WE PARTICIPATE IN RESEARCH

PARKINSON'S DISEASE CLINICAL RESEARCH PARTICIPATION IN THE BLACK COMMUNITY

ILLUSTRATIONS BY RANDELL PEARSON

DEDICATED

to all people and families living with Parkinson's Disease.

Special thanks to those members of the community who are, and will be, helping to advance science by participating in clinical research studies.

THE PD MOVERS – WE PARTICIPATE IN RESEARCH
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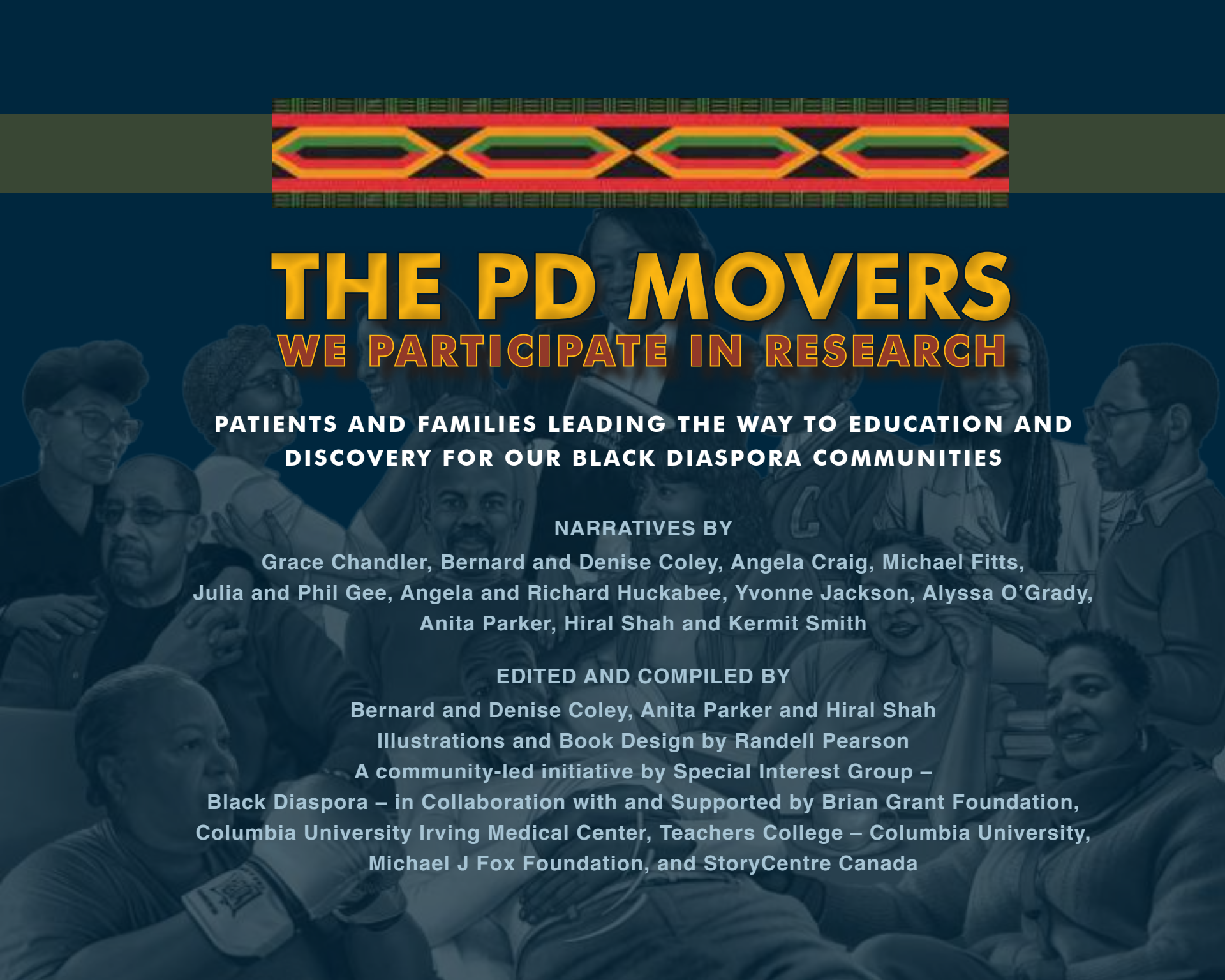

