco cognizant that I needed to follow your lead when I was going into the community because you as a faith-based leader, have that trust of the community. And as you said, people will move, you have to model the behavior for the rest of the community. So, they see you coming out, they see that you're not afraid to talk about this. They see that you're open to learning. And that is a model for the community itself because you're a trusted partner. And as you said, you know, we are also we're sure to educate that that's where we've started and educate and empower. And the more information we share, the more that the community wants to learn. So, I wanted to bring in some of our other experts that have expertise in the community. So maybe Wendy, if I could invite you to join the conversation in terms of how have you worked with faith-based organizations to promote Parkinson's disease or health as the CEO of Parkinson's Council.

Wendy R. Lewis, MNPL (Chief Executive Officer, The Parkinson's Council):

Thank you so much, Dr. Shah. And thank you for the panelists on here sharing your, your expertise and your life experiences. So, the way that we've used, our way that we've partnered, let me just say it that way. With faith-based communities and understanding that being trusted members of a community, particularly communities of color we understood that in order to be able to share our information or be able to learn more about the community, it was important for us to actually reach across that particular part of the organization. That faith-based organization was incredibly important for us to be able to develop a relationship and develop trust even with the faith-based organizations because just because they're sitting in a church, just because they're sitting in the community doesn't necessarily know mean that they're going to automatically trust who you are either.

So, it was actually helpful for us to be able to develop, develop those relationships with the congregants, with the leaders. And we're so thankful that Puerto Rico Wall, who is a part of the one first faith-based community organization that we went to Salem, was so helpful that her minister, her pastor understood the importance of having a place at the table when we have these conversations about educating community members about a disease that goes often underdiagnosed or undiagnosed in the African American community. So, it was important for her to be at the table to be able to share what the experiences are for her congregants, what the level of understanding they may or may not have about a chronic disease that will impact, maybe impact some of their family members. So, our importance was to develop that



relationship first within the leadership of the particular institution, the faith-based organization, and then to help them help to translate that information to their own folks. So, it's not just about like, here's to tell a bunch of information, can you send it to your congregant? It's understanding for us as well to learn about what congregants may know or not know about a Parkinson's. And then also what we can do to support them is all about empowering, engaging them in a level that empowers them about their own mental health. So, it was important for us to do that as a group.

Hiral Shah:

Yeah, that's so important. As you said, it's a collaboration and a partnership. It's not about organizations or researchers or medical providers going into the community and giving them things or asking for things in return, but it's really about uplifting the voice of the community and having a seat at the table. And I think that's a perfect moment for Ms. Waugh. If you could speak to your experience with working with Wendy's team as well as more broadly. Cause I know you've worked in the Alzheimer's space as well in terms of faith-based organizations promoting health.

Fredericka E. Waugh, MSW (Program Coordinator and Lifestyle Change Coach, PD Movers)

Yes, thank you so much. It's been a pleasure to work with Wendy and the Parkinson's Council through my church, which is Salem Baptist Church of Abington. And I have a pastor that is open to being sure that the congregation is healthy and open to the information. So, he has allowed me and appointed me, so to speak, to speak for him and to also bring in the information. So, we're still in the process of doing all of those things. And we are planning to do some type of workshop around brain health and just, you know, because it's important that people understand where this is coming from. As you know, frequently when you ask, well do you know anyone with Parkinson's? People say, no, then that's because they don't know what Parkinson's is. So, we know we have to go back and do this education and to allow the congregation to understand.

And for me, it was the same way with Alzheimer's is a disease and oh, you have to, you know, people have to understand what it is. And so since there are so many neurological diseases we are going to focus on Parkinson's disease, but we're going to bring in some of the others so that people can understand and make the connection and you know, and then that will hopefully increase the numbers of people that will come in and talk with us and understand and have a, you know, an experience around what are these neurological diseases. And yes, they probably will then say, I do know people with Parkinson's disease. So, the collaboration has been really good and continues to be really good.

