



PD Movers Webinar Series:

PD Movers: A Tool for Building Trust, Awareness, and Empowerment in the Black and African American Community

Davis Phinney Foundation

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

Jackie Hanson (Program Manager - Audio and Video Producer):

In 2021, PD Movers invited a group of black and African American individuals with Parkinson's and their care partners to develop an educational guide for Parkinson's, designed specifically for the black and African American community. This group of Movers includes doctors, researchers, and teachers from Columbia University, Irving Medical Center, and Teachers College Columbia University. What came from those initial gatherings is a beautiful storybook filled with narratives of African American and black individuals and care partners who are living and thriving with Parkinson's. The following webinar is the first in a series of three where you will get to meet the Movers of this storybook and advocacy coalition and learn how they have been removing the mysteries and misconceptions of Parkinson's in their communities through storytelling and more.

Claudia Martinez (MD, Hispanic Community Engagement Manager):

Hello everybody. It is my pleasure to be part of this first webinar of the series and learn a lot more about PD Movers with a wonderful group of panelists. And I'm going to get started by asking them to introduce themselves. So, let's get started with Dr. Shah.

Harold S. Shah (MDS, Columbia University):

Hi. Good afternoon everyone. My name is Harold S. Shah. I'm a neurologist and movement disorder specialist based here in New York, and I work out of Columbia University.

Claudia Martinez:

Thank you, Dr. Shah. And welcome, Denise.

Denise Coley (Founder, Enable Your Vision)

Hello, everyone. My name is Denise Coley, and I'm a patient with a person with Parkinson's. I was diagnosed in 2018 and I'm one of the PD Movers.

Claudia Martinez:



Thank you, Denise. And now let's welcome Wendy.

Wendy Lewis (Chief Executive Officer, The Parkinson Council):

Hi, everyone. I'm Wendy Lewis. I'm the CEO of the Parkinson Council in Philadelphia. I've been in this role for almost 13 years.

Claudia Martinez:

Thank you, Wendy. And last but not least, our gentleman in the panel. Go ahead, Bernard.

Bernard Coley (Founder & Principal, RBC & Associates, Morgan Hill, CA):

Hi, I'm Bernard Coley. I am a care partner first, and after that, I am also an activist who is working on engaging indigenous and minority communities worldwide.

Claudia Martinez:

Thank you, Bernard. And well, as you saw, most of the people who are here with us today are curious about learning more about PD Movers. And I'm going to ask Dr. Shah to get us started by learning more about what Peter Movers is and how the idea of Peter Movers was born.

Harold S. Shah:

Thank you so much, Claudia. I'm so excited to share this work with you all. So, it's certainly been a long journey, you know, to tell you a little bit of background of what led to this project, I'm the product of Indian immigrants. And growing up I witnessed healthcare disparities in India as like many of my Indian diaspora. We would travel every year to India. My father was a physician. So, from a very young age, I had a lot of great curiosity and appreciation of issues of health equity. As I completed my training, it became very obvious to me that in Washington Heights and Inwood, despite being nestled in a very diverse community full of ethnic minorities, our clinics did not represent that. So, I was really eager to try to understand why that was the case and what we could do about it.

And through a series of leadership and training opportunities, including one that was organized by Dr. Martinez when she was at the Muhammad Ali Center, she led the Hispanic Outreach Leadership Conference. And there I learned about her many amazing approaches to engage with the Hispanic community. And one of the approaches that she shared with us was the Promotor project, which included the development of a flip book with a fictional family and utilizing that as an educational tool to engage and empower individuals and families with Parkinson's disease. So, I came back to New York with those ideas percolating in my mind and met Ms. Anita Parker, who is the outreach director at St. Luke, a church in Harlem. And together approached her with this challenge of how we improve engagement of minorities in Parkinson's disease care. And we first had to take a step back and recognize that we wanted to



start with brain health, that in that community, it was important to begin education and empowerment.

Not with Parkinson's disease, but with just brain health generally. So, we started to have a series of brain health lectures that were very interact. This spawned other relationships in the community at tenants associations, housing projects as well as senior centers. And over time, we built our relationship-built trust and began to have yearly health fairs to further engage the community, and later did focus groups. And Ms. Parker taught me that what we needed was to conduct a training for care partners about Parkinson's disease. And what really was missing was the individual's journey with Parkinson's from the perspective of African American, black, and brown individuals. So, we brought together a group of individuals, which we later named the PD Movers. So, they're individuals and care partners who are African American, black, and brown, affected by Parkinson's disease. And our mission is to develop culturally sensitive educational information and establish a network of trust and support.

