



Raising Awareness and Hope in the Black and African American Parkinson's Community

PD Movers Webinar Two

Davis Phinney Foundation

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

Sara Linn (Ambassador Leadership Program Manager, Davis Phinney Foundation):

Hello and welcome everyone to the second webinar in our Raising Awareness and Hope in the Black and African American Parkinson's Community series. Today's webinar is called The Power of Story on using narratives in the Black and African American community to connect and inspire those affected by Parkinson's. My name is Sara Linn, and I am the program manager for the Ambassador Leadership Program here at the Davis Phinney Foundation. I am joined today by my amazing colleague, Gabby Dimotsantos, who will be helping me lead the discussion with our panel of storytellers here. Hi Gabby. Would you like to introduce yourself?

Gabriella Dimotsantos (Community Engagement Manager, Davis Phinney Foundation):

Hi, yes. Thank you everyone for joining. My name is Gabby Dimotsantos. I am the Community Engagement Manager here at the Davis Phinney Foundation, and I'm just grateful to be co-facilitating here with you today, Sara.

Sara Linn:

Thank you. With that, I'm going to invite our panelists to turn their videos on, and I'm going to kind of pass it off to Gabby to start introductions for us today.

Gabriella Dimotsantos:

Hello. Wonderful to see your faces again. Thanks for hopping on. So, I have the joy of introducing our panelists here today, and what I'll do is just go around the screen in the order that I see you and we'll see if it's congruent with the way that the audience sees you or not. And as we go through the introductions, I would love to hear a little bit about your story and how it has personally impacted you being involved with PD Movers. So, Mr. Kermit Smith, I have you first on my screen as our PD mover, if you'd like to introduce yourself.

Kermit Smith (PD Mover):

Yes. Good afternoon, everyone. My name is Kermit Smith. The first thing I'd like to do first is to say thank you to the host for giving us the platform to share what's going on in our lives as far as living with Parkinson's. And I often say, I mean, everyone knows Harriet Tubman was a slave,

Frederick Douglas was a slave, but they needed platforms to bring forward the plight of the slave and what it was like to come to Freedom. And that's what this does: gives me a platform to let people know that you can live, and you can thrive with Parkinson's, but it takes work. I mean, I'm 67 years old, next week I'll be 68. And I was diagnosed with Parkinson's in 2015. The first thing I noticed was that it wreaked havoc with my life, I didn't really realize that I had Parkinson's. My doctor said you need to go to a neurologist and be checked out.

I went to the neurologist, and he told me, he said, I think you have to beginnings of Parkinson's. And I ran away, said, no, not me. I don't think so. That's for Muhammad Ali and other people, I don't have that. Then I prayed for longer life. I realized the differences, you know, differences, the way I was walking, the way I was talking, the fact, you know I didn't have much of a tremor, but everything else seemed like it was off. My fine motor skills were off. And then I said, well, you know, maybe they have something here. Maybe I do have Parkinson's. And that opened up a door for me, a door to let me know that, you know, I was in for the fight of my life. I was in for the fight of my life. I wanted to succeed in life and do the things I wanted to do in life.

I need to learn how to have, how to fight, how to live with Parkinson's. And I often say I'm very mindful of the way I speak about it. I never say I suffer with Parkinson's. Never. I live with, I have a funny way, I have a, my own way of speaking about Parkinson's. I call Mr. Parkinson. I call Mr. Parkinson's because I have a healthy respect for him, but he plays havoc with my life. My job is to not let him do that. Find ways and means to not let him do that. And there's help out here for, you don't have to suffer with Parkinson. You can do whatever you want to do. Brought me the PD movement, my neurologist, she asked me to be part of the group that wanted, to bring awareness to the African, African-American, or community about Parkinson's. And that's right.

I love doing that. Anything that I help my people, I will do basically anything that helps anybody I would do when it comes to our people, I would do it, you know. Cause as first and foremost, my mother was an activist, my brother was an activist, and my sister was an activist. So, I'm an activist also. So, this, you know, being a PV is very, very important to me. Very, very important. It just, you know, it's just something that I'm born to do. And God gives us all something to do in life. You know, we find what we need to do. God gives us something to do. My job is just to be obedient to God and just do it. I'm very happy to be a people mover. I'm very happy with what I've been presented with today. Thank you. Thank you. Welcome for coming.

Gabriella Dimotsantos:

Yeah, thank you so much. And we're so grateful to have you here and share your story. It's so powerful and really appreciate your metaphor in naming Mr. Parkinson. I think that's such a nice way to kind of identify and separate that part from an identity. So, I think that's really powerful. Thank you. Richard, I have you next on my screen. If you could share a little bit about yourself, your story, and how it has personally impacted you being involved with PD Movers.