Hiral Shah:



Yeah, that's right. So, it sounds like there's, there's an importance not only of education, but also recognizing and aligning one's priorities that, you know, what are the priorities of the congregation or organization in the community, which is of course health. And people are, I keep hearing they're concerned about mobility, they're concerned about falls, they're concerned about their memory, and people may not be aware of Alzheimer's disease or Parkinson's disease, but once they come to know about it and learn about it, they're hungry to learn more in a way that is approachable and impactful that they can understand how it affects their everyday life. So, Nia I'd love for you to jump in at this point and speak to some of your work that you've been doing at Mount Neboh and beyond in terms of the role of the faith-based organization and health promotion.

Nia Mensah, PT, DPT, PCS (Assistant Director of Clinical Education, Long Island University Brooklyn's Physical Therapy Program):

Oh, well, thank you. It's an honor to be here. I am more of a newcomer. I give honor to the leaders in the community that have been doing this for decades. And I will want to say this just out the black church has been the cornerstone of an African American community since the inception of African American communities in the United States of America. So, the black church has continued to bring leadership political leadership information the cornerstone of the black family. And so, it is no different today. I know it's; it seems to be watered down with the climate of social media and all the things we see in negativity we see. But the black church is still the cornerstone, so it only makes sense that they're leading the charge with healthcare and breaking down the walls of health disparities in the black and brown community.

And so, like Ms. Waugh, my pastor is very passionate about educating the community. He started a coalition of pastors to impact to help educate black communities, not only in New York City, but in other cities in New York, in other states to help bring awareness to conditions like Parkinson's and other brain-based disorders so that we can get early diagnosis. I think that's the continual pro, the pro problem in our community. We are diagnosed late in many of these instances. Personally, my connection with working with the faith-based community how it got tied to me as a physical therapist was when I first got really saved and born again. After college, I really took to the mission field with a group of therapists PT students. And that was, it was then where I was connect.

It was clear to me that my purpose was also not only to share the good news of Jesus Christ and his love, but also to share my knowledge as a therapist and the position that my family and God has placed me in to be upfront and honest about what is available to our community and so that we can break down these barriers. And so, the great commission is gone ye therefore right to baptize and teaching others and making disciples. But we don't have to go across, overseas. We can do this right in our community. And I think the black church continues to do that with the sick and shut-in list with people that are not able to get out of their homes. And that's the case with a lot of people with Parkinson's. There is some, there's, it's come down, but there's



still a stigma about movement disorders or even postal stroke or something that is limiting movement where many people are not necessarily comfortable with people seeing, physically seeing that there's a challenge going on.

We're very private people, you know, especially people that are not part of the community. So, I think that is part of the challenge when you're working with movement disorders. And so, the black church continues to go out in the community. The black church continues to reach those people in their homes. And I think that's maybe a good place to start as we continue to grow these efforts by reaching those individuals that can't, that may not be able to make it out to church or to the health fairs so that we can have a globe more of an impact.

Hiral Shah:

Absolutely. And I think you speak to even the folks that maybe can't get to their medical appointments, but the church is still committed to reaching them. So, it's about reaching, engaging, and empowering. And I think that the church is so well positioned to do that and is doing that work. I mean, I know that I remember Wendy, we had in a previous conversation where I think that Covid brought this to light, given that we saw that our faith-based organizations were doing this work. They were already out there, they were already engaging and reaching the community. And me, I want to just highlight something you said about stigma. I think that often in many communities, it's the norm to stay quiet about conditions like Parkinson's disease, Parkinson's conditions where many people may have different abilities, not so many disabilities. And it's a prideful community, much like my community of the Indian community. So, I think I can definitely relate to that. And I think that engaging and empowering is one way to address that stigma. But Wendy, please add to that conversation. I saw you came off mute and I was just trying to wrap up my thought.

Wendy Lewis:

No, I love that. And I appreciate that. I think that for us as an organization, we typically would like to think of ourselves as enter the intergenerational in a lot of ways, interface collaborative and in a sense that we tried to make sure that other organizations that were working in space also have a voice and a place at the table. And it's, and it, and it can be a very difficult conversation when everybody is, has their own needs and they have their own wants and they have their own activities, I think. But once we put the clients, the community, the family at the center of that work, it becomes a lot easier for us to work together because we're building towards the same mission, which is to improve quality of life, to create a pathway for communities of color, black, brown Asian communities to access healthcare high-quality healthcare, like those with more privilege and more resources available to them.