And so that's kind of how the PD Movers were started, and it led to the development of the storybook. That's really been just such a beautiful project to see come together. It's a compilation of first-person narratives that include really vibrant images that underscore the importance of representation combined with these authentic voices so that you can learn directly from the individual rather than a physician or other healthcare professional trying to educate the community about Parkinson's disease. So hopefully that will get our conversation started, and I'm eager to have the others jump into

Claudia Martinez:

Yes, this wonderful start. Thank you, Dr. Shah, for giving us all that information. And first thing that comes to mind is something that I many of us have heard when outreaching to underrepresented communities, and it's the fact that many times we're told, oh, it needs to be somebody from the community doing the outrage or being front because that's a person who's going be easier, doing easier to trust of everybody. But Dr. Shah is not that case, right? You are not part of this community. And I'm curious to know or hear from people from the community who are in the panel, what things, or what steps or what is that Dr. Shah did that helped her win that trust in your eyes and in the eyes of the black and African American community. So, who would like to,

Bernard Coley:

So, I'll handle that one because I, this is one of, of the ones that I really like to talk about. So, the way to say it is, what, what do I think were the important things that Dr. Shah did leading up to this project and the, and the wonderful outcome we are achieving? So let me start by saying this I have a slight disagreement. Dr. Shah is part of the community. In fact, the steering community that we lead on engaging the black community. One of the things we talk about is the black diaspora. And we like to define it this way, included in the black diasporas, all those



who are treated like they're black in the United States. And clearly, Dr. Shah falls in that category because what we're really talking about is the conditions under which we work, live, and play.

And Dr. Shah falls in now, but there's an important piece, and that's where I'll start. So, the first thing I'll say was important about the way Dr. Shah proceeded is she was willing to check her ego at the door of the community. And let me explain why that's really critical. Dr. Shah sort of hinted at it, but Dr. Shah has an impressive resume out graduate or prestigious institution. She has all the credentials you need to talk about brain health and Parkinson's disease, but that was not going to solve the problem. There are plenty like that. Okay? And to her credit, she recognized that at the door and said, maybe I have something to learn, to be culturally sensitive, to become a resource, not to be the spokesperson or to tell you how to do it, but to become the resource I need to sit down and learn.

So, point number one was she checked her ego at the door. Second thing is she was willing to be led by a trusted member of the community. Mrs. Parker was there; she'd been a practitioner. She'd been talking health in the community for many, many years. And Dr. Shah was willing to say, okay, I'll let you tell me I, and I won't tell you everything about what I've got. I'll just listen and come along. So, she became, and it's an important thing, a collaborator. She worked with Dr. Parker. She treated Dr. Parker and those around her with respect for their expertise. So maybe she knew more about than anybody else about Parkes's disease, but she understood and respected the fact that they knew more about how to reach the community. And if the goal is ultimately to uplift the community, raise awareness, and do hope, it doesn't really matter what everybody else's credentials are, what matters is how do we get there?

How do we get the goal accomplished? The third thing is, not only was she willing to be led by Dr. Parker, but she also joined Dr. Parker. So, when we talk about how you earn trust in the community, Dr. Shah said this was years in the making. And that's right. That's a very critical step in reaching communities. You must be present, but not one, and done not throw up a webinar, not, okay, we're done. I don't, you should know everything about. No, you have to be there month after month after month, year after year after year. Because quite frankly, this is human nature. You're not going to trust someone who simply shows up and tells you what you ought to be doing. That's just not the way people are built. So human nature is, I, I, you know, I want to really understand and believe that you are committed to this.

And Dr. Shah showed that. And she didn't just show it by being there. She was willing to admit where she didn't know, and if she made a mistake and willing to adjust and willing to follow along. And those are absolutely critical and often missing in initiatives to engage the community. And I'll say two more quick things. I mentioned that she valued and respected those she worked with as peers and for their particular knowledge. Well, let me take it as a step further. She also recognized and valued that no one is better at explaining the PD journey in communities of color than members of the community of color. And so, she has made her



mantra to uplift the voices of those in the community, to state their own priorities, to say what's important to them and to, and to identify what their needs are.