Richard Huckabee (PD Mover):

Well, hello everyone. It is a pleasure being here, and I'm just excited to be able to share my story because I'm just so grateful that I'm able to, you know, I wake up every morning with joy and gratitude, and thankfulness that I'm still here. I would like to definitely thank the Davis Phinney Foundation for giving us this platform. I would like to thank everyone involved and the PD movers because this is an outstanding resource and an outstanding book, and we hope to reach the black and African American communities so that they will understand that there's hope. So, we'll get into that. But like I was saying, my name is Richard Huckabee. I was diagnosed with Parkinson's Disease in 2013, but my story really started nine years before that time, it was in 2004 that I realized that something was wrong with me. I knew something was going on, so I went to the doctor and all I could say was, I just don't feel like myself.

I just don't feel right. So, he gave me a number of tests and said, you're fine. I would do that for the next nine years. I would be diagnosed with Lyme disease, vitamin deficiency, stress, and panic attacks. I would just have so many misdiagnoses during those years, being in two 13, my doctor was getting transferred to Florida. So, she said, we done tried everything, Richard. We done had you hooked up to machines, MRIs, everything. And I just don't know what's going on with you. But since I'm getting transferred and before I leave, I'm going to send you to a neurologist. I went to that neurologist's office and within the first 10 minutes of doing certain procedures, he had me touch my nose, touch his finger, touch my nose, touch his finger. He had me do this. He had me walk. Then he said, you have Parkinson's disease.

And I tell you, I was devastated. I was happy on one hand to know what was wrong with me, but I was devastated that it took so long because so many things had happened to me along that journey. I lost my job because I couldn't maintain, I was having cognitive issues on the job, calling people by the wrong name. I had an executive management position, so I had to do a lot of tasks, and I just couldn't remember. It was, I was freezing when I talk. I would hold a manager meeting with 40 people in the audience, and I'm leading the meeting. And you could imagine I'm the only black face in the meeting and I'm hosting it, and I'm freezing up there not understanding what's wrong with me, and having to tell them, I'm sorry, I'm going to have to finish this on email, and I'm going to have to call an adjournment to the meeting because I froze.

It was just devastating going through the nine years before I got diagnosed. It was just a whole lot more involved in that. But I was happy to get diagnosed. And the one thing the neurologist did for me, because he couldn't really give me any answers other than you have Parkinson's disease, he almost made it sound like it. I was doomed. But he said I will give you therapy. You could go get Parkinson's Pacific Therapy. And really that changed my life because when I went to that therapy session, what happened there, it was a drumming and exercise study that was coming up, and the therapist invited me to join that exercise study. And in that exercise study,

it was a group of people, other couples, and individuals, and we met, and we actually became friends. And this was in 2013. And still today, we are friends.

We get together for hikes; we get together for breakfast. We get together for birthday parties to celebrate with each other, and we talk. And from that connection, doors just started opening up. I learned about exercise. I learned about I should be going to a movement specialist or neurologist instead of sticking with my general neurologist. So, when I went to the movement specialist, and neurologist, the first thing that that specialist did for me was send me to a PD 1 0 1 class. Now, this was two years after I was diagnosed. I got sent to a PD one on one class. I talked about all kinds of resources available in my area from support groups, and seminars. It was just a wealth of information. And it was there all along. I couldn't understand why the general neurologist didn't know about that class. It was the same hospital system, but they just didn't talk to each other. The right hand didn't talk to the left hand. So, we was missing out on so many resources.

But this neurologist did something that I talk about in the book that really set, set me back. He prescribed a dopamine agonist. And that dopamine agonist had negative side effects on me. So, I want people to be warned about what dopamine agonists can do for you; it increases your dopamine. And what it did to me was give me compulsive behaviors. All of a sudden I started gambling like crazy, didn't understand why. And that behavior almost cost me my marriage, finances and so much more. But I was able to get a grip on it by getting help. I went to see a psychiatrist who told me about gambling Anonymous, went there, and tried everything I could. And finally, and speaking with my doctor, telling my doctor what was going on, he described something else, but it was still a dopamine agonist. He prescribed Ropinirole. First, it was Nepro, then it was Ropinirole, the same thing.

Finally, he took me completely off the agonist and my compulsion went away. But in the meantime, I had talked to lots of people telling my story, that particular story. And they were saying they had compulsion shopping, compulsion, sex addiction, porn, addiction, just whatever. They had the propensity to; they were experiencing it. And I was saying, talk to your doctor. It may be that agonist that's giving you these urges and let's get off of it. So, I definitely want, wanted to share that part of my story, but it's just so much. But the story ends in hope because throughout everything I learned about exercise, and I'm fortunate that I live in the city outside of Cleveland, where there's a wonderful facility called In Motion where you can learn about exercise, Parkinson's education, do as much exercise as you can, boxing, spinning related disease type exercises. It's just wonderful, a wonderful resource.