THE PD MOVERS

WE PARTICIPATE IN RESEARCH

PATIENTS AND FAMILIES LEADING THE WAY TO EDUCATION AND DISCOVERY FOR OUR BLACK DIASPORA COMMUNITIES

NARRATIVES BY

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THE PD MOVERS•WE PARTICIPATE IN RESEARCH

INTRODUCTION

GRACE JONES-CHANDLER I am a retired Contract Analyst from Northrop Aerospace Corp. I am the founder and CEO of a 501c non-profit organization (established in honor of my deceased mother) that caters meals for the families of terminally ill loved ones in the community. Also, I am a care partner for my spouse who was diagnosed with Parkinson's Disease in 2014. Until his diagnosis, I didn't know anyone personally that had PD. It is a life-altering experience for both the individual with PD and their care partner. Quickly, I realized that as a person of color, I have the responsibility to do as much as I possibly can to spread awareness of this disease and assist in helping those who are affected by it to cope and find resources and as much information as possible. I know that with Jehovah's help, I will be able to succeed at this.

R. BERNARD COLEY I am a retired high-tech executive and business development management consultant. I have received many awards for dedicated hands-on attention to volunteer community service (50+ yrs on non-for-profit boards). When my wife was diagnosed with Parkinson's Disease, I not only became a PD care partner, but also dedicated my talents to research and patient voice advocacy. I initiated this project out of a desire to see greater health equity and inclusion of under-engaged communities in PD research and healthcare delivery. I firmly believe in enhancing scientific accuracy and equitable healthcare via inclusive clinical research for the benefit of the entire PD community. To improve community access, I serve on The Multi-Regional Clinical Trials Center of Brigham and Women's Hospital and Harvard Plain Language Glossary Development Team and numerous patient advisory councils.

DENISE COLEY I am a retired global business development mentor and supplier diversity executive with leading high-tech firms. There I learned the importance and techniques for reaching the indigenous, minority, and women's owned businesses worldwide. My passion and purpose have always been to help others, so no one is left behind or is the missed seat at the table. So, I created mentoring and education programs in most of the positions that I held to help people through systemic challenges and barriers. My participation in this project is important to me, to level the playing field, so that generations after me have treatments and access to quality PD healthcare. I want to empower individuals to have Quality of Life.

ANGELA CRAIG I am a lifelong learner both professionally as a licensed certified Speech-Language Pathologist and personally as a Person with Parkinson's (PWP). I have repurposed my life through medication management, diet and exercise. To stay abreast of current trends regarding PD, I have joined professional associations and attended seminars. I currently advocate for people with Parkinson's by participating on advisory boards affiliated with hospitals and universities, providing guidance and support to PWPs through peer-mentoring and recently became a PWR (Parkinson Wellness Recovery) certified instructor. As a PWP, I want it to beknown that the PD diagnosis does not have to be a death sentence. My motto is PWPs have a voice….Let's stand up and be heard!Researchers need to know our stories of lived experiences.

MICHAEL S. FITTS I am a native of Huntsville, Alabama and a recently retired educator at the University of Alabama at Birmingham (UAB Libraries). I hold a B.S. in Management from Miles College and a Masters in Library & Information Sciences from the University of Alabama. In 2001, I became the first African American faculty member of the Lister Hill Library of the Health Sciences. In 2015, I became both the first African American Assistant Director and later moving up to rank to Assistant Dean. I have become an advocate and a cooperative example of humanitarianism. My personal passion is to educate underrepresented individuals (i.e. young-onset and people of color) on how to successfully live with Parkinson's Disease, a condition that I was diagnosed with in 2011, at the age of 38.

JULIA GEE I am a dedicated care partner to my husband Phillip who lives with Parkinson's Disease. Following his diagnosis, his medications were initially minimally effective and over-prescribed, a challenge exacerbated by the lack of reliable information or trusted resources for us. Motivated by this experience, I committed myself to ensuring others—particularly within the African American community—would not face similar hurdles. I view the PD Movers book as the perfect avenue to share our PD story and advocate for better awareness, emphasizing that it truly takes a village to navigate health challenges. Even though I was a researcher, I still have some reservations about some clinical trial research.

PHIL GEE Following a successful 33-year career, I retired at age 56. Shortly after, my wife Julia and I were planning extensive travel. Then I received the life-altering diagnosis of Darkinson's disease. Stunned, but calling on all my resilience, I channeled my energy into the Parkinson's community. I became a dedicated advocate, driven by a God-inspired life purpose to improve the quality of life for others living with the condition through education, community support, and advocacy efforts. I am telling my story because I know the frustrations of trying to participate in clinical research.