So rather than the voice of the practitioner, the service provider saying, well, this is what PD is and this is how it impacts you, and this is what it's going to do to your life, she says, no, what's more, important is, and the result is the PD mover's book, the voices and the stories of those who are in fact, the actual experts on the subject, their lives, their stories, their needs. So, I want to commend her for earning the trust of the community by being there, learning, opening up, being receptive, and going beyond simply the technical expertise of the disease. And she didn't say she wanted to continue to just tell people what PD is. She said, no, I want to become a trusted resource when you need me. You can find me. You can come to me. I'll be right there waiting. But I'm willing for you to tell me what's important. And I will step forward with my resources to assist, to help, and be there.

Claudia Martinez:

Well, thank you. Thank you, Bernard. I think that you pointed to very, very important aspects of building trust and also representation. And PD Movers is a wonderful example. And actually, Sarah just posted on the link. So, for those of you who are not familiar yet with PD Movers, then you can download the PD Movers book. So, make sure that you check it out or click on the link, so you have it available. But as we move forward with this discussion, I would love to hear when this point of view on these important topics that Bernard taps into when the, what has been your experience in outreaching, and what has been the challenges that you found that also those key points that have helped you open the doors when, you know, trying to outreach to the black and African American community in the Philadelphia area?

Wendy Lewis:

Well, thank you, Claudia, and thank you for Bernard for like really synthesizing what it means to be part of a community and how to build that trust in a community. And Dr. Shah, obviously, thank you so much for, you know, just your hard work and dedication and stick to this in this process. So, I'm, and speaking from the behalf of the Parkinson Council, sitting in a community which has about a 46% rate of people of color living in the region. And that, and that reach that region ranges from African Americans to Hispanic, Latinos Asian it has been a challenge for organizations to reach different communities with different messages that resonate. And so, one of the things that we talked about as an organization is that as we partner with these big institutions that we consider like really very strong partners, Penn and Jefferson and Moss, and, you know, all these amazing groups that are doing this work that are just doing it every day, is that we realized that sitting in a community with a majority of people of color and having a waiting room that doesn't represent that people of the people of color, was an eye-opening experience for a lot of our partners.



And I think all of that resonated for us during the summer. I call it the summer justice Summer of 2020 when we realized and recognized that there were some systemic barriers to care to, in, within these institutions, we realized that you know, whether it's access to appropriate insurance or the right insurance or transportation or, you know, just even understanding Parkinson's, we knew that there was something that we could do better. And actually, helping first for us to learn who the community is, where the community is within our own, within our own systems, and also to like look and reflect back on how the community sees us. So, it was really important for us to do that deep dive, be really reflective about the fact that where all these have these institutions that have all these resources as all this expertise, they had a little trust from the communities they were trying to reach and serve.

And so one of the first things we looked around when we created this group called the Diversity PD, which stands for the Delaware Valley Endeavor for Racial Solidarity in Parkinson's disease, which thankfully to the Davis Phinney Foundation, we can do some of this really good important work, this vital work because we're a grant, community grant team, is that we realized that the first thing we need to do, educate ourselves because we wanted to go in and guns blazing. This is what we have, you need it, you'll take it, and then everybody will be fine. And it just did not work. It hasn't worked for years. And so, what we realized is that we had some people that were missing from around the table. We had those faith-based leaders that were trusted in the African American community, the Latino community, and the Asian community that we had not done any really real outreach to or any real, you know, sit downs with or hearing what their issues were.

And so, what the first thing we needed to do was to reach those trusted members of the community. Even though we had all this expertise, we had movement disorder specialists, we had nurses, we had outreach coordinators, nurse navigators, social workers, we had every single member of a comprehensive care team that was trying to do this work. And they couldn't really get to the point where they could do the work in a way that was viable or even sustainable over time. I mean, yeah, they put money into like, you know, providing outreach coordinators or you know, somebody who can get out into the community and into the education. But it was really kind of a fit and start, you know, somebody will do a little program and they'll come back into the institution and then they'll do another little program and they'll come back to the institution.

And the institution put tremendous amount of pressure on those folks who are doing that kind of work. Like, okay, well we're investing in this and, but where are the people that you're talking to? Why aren't they coming here? And so, it became really clear that it needed to be done over a sustainable long period of time, that it was a, an opportunity for those institutions to listen to what those communities say they wanted, not what the institutions thought they needed. And so, it does take a lot of time. And so, after two, almost three years of doing this work, it is, we see, we still see these gaps that exist in terms of how we are communicating not just among ourselves, because I think we all want the same goal, but how we're communicating



because things, in times things shifted, I think the pandemic really shifted a lot of people's mindset, you know, if, you know, isolation happened.