So, once we are all on the same page, bringing in people from different faiths, different backgrounds, and different beliefs are a very easy thing to do once we set aside our own needs to be front and center of these projects. So, I'm so grateful to have all the folks on the screen



doing that and being a voice and being an advocate. Cause that's what we think that the church actually allows us to do a little bit more of. And as, as you said, that the, been the cornerstone of this work for hundreds of years since we've stepped foot on this on the continent, and it's a way for us to be able to get not just the information, the news, the resources, but it also is a, it's a word of a lot of word of mouth of who's doing well this way.

And the goal for this group is to make it through maybe a little bit more public so that people aren't afraid to speak up when they need that help and care and support. So yeah, I think definitely we don't want to ensure, we want to ensure that everyone has a place to the table has a voice and that we also actually believe that having organizations, faith-based other organizations have the internal structures available to make sure that those resources get, get into the right hand. So, the infrastructure has to be in place as well. Just throwing out a bunch of information and not having someone who is willing to filter and promote and just or distribute is as important as anything else.

Hiral Shah:

And I think that so much of what you just described is mirrored in the PD mover's book and approach. So, this is exactly why it's been successful, is because we got out of the way, and we let the people and care partners who are living with this condition take front and center. We allowed the book to uplift their voices and blend validity and credibility to their experience. And we've created a tool that has legs, it moves on its own, we can now share it. And it's allowing this type of conversation, which I think is not so common about the role of the church or the role of faith-based organizations, but it's allowing for that conversation to happen. And not only that conversation, but so many more because we've put the experience of the person at the center rather than thinking about how do we educate the community.

So, I just put that as another plug for others that are listening to consider always including the patient's voice and the care partner's voice and allowing that to take the lead to dictate priorities, themes, concepts that are critical and important to the community member and putting our own ego and priorities aside. And then once that's done, the work does, you know, happens itself. And we've used a similar approach that's mirrored in the church with giving testimony. This is exactly where the inspiration for even the packaging or concept of the book came from. Because we sat in the church and at Brain Health talks people and often would stand up and give testimony spontaneously. And it was such a beautiful expression of hope, optimism, and the way that people in the community challenges when they face them. So that's where that came from, from the church.

And so, it may not be the same in all communities, but that's why you have to go into the community, listen, listen, listen first, and act next. And so, we then have used word of mouth, just as Wendy pointed out, that's the best way that this message gets out. And when people hear about the resource from a trusted individual, they pass it on. And so that's allowed us to not have to do the hard work of spreading the word. I went to the Unity walk this weekend and

was walking around to the various booths asking or just mentioning, if you haven't heard of the book, I'd like to share it with you. Oh, we've heard of it. We already know it. We have it. We have it, Anna. So, it's just so wonderful. So, I wanted to now invite the whole panel now that we have this wonderful start to a conversation for the next few minutes. If we could speak to, you know, how can faith-based institutions, communities continue to serve as a space that's a safe space that creates community and that creates connection for those that are living with Parkinson's. So, I'll open it up to anyone that would like to jump in. Maybe Ms. Parker, if you don't mind, I can pick on you.

Anita Parker:

I think most important that they're having access to get into the church and every church as far as the ramp, whatever they need, the access is there for people living with Parkinson needs to be there as a challenge in some churches, but it can be done with support. I mean, especially in different communities, they have organizations will help the church set up that system where they could put a ramp in, could have access and also lower levels where they could have a fellowship or not walk up the steps. There are some, I have talented. So again, those are the things I know, and I've observed that made a difference. Sick and shuttled less visit phone calls even every day, a lift of encouragement, a word I, that's something that I do. And it's so important. You can't imagine how it just waking up and seeing someone's thought about me.