ANGELA HUCKABEE I am a retired educator, world traveler, and avid hiker who brings curiosity and compassion to every part of my life. I now serve as the care partner for my husband, drawing strength from our shared journey. My lived experience continues to inspire my advocacy within the Parkinson's community. Normally shy, I was hesitant to speak up at first, but I am telling our story because I have seen first-hand the transformative benefits of clinical research participation.

RICHARD HUCKABEE I am a devoted husband, father, and retired executive whose passions include global travel, hiking, and photography. Since my Parkinson's diagnosis in 2013, I have turned the challenges into purpose, becoming a dedicated advocate for the Parkinson's community around the world. I am a proud recipient of the 2023 and 2024 President's Bronze Volunteer Service Awards, signed by President Joe Biden. I joined this project to help inspire others and show the power of perseverance, connection, and hope. Research participation gave me back my life.

YVONNE R. JACKSON My husband and I were diagnosed with Parkinson's disease within two years of each other, and we faced nearly a decade of living with the illness together. My business career spanned four decades, and I held leadership roles in multiple industries, serving as a C-suite executive for three Fortune 500 companies. I conducted extensive research and learned that while adherence to medication was crucial, maintaining a solid exercise routine was equally essential. I discovered Rock Steady Boxing in my community and incorporated it into their weekly treatment regimen. Over time, I became the go-to resource for friends and colleagues seeking information about Parkinson's and relevant resources in the two communities I reside in. I shared my story as part of dedicating my time and talents to serving the Parkinson's community.

ALYSSA O'GRADY I am a champion for equity in Parkinson's research, leading efforts at The Michael J. Fox Foundation to ensure Black communities are seen, heard, and included in the search for better treatments and a cure. Drawing from my own family's experience and my commitment to dismantling barriers to participation, I work to build trust and expand access to clinical research. I chose to share my family story in this project because representation is essential — every community deserves a seat at the research table.

ANITA PARKER I am a 30+ year licensed medical social worker (LMSW) and serve as the Community Outreach Director of Saint Luke A.M.E. Church. I am a community partner to research teams and a staunch advocate for bringing resources to NYC Black and Hispanic communities. The key to understanding my role is that I am a firm advocate for utilizing community-based participatory research principles and methodologies. I serve as the community conscious and spiritual voice on our leadership team and in our PD Movers' work.

RANDELL PEARSON I am this book's, as well as the first *PD Movers* book's, illustrator and graphic designer. I am an independent visual artist with over five decades of professional experience in both the corporate and private sectors. "I am an artist who strives to capture the culture and essence of people's voices via the visual interprtaion of illustration." I have garnered awards from the Art Directors Club of New York, The Society of Illustrators (NYC), The Type Directors Club (NYC) and the Society of Publication Designers (NYC). My work has been exhibited at the Brooklyn Museum of Art and Parke-Bernet Galleries (NYC). I have received special recognition from the late Coretta Scott King, actress Jane Fonda and America's Cup winning sailor and businessman, Bill Koch, to name just a few of many notable individuals who have appreciated my work.

DR. HIRAL SHAH I am an Assistant Professor of Neurology at Columbia University Irving Medical Center in the Division of Movement Disorders and Medical Director of the Parkinson's Foundation Center of Excellence. I am a champion of uplifting patient and family voices as a mechanism to improve access to treatment and care for those living with Parkinson's disease. As a researcher, clinical healthcare provider, and advocate, I continue to learn from listening to my patients and community members as collaborators in all aspects of their care.

KERMIT SMITH I am an enthusiastic football coach, Broadway theatre enthusiast, and avid traveler. My life turned upside down when I was diagnosed with Parkinson's Disease. However, with my faith and the help of a neurologist and psychologist, I have found the strength to continue doing what I love. I am naturally cautious, reflective, and pensive. I joined this conversation because I was asked by PD Movers who respect my views and care about me.

THE PD MOVERS GATHERING · OUR STORIES

We are the PD Movers, and we are gathering again to share our stories. We have Parkinson's Disease or are care partners for someone with the disease. We have faced challenges participating in, or attempting to participate in, Parkinson's Disease clinical research studies. An issue we face is that for decades in many clinical research studies, our marginalized community has been missing or underrepresented in the PD study population. In most cases, we have overcome those challenges to advance science forward and provide hope for our families and our Parkinson's Disease communities. These are our stories.

Bernard asks, "Kermit why haven't you participated in any clinical research studies?"