And so now not only do, are you dealing with the physical, the veer the visible aspects of Parkinson's, you're also now dealing with some mental health issues from social isolation. So now we have to shift our language and I, what are we going attend to now? What is the thing that we need to, you know, be most aware of related to these communities? Depression and anxiety already exist in a lot of these communities. And when you're ping on a chronic disease, how are you, how are you communicating those things of, of what you're able to provide to both respond to their Parkinson's? And then there are mental and emotional needs. And so, we're shifting a little bit, A lot of the folks that we initially relied on, which were the moving disorder specialists, they're there, but we know that the social workers are now front and center of a lot of that work.

You know, when you're talking about, you know, working with care partners and how care partners are able trying to navigate these, not just what's happening to their loved one, but what's happening for them as well. We're relying on the nurse, we're not relying on social workers to be able to come back to us and say, this is what we're seeing. This is what they're saying they want, and how are we going respond to that? So, while, you know, Parkinson's is so many layers and tears to, you know, how Parkinson's impacts families, you know, you have to be on the lookout. You have to listen, and you have to be aware of what the community is saying they need over any given time. So, it will, you have to keep an open mind, you have to be able to keep an open heart and you have to like to be very aware of what's happening within your own community.

So, I really commend Dr. Shah and, you know, others on this screen for all the work that that they're doing to make sure that there's a holistic approach when dealing with Parkinson's. It doesn't Ch but it, but it's not a one and done it constantly evolves, and you have to keep on top of what those needs are within the community, which means that you have to put yourself in a position to be able to listen and be available and be present and be authentic. And that's hard because people want to, you know, solve things. When you're in this position, you want to solve it. And sometimes the answer comes from that community. It doesn't necessarily come from your lab or your clinical social, you know, or your clinical, you know, research or it, it will come from the community. They'll tell you exactly what the things are that are important to them and how you respond to that. Did that answer your question, Claudia?

Claudia Martinez:

Yes, Wendy. And you touch on so many important points and I'm really happy that we are getting comments and in the chat saying, you know, how interested different participants are in learning more about this topic. So, we are also really gr grateful that we're not going just have this opportunity, but two more webinars that are going take place, you know, in the months of February and March so that we can continue talking about this important topics and how we

can, you know, do a better, better job when trying to outreach to diverse communities. And Wendy, you ta you talked about the importance of listening and also giving, giving the people the opportunity to say what, what their needs are how we should approach them. And I think that's part of the beauty of PD Movers as we've noticed before, that this is the voice of the, of the community, the voices of real people living with Parkinson's and with their families as well as their care partners. So, I want to ask Denise, because Denise and Bernard are one of the couples whose story is part of the PD Movers. So, I want to ask Denise, what or how first, how you decided to be part of this project and what's the value that you think that all these stories have when you know, they were put together in PD Movers?

Denise Coley:

Well, I have been a Parkinson advocate shortly after my diagnosis, and I've been doing a lot of talks and webinars and I actually was on a webinar with Dr. Shah, and she was talking about her thoughts and what she was going to do. And so, it was a natural synergy and we got together and started talking and we went to the meeting. And the thing that I had to say touched me most as a patient or a person with a Parkinson's, you come to the Zoom meeting and the whole screen is full of faces that are black and brown. I have never been in a single meeting where there are that many people who have the disease or are community members or care partners. It was a touching moment for all of us, which never went away. And that's probably the only time I've met that many people who are people black and brown.

But most importantly, it falls into what everyone else has said before. It's about trust and communication. And so why would I want to do this? I want people to know that there are people who look like them, who can get the disease. Parkinson's is an equal opportunity disease that doesn't care about your age, it doesn't care about your ethnicity, it doesn't care about your sex. You might get it or one of your friends might get it. So, it's really important to go to the community to have conversations, to talk about Parkinson's so that they can help people have hope and have quality of life. So, when I thought about my story, I thought every story in that book is genuine and authentic according to the person who said it, because each of us has Parkinson's, but each of us has different aspects of symptoms or reactions to Parkinson's and it changes over time.

And that's the beauty, the fabric, the cool, the tapestry of the PD Mover's book. We're seeing all these different individuals personally sharing their stories as they live through Parkinson's. And each of us had different reactions when we first got the diagnosis, I told the doctor that he gave me a death sentence. Other people said, well, during the journey I looked about several linings and having hope. So, it was a beautiful collaboration to look at it. And it goes back to, if you can't share and tell it to other people, how will they know that there's somebody there who's suffering, who looks like them and can give them good advice through their life experience? So, each person in the book took their life experience and told the stories of different things that happened so you could see the diversity in it. And then on top of that, we

had Dr. Shah who talked about the symptoms, the medical, what you should do, what are miss, what are not miss. So, you have one nice educational tool or handbook, whichever way you wanted to look at it, that can take a person through the Parkinson diagnosis, what to expect, what you can do, and hear personally from the individual. So, when I look at it's important to first tell a story. All of my meetings that I've had before Parkinson's and after, we always have the first couple of minutes where each person tells their story. So recently I've been going out with people in the last few years. I will tell my story, then they have questions, then I say, now you had to tell me your story. And that really brings a good com camaraderie and collaboration. So, if we look at the PD Movers tool, we're telling our story, why is it important?