So, at one point I was going down, down, down, down, walking with a cane, couldn't drive, falling all the time, and having all kinds of issues. But because of the exercise I've built up and I'm able to do more than ever, I travel. Now I can drive. My wife used to think she would've to drive me around everywhere, but she doesn't because I'm driving her around everywhere now. So, it's hope. I have lots of friends. It's opened up a whole new world for me. And I'm just



having the best time of my life, even though I have Parkinson's disease, I'm keeping it at faith and just enjoying life. I think I went a little long, but thank you,

Gabriella Dimotsantos:

Thank you. You, your story is so powerful and really such a strong story of resilience and persistence. And so, I really appreciate you sharing that. And especially in this space where certainly there are others who are going to be impacted if they haven't already been impacted by your story and your experiences of that persistence with the medical community to say, it can be better, and I know it can be better. And then to finally be in a place where you're like, yes, it is getting better. That's really powerful. So, thank you for sharing that, and not an off-course at all. So, thank you. Dr. Shah, last but not least, I have you on my screen here.

Hiral Shah, MD (Movement Disorder Specialist, Columbia University Department of Neurology):

Thank. Thanks, Gabby. So, I'm Hiral Shah. I'm a neurologist and movement disorder specialist at Columbia University. I think some of you heard from me last month as we brought together Denise and Bernard Coley, who are two of the other individuals featured in PD Movers, along with Lewis, who's CEO of Parkinson's Council. And you know, during that webinar we talked about the importance of building trust. And I just want to kind of underscore that today that this work and development of the PD movers came after years of working with our partner, St. Miss Anita Parker, who's the outreach director at St. Luke AME. And she taught me so much about how we can best engage with the community. And one thing that I think along the way, as I would go to events at church health fairs, I saw what spontaneously would happen is testimony in church.

And it was often a way that individuals participating in our brain health discussions would share an obstacle or hurdle or challenge that they faced and their journey and how they overcame it. And that along with you know, one of my training experiences where I attended a leadership conference hosted by Dr. Claudia Martinez where she shared her work of the Proma Torres, where she had developed a flip book as an educational tool. But I think it was all of that put together that really created this idea of creating a book that includes first-person narratives, where you're really hear hearing from the individual, because obviously I don't need to tell you all, but how powerful stories of Mr. Smith and Mr. Huckabee are. And that goes far beyond anything that I, as a medical provider could do to educate the community.

So, I think that's why this tool, the PD movers has really taken off and, and been so engaging and well received, is because of the first-person stories of these remarkable individuals that you're hearing from today. And that coupled with the illustrations, I think it just shows us the importance of representation, the importance of the illustrations as another tool to tell stories and give you the emotion that's happening behind the words, which are so powerful. So, you know, I think at the beginning of this webinar, Gabby asked the question, how have we been affected by being a PD mover? How have we been changed? And I just wanted to mention that



for me too. It's been a very powerful and transformative experience. I've gotten to know the Huckabees, Mr. Smith, as well as the rest of the PD movers.

I've gotten to meet advocates like Wendy Lewis and others in the field. And I think that it's also just continues to enrich and inspire me to make sure that we do everything we can to empower individuals so that they can live and thrive. And I think that's one of our greatest missions is that everyone may not have access to a movement disorder specialist or even a neurologist, but if we can somehow get a tool like this into their hands and they can educate themselves and be empowered, then nothing can stop them from making sure they get the care and treatment that they deserve and need. So, I think that's the power of story, that when you share your story, it encourages others to open up and share their stories. I think many people are unfortunately living with this disease isolated and alone and feeling disconnected from others. And so, we hope to use the power of story to connect those so that no one feels that they're alone in this battle. That we are all here. And that we hear you, we see you, and that we want to understand where you're coming from.

Sara Linn:

Well, well really beautifully put Dr. Shah, thank you so much for sharing that. And thank you Richard and Mr. Smith for sharing a bit more about your story and, and what you've shared within this. And I think we're hearing a little bit about how that's really impacted you and, and you know, how storytelling can be so powerful for not only you, but for those around you. And so, I want to take us maybe a step back and hear from, from you, Mr. Smith, and Richard, just what really drove you to be a part of PD Movers? What really made you want to share your story and, and share those testimonies with others? Mr. Smith, I have you first, if you want to unmute yourself and share with the group.