Never send me a text or a phone call ministry or presence. That's what I would like to see more of. Even with now with food insecurity and the children, making sure it's not just for parents. Because sometimes parents lock that cabinet. So we as a church have to go out there and be out in front of that on our corner with our little goodies for the snacks with the parents because they can't afford to buy the snacks because of the economics of this country right now. Those are the things make a difference. That's what I would love to see more of in giving them information. Why are we passing out the snacks? Here's the PD boo's book. Read it, share it. And we have a multicultural community that is waiting for it in Spanish and other languages. So again, but the children will read to their parents, to the grandmother, to the cousin. So that's what we foster. They know that we are there for them. And then if more churches will just do this, it's not going to hurt. They paid light and gas bill anyway. They might as well do it. That's the way I see it. <Laugh>, that's what I'd like to see more of. Outreach. Okay. Thank you.

Hiral Shah:

That's right, Ms. Parker. So, I think you're saying that, you know, the church often bears witness to these challenges that individuals are going through, and I think that even as healthcare providers, organizations, individuals, and families, we need to recognize the importance of that being that steadfast source of, of faith and bearing witness to some of these challenges is also important. But that these types of resources might get into the hands of people that need them, not just from the adults and older adults in our communities, but the children. And so, we have to think about the community and as a family or as families and what their needs are,



not as individuals. Ms. Coplin, I wanted to invite you to comment again on what, what are your, some of your thoughts as a person who is living with Parkinson's?

Sandra Coplin:

Well, I'd like to comment and include in that answer my grandchildren. I have two grandchildren seven and 10 years old. And it's important that they know too, and that there's not a fear. Like, so if they see me with the tremor or if they see me walking slowly, you know, they're very outspoken. They will ask a question and say, grandma, why are you moving so slow today? But it's very important to get them informed as well and accurately informed through media. Like you had sent me some books that you recommended that spoke to children about Parkinson's because there should not be a fear when they see some of the side effects maybe or witnessed some of the side effects. My grandchildren have not seen much, but you know, as time goes on, they probably will.

And I like knowing that they are informed at an early age where absolutely Cynthia, and they can communicate that they were very, they were included in the book. Their little pictures were part of the PD movies book, and they were just so happy to see themselves. But in terms of, they were only interested in my story, unfortunately, but it's a way it was done so well. And Randy's illustrations, the book was just so, the color and everything just drew your eye to it, that they immediately picked it up and that that definitely is something that we can think of and should be thinking of. But our generations down the road, hopefully by the time they're much older, you know, the situation will be better medically where people are able to be helped a lot more.

Hiral Shah:

But educational material, you never know who it will reach, right?

Sandra Coplin:

And unfortunately, they don't have the strong faith background that I have. You know, the generations, unfortunately, some of us I raised my son in the church and so forth, but they're not raising their children per se in the church. Which again, as I said, I don't believe that that's absolutely necessary. But I do believe that the practice then has to be in the home. And so, I find myself, because I watch them in the afternoons when they come from school, I just bought, offered a pearl of grandmotherly wisdom to talk about certain things with them. And I just feel that when it comes to faith that they're told that to have that passed down from one generation to another. And if that's being skipped by the parents, then I look forward to doing it myself.

Hiral Shah:



Thank you for sharing that. Ms. Waugh, could you maybe, or Nia, I'm sorry. I saw Nia came off of Mute.

Nia Mensah:

That I just wanted to piggyback on Ms. Coplin. Specifically, you asked the question about, you know, what can we continue to do? Well, conversations like this is, I mean, just so important. So, continuing to have the conversation, like not just stopping would be my first thought. And then the second thought, because I remember the brainstorming conversation when PD Mover's book was birth, and it was a conversation about how we can engage. Ms. Parker, I believe, is on that conversation. So, was about how can we engage our community and how can we share? And we talked about culturally African American, we are storytellers and Ms. Copeland, that's what you're doing, you're sharing with your grandparent grandchildren and how fortunate are they to have access to you directly to get the glean the wisdom that you have on a regular basis. And I say that to say it was that conversation that I was fortunate to be a part of because of my ancestors and what they went through to allow me to be in a position, to be a PhD candidate at Teachers College to share about my heritage and what the African American community looks to and what will help build trust.