Because in the black community it builds trust. But another important thing about stories is culturally, there are a lot of cultures that storytelling is so important and is oral history that is carried from generation to generation. This book is an oral history of black and brown people with Parkinson's. So that is a good way to come into the community. Second of all, when you go to the community, you go in with someone who is actively engaged. And that was Ms. Anita Parker, who is a social worker and with the church. And she bought the church and community in through her faith-based organization. And through her job as a social worker. Then once you have everyone together, you can't just tell them, you're not going go in there and sell lemonade if that's what you're selling. You want to know what is going on. So, when you go into the community, you tell your story, they tell their story, they tell their needs.

So, you're there to listen and learn. And once you establish the trust, continue to come back so that they know that you'll come back again and again and work together to bring the information and resources and help people in the community know what is so important. Because when you get that Parkinson's diagnosis, at least for me, I had this moment like, okay, so I thought it was a death sentence. They said, you can have a good life. What does quality of life mean? What do you have to do? So, there's stories about exercise, about food, about hydration along with the medication that you take. So, it is really important to have in one place everyone talking about the different aspects so people can relate to what's being talked about. And then last, once you have that trusted relationship with the partners in the community, you can come back and give more information and hopefully that they'll pass it on.

The greatest hope for us is that this book started out as an eBook. Anybody could get it in distribution, which makes it livable. I've had friends from all different cultures ask, where can I get the book and when will the hard copy come out? Because I'm sharing it with my community because it's so important. Everything here and one page one book that shows culture. And so, as a need that is really great. I'm thankful that all my peers also tell their stories because it's a difficult thing to sit back and think about when you got the diagnosis and the journey you've been to this point. And it takes a lot for some of us or most of us to share the most personal instances so that others can have hope. So, my greatest part of it is the value of telling my story and hearing everybody else's story, and that people will know that they can live well with quality of life and have hope with a disease that's not curable.

Claudia Martinez:

Yes, thank you so much, so many valuable things that you've shared with, with us. And then one of the things that that I want to point to before I forget is that in the chat, besides the link to access to the PD Movers, you can also find some social, social media pages that are also important in order to continue learning and sharing about PD Movers. So please don't forget to check those. And also, I want to share that for net the next webinar, we will invite the illustrator who was part of PD Movers. And I think that that that was also a really interesting approach and very successful approach to have this person to be part of the project. Dr. Shah, would you like to share a little bit about it?

Harold S. Shah:

Yeah, sure. And so, in terms of the illustrations and the entire production of the book, another thing I just wanted to mention is that it was really important for me that it was collaborative, and everyone was included from the start. So, from our very first meeting after we planned and invited the participants, we had a video producer and an illustrator all on the call from the first meeting. And so, they observed that powerful moment that Denise described when everyone looked around the zoom room and saw faces that looked like themselves. And I think we all felt like something really special and powerful was happening. There was such a powerful moment of a sense of connection that happened right then. So, and from the printer as well, we wanted to support, you know, a black printing press so that from start to finish the project was really built around identifying that as the community partnership.

So, in terms of an illustrator, it was also through word of mouth. But, you know, I looked for instance, like on Etsy, on different platforms for illustrators that might be appropriate. And when I saw Randy his work, I think it really resonated with me because the images were so lifelike and you could, it brought the person to life. And having illustrations allowed us to tell a story in another layer. So, you could have the images of the individual in the church, you could have the image of someone in a hospital bed with the picture of their family at the foot of their bed, and how the hospital room feels a bit cold and isolating. And I think that the pictures became another character. As a part of the PD Movers, we also included a little shadow figure that some may have noticed in some of the illustrations, which was thought to be a metaphor for Parkinson's disease, where it becomes like this extra person that somehow is in your life and has become this intruder.