Kermit Smith:

I guess the first thing that got me, that got me wanted to be involved with PD movements was my neurologist. She, she's a very, very, very important part of my, of my dealing with Parkinson. You know it's very important to get the right kind of doctor on your phone that you can work with. Could you get another, you have to have a bond. You have to have a feeling that she wants the best for you as much as I want the best for myself, you know? So, by speaking with her, she made me feel that I was just important, like anybody in the world, she didn't me know that she cared about me. She cared which direction my life was going to go. And she, she wanted the best for me. She wanted me to succeed in life. So, if she asked me a part of PD movers, I, let me first give you a little background.

I'm a person that I never wanted anybody to know I had Parkinson's. No, I didn't want anybody to know the last people that knew the better off I was. Cause that's just the way I'm very detective of me of, I coach football and I didn't want any coach to know I had Parkinson's. I went to the gym. I go to the gym every day. I didn't want anybody in the gym to know I had

Parkinson's. I go to physical therapy. I didn't want anybody there to our, although they, they had to know I had positive, you can't go to the therapy for getting the diagnosis. But I'm very protective of it. So, the, what really happened was that she let me know that I can't help anybody and that I let go of that. And there's something that's very important for African-American understand. I want, I'm very protective of the word psychiatrist.

I don't want to go to a psychiatrist, you know, going to a psychiatrist met, he's going to prove medications and he's going to make me feel like I have to survive these medications. So, getting a neurologist and a psychiatrist to work together is very important for the betterment of my, of, of my life. Now, I've gotten, I got followed psychiatrist that was very, very helpful. He didn't push any, he never pushed medication. Only once he said, he said, Ker, I believe that we could talk our way through. He's the one that he, he got me back into coaching football. He got me back into traveling. He got me back onto the world of life just by speaking with we, we would meet once a week and we develop a bond. I trust him having an allow and she trust to have a psychiatrist that you trust, having physical therapist that you trust.

It's all a family that are working for the betterment of me. So, becoming involved with PD rubs was a way for me to pick the mask off and share what, what I commonly call my experience, strength and hope with other people. You can't help anybody unless you let down the mask. Let people see who you are coming, let people feel who you are coming. You can help people. If you let people feel who you are, you can reach out to people. People feel who you are. They don't know who you really are. And that includes my family. Cause I remember going to Boston and being in a hotel room with, with my brother. So, people, yeah, I live by my social people never see me in the morning. They see me after I had my medication. I'm doing pretty good after I, my first medication.

But it happened in a hotel. My brother called me, and the medication didn't kick in yet. So, I was taking these little, small steps without having them breakfast. I was thinking about these little, small steps. He says, who floors? I said, I, he said, it makes you do that. I said, yeah. Said, give about 15 minutes, 20 minutes, and you see them differently. So, the lady, I had a little cup of coffee got kicked in. Now taking these long steps said, wow, that's incredible. I said that's what we do. So, it did. I opened up my family to the fact I nurse practitioner, she realized there was something wrong and she didn't know exactly what she know. The, a difference in my voice. She knows that I was dropping weight. She knew was my gait was off. So, she knew something was wrong with me. You know, I'm very lucky to have a sister like that, you know.

So, the bottom line is that if a, if a family disease and my neurologist and my psychiatrist let me know that the family disease, there's disease and people can help you. If they know what's going on, no one can help you. If they don't know what's going on, come no one. I suffer. You know, like heard to one time, you know, when the doctor did you, what happened, doctor, that you, you suffer. If you suffer peace, you don't stop suffering with yourself. Peaceful. So, I don't want something like that. I want people to know who I'm, and by letting people to know who



I'm, I can help people. Cause give prime example, a friend of mine called there, I an invitation to this, called them and said, doctor, said, I may have Parkinson's because wow, I get an invitation to this webinar. And my doctor told me today that may have Parkinson's.

He called me, he knows I have ps. So, I gave him to direction. He said, well, you know, go, go see what happens when you go to then get a second opinion and get a third opinion. Be show the diagnosis, but don't just fit on it and wait, be proactive. And that's what I learned how to do. I learned how to be proactive. You know, you see pictures up in the background. Those are my pictures of when I went to Egypt in 2018. I learned how to do things. I go to the theater, I to at least two times a month.

Sara Linn:

Yeah.

Kermit Smith:

And I learned how to take cause because I learned how to take my medication. I can't take it like I normally take it. I have to kind of change it around so that I can function at the theater and not have the action of I'm going down low. I can stay high, I can enjoy the show, very important. But you, you know, I have to learn how to listen, what they were telling me to do, to enjoy life. I've been, I'm planning to go to Ghana. I mean, I go to the gym every day. Like I said, I go to dinner. I mean, I live life. Life is a small worst thing. And I want to do the best I can to sing this song called Life as long as I live. And I better stop talking.