Not just coming to do something and then leaving, but to build a relationship. And I think that is what has happened. And I'm so excited to see how vision has manifested into this beautiful illustration of storytelling and the conversations happening. And I think representation matters. That was just going to be my biggest point. Having people at the table from every level, people with Parkinson's, African Americans, medical providers, African American researchers, African American aids, African American church workers, and having the relationships at every level because that is going to be what will be carried on down from generation to generation so that the playing field is even. And then we can break down some of these barriers. So that was what I wanted to piggyback off of Ms. Coplin, what she's doing, and how she's sharing wisdom. It is that wisdom that will be continued to be passed down and that is the representation that we need as we continue with these conversations.

Hiral Shah:

Thank you, Nia. So well said. Ms. Waugh, can, I'd like to invite you back into the conversation from your perspective.

Fredericka E. Waugh:

Well, I think what Nia just said is very true. And what all of the people on the panel have said, we have to bring in the community. So therefore, they have to trust us as an organization, as a church, and as a congregation and we have to be able to have the resources, we have to know who is in the medical community and the information community when it comes to Parkinson's or any of the other neurological diseases. So, if they're going to, in order for them to look



toward their faith in through their church, they need to know what is there. They need to know that they can trust the fact that we have the information. We may not be the experts in the field. We may not all be the doctors and the movement specialists, but we can hook them into that.

We can share that information with them. And so that is what, you know, we are trying to do at, at my church and the churches that I collaborate with through the Parkinson's Council. Yes, it's about allowing people in the community, the faith-based community, as well as just the physical community to know that here's a place where you can get the information, here's where you can get some of the answers. And if we don't know every little thing, we do know whom you can call, we can refer you to a doctor, refer you to Jefferson Hospital and the social worker there. And so, we, those are the kinds of things that churches need to know. We do, like Mrs. Parker, were saying we have the food banks, and we have all these other things. In fact, one of the ideas is to put maybe the PD mover's book as we are passing out food, you know, on Thursday afternoons.

Just give them a book at that time because we have to begin to talk with them and have something that they can hold in their hand and read. Our pastor is very much in love with all of the children at our church, so this book is going to be wonderful. And if he passes it out to them, they will read it and they will begin to learn. So those are the things that I will have a discussion with Wendy and with Marshall Mitchell about, is how can we get this into the hands of the people that are going to help us understand what is Parkinson's disease the same way that we worked on what is Alzheimer's disease, you know, and I know it can be done, but we have to keep working. It's not easy work. Wendy knows it's not easy work.

Ms. Parker knows it's not easy work, but I'm willing to do it. And I know everyone here is willing to do it, and you just have to keep, keep doing it. Little, little pieces at a time. But I think when it comes from the church, and especially when you have a pastor like we have who is very inspiring, who is out in the community, you know, like the pastor at Mount Neboh, they're out in the community, all of the C communities, he's here in our suburban community and he lives in Philadelphia. He's with the Philadelphia community. And so those are the things you, you need. And when you have someone like that, it can be difficult to catch up with them to have them work in these, these areas with you. And that's why he appointed all, all of us to do the work. However, we know that sometimes he's going to have to step out. We need to see his face. And so that's the other thing that Wendy and I work on is getting him out. And with the other church that we work with right now, we're getting ready to do a program that's Sunday with Enon, and Enon is one of the largest churches in Philadelphia. So, you know, we, you, you have to keep pushing little at a time. It's not always the way you want it to be, but every little bit, every little step helps.

Hiral Shah:

Absolutely. you said that all so beautifully. I was trying to mentally take notes, but I think you touched on and almost summarized the conversation that we had, the importance of trust, the importance of education and empowerment, the importance of having a seat at the table, the importance of communication and being present and consistent. And with that in mind, you know, on May the sixth Nia, we have our fair coming up at Mount Neboh Church where we'll be having conversations about cognition, brain health balance, we'll have yoga demonstrations, hopefully some music. And then May 20th, we have the health fair at St. Luke, a m e church in partnership with St. John's. And we're so excited for those events to continue to spread this message because we know the church is a place where people come through trusted information and when they'll, when they're feeling vulnerable.