I think many of the PD Movers shared how there was this uninvited guest that now was a part of one's life. And I think that having that shadow was another way to communicate that. And I think that, you know, people have looked at the storybook and some people start with the pictures. Some people are the pictures are what draws them in, and it makes them curious and wants to read the book. And I think what we keep hearing over and over again as this resource has been shared is that it's a 62-page you know, item, and people read it from start to finish. And so, to have someone reading an educational resource I think it speaks to the compelling

nature of the images, of the authentic voices in the stories. And that's really what's made it resonate and relevant.

And when we, you know, you read the literature about community-based participatory research or community engagement and how that really increases the relevance of the item to the community, I think this is that in action. But I do want to say it was not easy. So, I don't want people to think that you could, even if you go into the community and you listen and you have all of the best intentions, as I think I do and many of my colleagues do, of course, we all want to help. But I think that we have to recognize that I made a lot of missteps as well. And I think I was very open and willing to admit, you know, that I needed to learn to. So, there were periods of time where there were lulls because some of the participants, I think naturally as Denise said, it's hard to share your story and be vulnerable.

So that took time for us to develop that kind of trust and relationship where someone's willing to talk about that really low moment where they were diagnosed and maybe on the floor crying because they didn't want to take their medications or you know, the moment where they admitted to their doctor that I, I'm not taking medicines for whatever reason, and these are not moments that are easy to share. So, in some cases, you know, some of the stories poured out of the members and others, we had to, it took time to cultivate that trust and ability to share. So, I just, I also don't want any of the listeners to think that it happens overnight or easily. It takes time. And we of course made our own mistakes, and we continue to make mistakes and our learning. But I'm trying to be open and even if I'm like, oh my gosh, I don't think I can do it. I keep making these mistakes or I'm, I might have upset someone, or maybe we could have done this better. I think it's important to start the new day and say, okay, you know, what is our mission? What is it that's driving us to continue this work and how can we take it forward? So

Claudia Martinez:

Yes, thank you Dr. Shah. And as you said, the book itself, even if it took time for the stories to be able to be, to be shared, I think I've heard in one of our previous conversation that just the fact of having the book, I think it was ese that said that it makes it so much easier for some people to start those conversations because some of the, some of the people who have been diagnosed with Parkinson's many times even doubt or take time for them to be able to share the diagnosis with their own families and to involve the younger generations in their families. And so, the kids, the people who, who have young kids or who have teenagers this has in any way this this book being a tool for them to approach their own family in, in your experience.

Denise Coley:

I'll go and answer that one because I wanted to follow off on what Dr. Shah said. The job that Randall did is the best that we could ever think of. I had not personally talked to my grandchildren about Parkinson's, but with the book, I could take the book with two at a time, two at a time about Parkinson's and starting with the eight-year-old and the 11-year-old, they

went immediately to the pictures, and they went through the whole book, and they had a thorough understanding and asked one or two questions, and the youngest one walked away, but the 11-year-old read the book. Then we did it with the 13-year-old and the 10-year-old, the same type of thing. Taking the pictures that Randy had put out as a story base going through the whole book and then going back to read the book, it made a tremendous amount of difference. And it was much easier for them to understand the disease as opposed to, well, why grandma does this, that, or another. This is a very holistic way to do it. And it worked quite well. And I think that for people who are hesitant to talk to little ones, this is a perfect tool to use that.

Bernard Coley:

I want to add a couple in the series coming up, I invite you all back to webinar series two, where you are going to get to meet many of the people who told their stories. And I'm just going to throw one out on this topic, which I think is absolutely critical. We got many benefits out of the book that we, that weren't part of the original plan, not expectation. One of 'me was one of our members Mr. Smith has had Parkinson's for many years. He took the book with him to his family's holiday dinner and shared the book. And he, when he came back, he shared with us what an amazing experience it was as his brothers and sisters relayed to him that for the first time in the, I guess his 15, 18 years he's had Parkinson's, they began to understand what he was going through and why he wasn't communicating.

So, we are extremely excited that the communication isn't just reaching Under engaged communities, it's helping members of the Under engaged community reach each other, their families, the important people who will make up their care team, who will be there to help them out now that they understand. So, we've gotten this benefit out of the book that goes beyond the technical part of explaining to people what Parkinson's is. It's letting people understand what the Parkinson's journey is and allowing people's voices to come out. Mr. Smith got to talk the family, his voice matters now in the family, they understand more about why he is the way he is and what he has done and are able to express back to him. Not so much sorrow, oh, it's too bad you're going through this, but more we're there for you know we understand what we can do now.