Sara Linn:

No, thank you. No, no, no. That was amazing. And I, what I heard and was picking up too, from what got you to the phase of wanting to share your story after not really wanting to share with others or be vulnerable in that, in that sense that you found vulnerability with really trusted individuals that you had built those strong relationships with through, through your physicians and, and through those, those individuals that you have really small one-on-one interactions with. I think a lot of our, our audience can resonate with not wanting to share this aspect of their life, but noticing once, it doesn't have to be such a huge you know, shout out from the rooftops, but just those small interactions that then lead to these bigger steps is, is so important. So, thank you Mr. Smith for sharing that. Richard, I'd love to hear from you. What, what got you interested in getting involved with PD movers and sharing your story?

Richard Huckabee:

Well, for me, it was a natural progression of events. As I stated, when I first went to a neurologist, he got me involved with the physical therapist who got me involved with the exercise study. And from the exercise study, I met people that introduced me to seminars. But



the seminars on Parkinson's was great, but they would only come once a year. What do you do in the meantime? Well, then one of the friends that I met in the exercise study told me about a place called in Motion. Then in motion was a place where you could get exercise at no cost to people with Parkinson's disease. And then from there, I learned and met more people and got in and got more contacts, and then started learning more about exercise research studies. So, then I started getting involved in exercise research studies down at Cleveland Clinic.

And from there, it was, it was wonderful doing those exercise research studies because it was like free therapy. I was doing psycho studies. I was doing a combination where you do exercise and cognitive at the same time. It was just wonderful. It was showing how good movement is. Then I started getting involved with the Parkinson's Foundation from there. And with the Parkinson's Foundation, I became a research advocate. And my specialty in research was exercise research. So, I was telling everybody about all the types of exercise researchers that you could do. Ken State was doing them, the veterans administration was doing them. We was just getting people involved in different types of exercises. They got exercises. Well, people, some people got a free, a free spin bite. It was just, it was just growing out of a movement revolution. I was moving. And then the Parkinson's Foundation representative told me about this organization called PD Movers, where they was trying to get some African Americans together to talk about their experiences.

And all of the studies I've been in and all of the support groups, it was just a small amount of African-American to know African Americans in the group, but myself or myself and my wife. So now I had the opportunity to get with a group of all African Americans. It was just something that was new to me, but so familiar that me and my wife jumped at the chance. And we loved it. To see all the black faces on the zoom screen, it was just unbelievable. And it just went with our pattern because we have become movers. I was involved with the Michael J. Fox races. I was involved with Parkinson's moving day. I was involved with Davis Finn, every victory count challenge. So, I was moving all along. And then the PD movers came along with all black faces. It was just unbelievable. So, I had to become a part of this, this movement, because it's just, it just fit. Movement is medicine folks. Movement is medicine. We're the PD movers.

Gabriella Dimotsantos:

Thank you. That's so wonderful. Thank you. And just such a beautiful tie to all of it in the name of the group. Oh, what a, what a wonderful story. Thank you so much. And,

Richard Huckabee:

And the illustrator did a beautiful job, and the writers did a great job editing it. It's just wonderful. You all have to get this book.

Gabriella Dimotsantos:

And Dr. Shah, I did get to speak with the illustrator doc, Mr. Randall Pearson, yesterday, and we did record our conversation. So that will be coming out as a supplement to this webinar series. And it was really powerful to talk about the impact of those illustrations. And I think anyone who has seen the PD movers book knows the feeling that you get when you see those illustrations accompanied by those personal stories and how moving that is. So, if you haven't had the chance to take a look at that yet, please do go do so. And then stay tuned for that recording as well. And before hopping into the next question, Dr. Shah, I saw you came off of mute, so I wanted to make sure you had space as well.

Hiral Shah:

Thanks. yeah, I just wanted to add and underscore, you know, as Mr. Huckabee and Mr. Smith pointed out, I think that something really beautiful that we were able to do is, you know, these, all of these individuals, the PD movers, they all have their voices and their stories. We just created a space where they felt comfortable sharing that. And I think we were very mindful of including members of the team that were representatives. So, we were all black and brown in that core team, including Ms. Parker, our outreach director and community partner, as well as the illustrator, Randy, and a videographer Caleb, which who's helping us develop some videos to kind of accompany the storybook. So, stay tuned for that. But just how important it is to see and recognize yourself amongst this group. And so again, we just can't underscore the importance of representation because it allows for people to build that community and trust and a sense of kinship.