At the end of the month, we'll be at, or excuse me, not the end of the month, but at the beginning of next month, we'll be having a tabling event at the event for Michael J. Fox, PD, and IQ in Delaware. And thank you to Wendy for reminding us of the importance of that event. So, we can bring the books there. And in the summer, we'll be at World Parkinson Congress in Barcelona. So, you know, we are going to continue to do this work with PD movers and we'd invite anyone to join us or reach out to us to collaborate and partner. I do want to, I know we only have five minutes left with this really rich conversation, but in the event that there's questions from the pa participants that we wanted to get through, Kayla, did you want to maybe bring up one of the questions and we could see if we could squeeze in a few more nuggets of wisdom from our panelists?

Kayla Ferguson:

Sure. It's I know, I feel like we could keep talking for such a long time and there actually was a question we wanted to close out with, and six minutes is not enough time to do this question justice, but I guess it, hopefully, it can maybe leave people with some action items because I do know one of the audiences for this webinar and this webinar series is people who recognize the need to outreach to these communities, but maybe haven't necessarily figured out how, and they might be asking, oh wow, faith-based communities are such fertile soil for education and for the community. How do I reach out? Because I'm also hearing in this webinar, so much of it is relationship-based. You know, you all have done so much relationship building over decades, even to kind of like build this network within these faith-based communities. So, I don't know if there's an easy answer to this question, but for people who might be sitting there saying, this sounds great, I would love to do this. How do I get started? What would be a suggestion of how to take some of those first steps in building those relationships or really kind of cultivating that network, if you will? Which again, hopefully I've given us this much time for that question.

Hiral Shah:

Parker, I hear, do you want to go ahead, Ms. Parker?

Anita Parker:

Yes. Yes. One of the ways it's person-centered. I have to say that because if you go into that, hear the message and you hear what the people, the different things they're doing and feel, stay after. And if they have a fellowship moment and introduce yourself, introduce yourself, come back again, what can I do to help and take baby steps? But it works. Coming back to New York, when I came back, it was baby steps going back into my church and I went in, they had a ministry going. I came in, I listened, and I, you know, they said, welcome home, but I'm here to work, not just to come home. And people in the community can make a difference by just going into a faith community or if you are in a faith community, joining one of the ministries listening to what they go do, what they have, do, serving whatever it takes, doing something holiday, come up, help with the feeding of the people, anything back through the Sunday school, books, folders, anything, anything you could do to begin to do baby steps to do, make a difference in regards to working and educating people about Parkinson's Disease and other health issues that impact your community. Thank you.

Hiral Shah:

And I'll just say from my point of view that, you know, it's better to give than to receive. So, start by just listening, listening, listening. You'll learn a lot along the way. While you listen, you may be provoked or feel the need to say something but resist that urge and just keep listening for a long time. And, you know, for instance, for, sorry, my but one thing I would say is also read the PD mover's book, share it, and see what happens. And I think you'll see the magic in taking this type of approach.

Nia Mensah:

And I was just going to add, God looks at the heart. Don't worry about, you know, anything from your past, what you look like. Your, the church is a great place to start, but it doesn't have to be the church. It can be a community center, it can be a senior center ho a senior home, you know, and just, you know, just remember that it's not about the outside, it's about what you feel in your heart and let that lead you.

Fredericka E. Waugh:

Yes. I want to just add that our senior center has been renovated and so they'll be opening a full-time in a few weeks. And so, I plan to, I am a member and I plan to be there and just taken those baby steps that Ms. Parker just mentioned and start talking it up. Because that's, you know, one of the pubs they have, you know, about a hundred or more members and they're not, you know, some, most of them are from the church, but not all of them are. So it is that is a place where I know I can, you know, stick my nose in and open my mouth and start to do this work there.

Hiral Shah:



I wanted to take, I see the time is two o'clock, and I also just wanted to un bath behalf of the PD movers and our whole team and all of the panelists that I've gotten to know over the last few months and weeks. Thank you all for your time and sharing with us. And thank you for giving the time and space to share this work about the PD movers. You know, I feel that I found the work that I've been meant to do, and I can't tell you how empowering it is to be able to be authentic and spread this information and knowledge with others. And I hope that others have found this series as moving as I have.

Wendy Lewis:

Thank you, Dr. Shah. Thanks, Davis Phinney, for this and the lending space for us to be able to share this information. Voices heard. So, thank you for including us, I appreciate it.

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