Tell us what we can do to help in, in a way that's really meaningful. Not just, oh, I'll be there if you need me, call me. It's like, oh, now I understand a lot more. And for us, that is just extremely exciting. We've got communication going on, as Dr. Shah said at many levels. And that's been a beauty of the book, and I've tied us together with the illustrator. Denise and I have actually talked about this book in several presentations, and I actually don't go past the first page. I can tell you everything about this book on the first page because what I tell people is this cover itself communicates and speaks to our community without reading a single word. You see hope, you see our future, you say faith. So, several people ask, well, how does it bridge the gap?

Well, let's how bridge the gap it speaks in a language that we understand it's immediately gotten; we have a translator. We, you see everything about our community and that family, et cetera. On, on and on. It all came off of this initial picture. Okay? And it communicates things that are important. The story adds the story wraps around education, but this is critical. We're talking and if you're going raise awareness, you've got to get discussion going. So, a key bridge that this book has, this why we call it now a tool, is it's been a tool to open the dialogue, it's opened up the conversation. It's allowing us to talk about what hadn't been there before and what's there now, what things are needed in the community and why certain other professionals in the community are just as important as the medical profession.

Claudia Martinez:

Yes, definitely so many, so many benefits from this tool and we want to make sure that we give some time for the, to get an, the answer to some of the questions that we get in the chat. So, I'm going follow up with this one that relates to the book itself and this participant ask the book, the book is so beautiful, in addition to being informative and inspiring, how did you determine the format you use for the book and what is the importance of the visual language? And I think the largest just tap into, into the importance of the visual language as well as the needs. But then what about the format then Dr. Shah, or would you like to an answer that? How was the decision made

Harold S. Shah:

In terms of the format? I'm not exactly sure what the question is about, but I'll answer it this way. That we knew we wanted to describe the journey with Parkinson's from, you know, when one recognizes initial symptoms to getting the diagnosis, engaging with treatment and care, and then living and thriving with the disease. And that's kind of the general story arc that we wanted to take. Of course, everyone's narratives didn't neatly fit into those categories, so, but we started with what narratives we did have, and we went through and kind of would plug it into that so that it would make a more cohesive story arc from beginning to end. And we wanted to also make sure that we captured and emphasized certain themes and messages that came across throughout our conversations, whether that be the fact that minorities often face delays in diagnosis, which was exemplified by Mr. Huckabee's story, where he unfortunately, you know, went through many misdiagnoses and the frustration that followed.

We knew we wanted to emphasize the role of faith in the community, and so we made sure to highlight those aspects of the narratives because I think in the African American black and brown communities faith spirituality is such an important part of one's life, but also how one copes with a disease like this. And then we wanted to also be sure we included the care partner and their perspective and a variation of care partner perspectives, meaning like the spouse perspective, which Bernard provided, but also lo Ms. Lorraine Hay, who is the daughter and juggling, you know, living her life, working with an older mother who also needed her care. So we were, you know, it took a lot of conversation and again, collaboration of are we getting the



message right? Are we, is this sounding right? Is this resonating with the PD Movers? And I hope Bernard and Denise would agree that, you know, they, they would get a lot of copies of feedback and what, you know, we would had a lot of back and forth. So, but I think those were the general principles that we tried to follow as we put together the product.

Claudia Martinez:

Thank you Dr. Shah. And we have another question that asks as how do you include the community without overburdening them and being sensitive to the emotional toll that it could take to share these stories?

Harold S. Shah:

Yeah, that's a great question. So again, I think it's about listening and respect that you ask, you know, even what time of day should the meetings be? So, we had some meetings in the evenings and sometimes during the day to kind of try to get folks at that, their availability and being respectful where some people could contribute more at certain times, and there may be an ebb and flow. Some people life went on during this period, right? So, there were times where some people were d pr were dealing with an illness or a family member that was going through a medical problem. So, I think it's about just, again, listening, being respectful and going with the flow to some extent. And, but continuing to lead and keep things moving forward so that we also didn't want the project to kind of stagnate and languish but recognizing that there was an ebb and flow to how much people could participate in at different times. And I think that when people feel, and maybe I should let Bernard and Denise speak to this, but it seems to me that when people feel heard, they're more motivated and more willing and more interested in being engaged and it becomes a natural dynamic that evolves.

Claudia Martinez:

Thank you, Dr. Shah. And going back to what I think Bernard tap into, there's a question that asks, what change have you seen in your community with this tool? How have people of color living with Parkinson's improved their quality of life through the connection to this tool?