You know, I wish we had recorded our first webinar. I think we all felt the magic in that virtual room looking around the screens of all of the black and brown faces. And I think we all felt like something magical was happening. And so, as you said, you know, even Randy, I think he brought his lived experience and so much that was unsaid to creating these illustrations that really resonate with the community that reflect the importance of family and faith. And that comes across without us needing to explain it. And I think that really resonates with the African-American, black, and brown communities, cuz we all have that in common. And again, just to say that when one person shares their story, it empowers someone else to share their story. And I think for the individuals that are out there that may be new to Parkinson's or don't have as much exposure or earlier in their journey, this can be a resource.

I know Wendy Lewis at the Parkinson's Council told me a story about how, there was a couple that came to her that was really struggling and she was so empowered to have this tool to share with them and say, look at this book, see the stories of other people that, and that might help bring you some hope, because as Mr. Smith said, everyone with Parkinson's can live and thrive if we allow ourselves to open up and connect to others. So, I just want to thank advocates like Wendy and others in the community who are sharing this resource. And you'll hear from Ms. Parker at the next webinar, because there's such an important role of faith-based organizations in storytelling and in reaching our communities. So, I think that that

connection can't, you couldn't, we couldn't have done it without that piece. So, part of the story also was the story of faith. And we'll talk more about that next time. So, I just wanted to be sure I added that piece in. And thanks again to Mr. Smith and Huck Huckabee for sharing that. If, if I might point out, I know that for Angela too, Mr. Huckabee's wife it was a really wonderful experience and I know that she may not be here or able to lend her voice, but Mr. Huckabee, I just wanted to remind you or ask was there anything that you wanted to share from Angela's perspective?

Richard Huckabee:

Well, Angela was really enthusiastic about the PD movers because she is passionate about reaching other blacks and African Americans that's affected by the disease and the, and that might have it, but not even realize it. So, she was excited about building the awareness in the black and African American communities and having this tool to talk and to introduce the topic. It's just a wonderful tool and she's really happy to be a part of it.

Gabriella Dimotsantos:

Thank you so much. And I just want to also take that moment with all of the power in how you've been sharing your stories. If while recognizing, being respectful of your time and want to have time for our q and a is just a couple of words or a sentence on what has been the result for you personally sharing your experiences and sharing your stories. What has that done for you? Yeah, Mr. Smith, I saw you come off of mute.

Richard Huckabee:

Well, for the first thing that has done.

Kermit Smith:

Is renew mother faith. God, I was first diagnosed. I was at, at a period in my life. I just lost my mother. I stopped working, I retired. I've been on my job 41 years. I was at a very low point, point in my life and then became a diagnosis of Parkinson's. So, I was crushing God. You know, why, why you, why you giving me this? I've done, I've done the things that you wanted me to do. And now you are giving Parkinson's, well, you realize, well, God give you Parkinson's. P byproduct of life. I deal with Parkinson's is, is my job. So, I wake up every morning and the first thing I do is thank God for the next thing I do. I talk to my ancestors, my mother and my father, my brother, and my great-great aunt. And I ask them all to empower me, to give, to help me to walk with them, not me. Walk, not them, walk with me, help me to walk with them. The next thing I do, I say affirmations. Cause Parkinson's is very, very tricky. Very, very tricky. Sometimes, you know, the day the Parkinson's wins, but most of the time I call the shots and I kill that, you know what? I may have Parkinson's in Parkinson's does not have me.



So, you know, I talk to myself, and I say, you know, I'm strong, I'm healthy, I'm disease-free. I can do anything I want to do. And I say over and over and over and over again to myself to become, it becomes a way of me taking back what has been given to my body and not, not triumph over me. Parkinson's will never triumph over his body. Never. I won't let it. And I'll fight, fight, fight now, keep fighting. Cause I know that's the way to has done. It reinvigorated me to want to fight and help others fight.

Gabriella Dimotsantos:

Yeah. Thank you.

Kermit Smith:

I'm a winner. We're all winners. As long as we keep getting up in the morning, we're a winner. Put positive affirmation that our, like we're all winners.

Gabriella Dimotsantos:

Oh, that is so wonderful. Thank you so much. Richard, how about you? Just a couple of words, takeaway on what this experience has meant for you.

Richard Huckabee:

Well, this experience has just really been fantastic for me, all inspiring. And when I tell my story, I think it inspires others to get involved and to keep moving because as the title states PD movers, we keep moving. Movement is medicine. And I just like everyone to know that there's hope. You can thrive with Parkinson's disease. You can still do things. It's not a death sentence as long as you keep moving, as long as you keep fighting. One of my daily mantras is every day I fight and all of us we're fighting something. I'm fighting Parkinson's Disease, but others may be fighting high blood pressure, diabetes, or something else, but if we keep fighting, we will have victory. And just telling my story through PD Movers has been all inspiring and I'm just grateful to be able to do so.