Bernard Coley:

Let me throw something out really quick. So as Denise and I have been on this journey working and trying to bring the Parkinson's awareness to our community, Parkinson's disease is not one of the big five in the black community. No hypertension, the heart, I mean, we just are not in the big five. So, you go in and initially, you know, nobody wanted to talk to you, what's this Parkinson's thingy? Whatever this book has opened the door to where the community health community want, sees the value of the tool, sees what it's doing, Parkinson's is now on the menu. So, the critical thing I want to say is that we've cracked the getting at the table with the big five, which he wasn't happening very well before because what you learned from this book



is more than just, again, Parkinson's disease. You learn about dealing with the generative brain disease, you know, the diseases with no cure people around you and how they are coping.

And that message exceeds just a Parkinson's diagnosis or a Parkinson's problem. It's how do we live, how do we go, how do we deliver the support that can be given. Raising the voice of people who, you know, for, who see themselves for the first time getting to talk. You know, I, you know, I don't want to criticize any other organizations doing to see specific work, but you know, a lot of people are making or have made the same mistake. They want to go into the community, tell 'me what to do, and there, and they're going. So, what this book has done is we hope that it will be a model. So regardless of what the primary is issue, the medical issue is that people see this is the way to get the conversation going. This is the way to inform people about how to have better lives. This is the way to help.

Harold S. Shah:

And just if I could just say one thing is Sure. One change I've seen even in my practice is just to underline, it's allowing people to feel like they're not alone, and it's allowing them to feel like they're part of a bigger community and they're connected. You know, I see general neurology patients and I can't tell you how many times after just sharing this more broadly to raise awareness about Parkinson's disease, people will come out and say, oh, my aunt has had Parkinson's for 15 years, or, my uncle or so-and-so has the shakes, or, but it's, and I keep hearing Ms. Parker's words that she would say that people are living in secrecy, that they don't talk about it, and we've got to get people to start talking about it. And so, I think that when someone like Mr. Smith, who's a football coach is a strong black man and is sharing his story and being vulnerable in talking about mental health challenges, I just think it opens the door for others to do the same. Right,

Claudia Martinez:

Definitely. And we have a question for Wendy in the chat, and it's it, this participant asks, have you introduced this tool, this Speed Movers tool into your work? And what have you seen happen with these stories in the work you're organizing in Philadelphia the Monday?

Wendy Lewis:

So, thanks for the question. So, we have shared that amazing book with all the members of our diversity PD group. They all are filling very excited to be able to take this as a tool first to learn themselves. I mean, it's a learning, it's a tool for the providers as well and the other community folks for first to learn and read those stories and hope it resonates when they talk to their, you know, their patients or their family members about the importance of having that support group to having, I think, think we've used it as a tool for education, but also creating that sense that you are not alone. That there are other people in the community here to support you, but



the hope that that specialist or that nurse or that, you know, social worker will say, well, I'm here too.

This is you. I am now part of your community. This is a tool to help you sort of see that there. That it takes a, for lack of a better word, takes that village and takes, you know, you can expand upon that village. You can include endive individuals from families. You can include part of your care partner team. You can include members of your church community or your, you know, your faith community to help support you. So that we've used it as a tool to actually have them expand their sense of awareness, those providers in, and allow them to open the door to have a conversation with individuals who typically may have been less forthcoming about their experiences. So, it's really been a tool for them to actually share, you know, what they've learned and also have the client, or the family members share what they're going through as well.

So, it is actually serves as a dual purpose for our group. You know, it is a not just a tool to give to the community, it is a tool for us as community to learn more about the work we do and how we can help and support families. So that's what we've done. We've introduced, and we're talking about a reach, if you're talking about sharing within the communities of Jefferson and Penn and Cooper and Temple, we're talking about thousands and thousands of opportunities for this book this tool to get into the hands of family members and people living with Parkinson's. So, they've, they've embraced it, they are excited about it helps open the door for conversation and it also helps us learn a little bit more about ourselves and how we can support the community as well. So, yeah.

Claudia Martinez:

That's wonderful, Wendy. Thank you for sharing. And also, we want to thank a lot of the participants who've left comments about, this series and including people from the Parkinson's Foundation in West Pennsylvania and our friends from the Michael J. Fox Foundation as well. So, we are definitely very happy to be able to put, put together this series and we want to make sure that you join us again next month for the second webinar. And we will definitely let you know or send you a reminder the fact that you register for this first session means that you will be automatically registered for the two following ones. So, we'll definitely follow up as well with the different links that we share today in the chat and we'll make sure that we are, get to answer any questions or comments that we weren't able to get to today.

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