Gabriella Dimotsantos:

Oh, thank you so much. And we do have a few minutes to jump into q and a, so I'll go ahead and let Sara take the stage for that.

Sara Linn:

Yeah, thank you so much. Thank you both. Thank you all three of you for joining us today and sharing these really impactful stories and important messages. We're, we're so grateful to have the opportunity to share your inspiring stories and how you all live well with Parkinson's today. So, thank you so much. As we kind of start to collect some questions as a reminder, please feel

free to add any questions you have for our panelists in the chat. Gabby's bringing up the PD movers slide that has a QR code on it for you to scan with your mobile devices so you can download the PD movers storybook on your devices and get to hear more amazing, inspiring stories from others as we hear, you know, the ripple effect of sharing this with others is, is so important and why it's spread. So, as we kind of let you all take some minutes to collect your thoughts and ask some questions, we've seen a lot of really just grateful comments come through around, you know, what wonderful, inspiring stories. Thank you so much for sharing with-

Gabriella Dimotsantos:

Oh, it looks like Sara Linn froze that there, I think she's been having some challenges with her computer of course, in this moment, unfortunately. But just to build on that, yes, we would love to see any questions come through the chat. I'm so grateful for everyone's engagement. And we do have one question that we can start off that was from our last webinar that we carried into this one. So, for anyone who it feels appropriate to respond there was a question, storytelling, and asking if the book addresses, does address the African American and Latino population to know if Indians are included.

Hiral Shah:

So, I might be of Indian decent, I might take that one on. Although, you know, I've been hearing and I also identify as a person of color, I think that more important than the social constructs are likely our shared experiences and what we have in common. But I think that in terms of addressing the Indian community, I can speak from personal experience that, as I've shared this with my family, and I think that the stories resonate with them. Certainly, there are differences, you know, in religion or culture, but I think that the stories do resonate. That being said, my parents are actually in India. My father's a physician and he has been sharing the book with his colleagues. And it's interesting how each community reacts in a really interesting way and his medical school classmates are so excited to see this book.

I think it's so unique and its storytelling that it captures the attention of anyone. And they all are asking, when are we going to do one for the Indian community? They've already translated into Gujarati, so we're looking to figure out, you know, how are we going to share that with others, but also how can we develop a similar tool that addresses any of the specific concerns that may be unique to the Indian community. You know, and I think that just speaks to when putting together a resource like this. I think we had a period of where we got to know one another as a group. And I think we were all mindful of what the key messages were that we wanted to make sure we highlighted as we created this resource. And I think the key messages for me if I'm not mistaken, and, and Mr. Smith and, and Huckabee can correct me if I'm wrong, but the importance of representation; the importance of faith, the importance of family, the importance of this being a positive and optimistic resource that focuses on recovery, including exercise and other things that you can do and be empowered to take care of yourself.

So, I think that that is just so important as we try to help other communities develop resources similar to this. So, you know, I think it's always important to include the voice of the community from the outset, which is why we were sure to make sure that the publisher, the artist, the videographer, that everyone identified themselves as African-American, Black, Brown, so that we created, had that shared experience. So, there was that immediate sense of trust and comfort as people shared very vulnerable experiences for themselves and even sometimes shared stories that they had never shared outside of this group. I know that Mr. Smith, that was true for you. So, I'll let the others, you know, jump in.

Gabriella Dimotsantos:

Yeah. Thank you.

Kermit Smith:

You want me to go?

Gabriella Dimotsantos:

You don't have to have a response if it doesn't, if you don't have one, that's okay. Ok.

Hiral Shah:

Mr. Smith has something he wanted to say. Great.

Kermit Smith:

No, I think Doctor Shah hit it on the head. When I think about it, I think that is very important that we get this out to the community. African American community is very, very, they don't like going to the doctor if you mention the word psychiatrist, that's a no-no. When I, when I was having problems with my voice, for example, when I was having problems with my voice, they were, I was speaking like this. So, Dr. Sharp, she recommended that goes to LSBT training, I think it stands for Lou Silverman Boy Strength. And I learned how to raise my voice to learn how to speak. So, whatever's going on in your life, we have things that are there for you. If you just open up and know what's going on, that will help you, you know, so I'm very, very happy to be part of this. And again, I want to thank you all for the opportunity so I can raise my voice and let people know that there's hope out there. There are people out here that want to help you, but you got to first want to help yourself. And if you want to help yourself, people will come to your rescue. That's the way God works.

You let people know what's going on. God, God let's argued on door to God. The universe. The universe will give you what you want, but you got to tell the universe what's going on with you.

Hiral Shah:

And if I could just jump in and add on to what Mr. Smith said about, I think he's not alone and having this experience of being reluctant to seek psychiatric treatment. I think unfortunately mental health and mental health treatment is stigmatized across many cultures including the Indian culture. I know that in my family, mental health is something that is brushed under the rug. We don't discuss it. It's seen as a weakness. It's seen as something that you should just be able to overcome with yoga or meditation or which are wonderful modalities and can be very effective. But I just think it's so critically that we work to normalize this in our community, including Parkinson's disease. So that having people like Mr. Smith and Mr. Huckabee who are willing to share their experience, willing to speak openly about being a gambler's anonymous or being in treatment with a psychiatrist is so empowering for others who look to them and see a strong black man who doesn't appear weak, doesn't appear in any way to be someone that what you would think would be stigmatized or have any vulnerability or insecurity.

And I think that when we share our vulnerability with others, it really opens the door to allow them to be vulnerable and to recognize that these are issues that are a part of life and part of humanity and the fabric of our communities, and that we need to talk about them and connect people to the appropriate resources because there's no reason for Mr. Huckabee to have suffered for so many years. And if him sharing his story prevents even one other person from suffering alone we will feel that we've really achieved something wonderful. And I just noticed Dr. Grutman has a question in the chat, if you don't mind, I'll just take it on about applying this model to other diagnoses with negative connotations that isolate people and discourage pursuit of treatment. I think he absolutely. I think that this model of using first person storytelling coupled with educational material where the book is developed or the tool is developed, rather with the community in involved at every step to make sure that, you know, we as doctors and me, when I say we are saying the medical enterprise may be very well-meaning and think that the educational resources there are patient-centered or culturally sensitive.

But I think unless you have a person with that disorder in the room, you can't be so confident. So, I think it's a really wonderful model to destigmatize and normalize as well as validate and give credibility to the individual. So, I think by printing these stories in the book, I think it also gives so much credibility to the experiences of these individuals. And I think that's huge for the community at large, who feels like they can identify with that. But I want to be sure, I let Dr I mean, excuse me, Mr. Huckabee speak too. Cause I saw he came off of mute.

Richard Huckabee:

I know we're running out of time. So, I just want to say one, one of my things I would like people to take away is to become an advocate for your medical health. Because if you go to the doctor and they can't find what's going on with you, just request to see a neurologist yourself because you got to become your own advocate. If you find that they, they're prescribing the wrong medications for you, talk to your doctor, let them know if, if weird behaviors start

happening, you got to talk and speak up so that you don't continue with long. Like for example, they prescribe four Cobra Carbidopa for me personally a day. Then after two years, they jumped up to five. During that time, I was doing an exercise study. I went into the exercise study with that fifth pill in me and the study people was telling me, you look lethargic, what's going on?

I said, well, my doctor gave me an extra pill and said, let me get used to it. They told me, you need to not take that pill. Let's talk to your doctor. Let's get you off that pill. You, you're exercising. You don't need that extra dose. So, he took me off. Then he told me, if I'm going to exercise and let that be part of my medicine, then work hard at it, sweat. So, I started to work hard and sweat. So pretty soon I went from four carbidopa/levodopa a day to three. And this was in 2019. And I'm still at three because exercise is one of my medications. So become your own advocate and know that this is not a death sentence. That there is hope that you could do what you set your mind to do even though you have Parkinson's disease. Because as Carmen said, you may have Parkinson's disease, but Parkinson's disease does not have you. Thank you.

Gabriella Dimotsantos:

Thank you so much. What a powerful message. And Mr. Smith, I want to give you some space if you have any, anything you'd like to say before we do some closing up and some housekeeping here at the end.

Kermit Smith:

I guess the thing I like to say, again, I want to thank you for the platform for being to tell my story. And I hope and I pray, you know, I don't, I told you all before what's going, what, what's happening here is it's blessed by God. It can't fail. This, what we're doing here cannot fail. It's going to succeed, it's going to grow, it's going to get bigger. And we are all blessed by us coming the contract with each other. This makes us family, my family just got larger this webinar. I appreciate you all. There's anything I can ever do for any of you. Just let me know. I'll be good.

Gabriella Dimotsantos:

Thank you so much and thank you again, Mr. Smith. Mr. Richard Huckabee. Thank you Dr. Shah so much for your time in advance of this webinar and today in sharing your story, sharing your voices, and such important information that is being shared with the community. And as we're wrapping up our session for today, I would just like to share a couple of reminders here. We have one more session in this series. So next we will be meeting on March 16th same time, 11 o'clock Mountain standard time, or one o'clock eastern time to talk about the role of faith-based leaders in health promotion and outreach in the black and African American community. In response to this webinar, everyone who registered and attended will be receiving a recording and some additional materials in their inbox within the next week. And thank you again, and we hope to see everyone here next month.



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