NOTE:During 2025, the PD Movers gathered to share stories of their clinical research participation experiences. Their goal was to produce an Education Guide of these experiences to inform the Black Community of the need for and value of participating in clinical research. This goal was expanded to include educating the research community on the barriers and challenges the Black community encounters in participating in, or attempting to participate in, clinical trials. What follows is the result of asking the PD Movers to share their lived experiences as we educate each other on this critically important challenge of increasing Black Community participation in clinical research.

"Nobody Asked Me, So Tell Me Why I Should Participate?"

KERMIT SMITH

KERMIT: Bernard, during our last PD Movers gathering you talked a lot about participating in PD research. You also spent a lot of that time asking us to participate in PD research studies; but what you did not say was why we should. So why was that so important when the conversation was about getting more exercise to help with Parkinson's Disease progression?

BERNARD: Well, I was reflecting on the research advocacy work Denise and I have been doing since her diagnosis, we recognized a concerning issue. We noticed that there were not many from our Black PD community participating in those studies. Members of our Black PD community are grossly underrepresented as participants in these studies. So, we decided to find out why and change this fact. Now that you mention it, have you participated in any PD clinical research studies since your diagnosis, Kermit?

KERMIT: No!

BERNARD: Wow Kermit! You are a community role model, coach, and PD Mover storyteller, why haven't you gotten into a Parkinson's Disease clinical research study?

KERMIT: Well, for a start, no one has ever asked me. None of my treating physicians have asked me. I don't even think about it. I do not have time to go searching for studies, I have a lot on my plate already, and I have other health issues as well. And wait! Wait Bernard before you go rushing off to find a study for me, I would have to look into many things about a research study before getting involved. I have heard a lot of things that concern me.

BERNARD: Kermit, you are bringing up some great points about time commitments and safety concerns. I think I should start by asking some of our fellow PD Movers about their research participation experiences and what their participation challenges were. Then, I'll get back to you. I owe you some answers.

"Movement is my medicine and I learned this from reading Research Studies."

YVONNE JACKSON

BERNARD: Why should the Black PD Community participate in clinical research studies? Yvonne, let's start with you.

YVONNE: Kermit told me you were coming, so I have been thinking about this issue. I think to start, we should tell people something about how we, the Black Parkinson's Disease Community can benefit from clinical research and not just assume that we all know the answer. I sure did not.

BERNARD: Yvonne, let's hear your thoughts on that.

YVONNE: My husband Fred and I may be somewhat unique. A couple of years after I got my Parkinson's diagnosis, Fred was diagnosed with Parkinson's. For two people in the same household, in a long marriage, our symptoms were as unique and as different as we were. Our outlooks on clinical research were also different. I suspect that is true throughout the Black community. If no one explains the personal benefits of participation (what's in it for being a participant) and researchers are not listening to our community, then no wonder our participation rates are low. I get that. So, I'll share from my personal story and perspective. Not long after I got my diagnosis and began my research on this disease, I came across some research results that showed the benefits of routine fitness on slowing the progression of Parkinson's Disease, specifically, participating in boxing workouts. I was all in as I had for some time been participating in triathlon events; the research just reinforced my beliefs with factual evidence. Now Fred was on board with our life plans for our golden years upon retirement, but he was not on board with this boxing and heavy fitness programs. I joined and threw myself into the exercises. Just like the research predicted, I started showing significant improvements and reductions of my Parkinson's symptoms. Eventually, Fred took note of the obvious benefits and began to join me. Unfortunately, Fred left us recently, but I never forgot the benefits we gained from the Parkinson's research study reports. I also would be remiss if I didn't tell you that I noticed that our Black PD Community was barely represented or not represented at all in these studies. While this might not be considered an issue in fitness studies, I do not feel the same way about clinical trials developing drug therapies. I worry about the PD meds I take not having been tested on people from my Black community, with my genetic makeup.

Although Fred was hesitant to participate in clinical research, I owe it to Fred and my family to participate and explain the benefits.

“Participation is too important, overcoming Quiet Denial.”

GRACE CHANDLER

BERNARD: Grace, you often talk about the role of faith in your life. We hear from some in our community that because of their faith, they do not need to participate in research. Grace, do you see faith and research as competitive?

GRACE: As a care partner, it is tough to witness your loved one’s progression with this disease. Leonard, my husband, has had Parkinson’s Disease for some time now. We had a bucket list of plans for when we retired. Now our lives have changed forever, and I do not know where that bucket list is. I lean on my faith to get me through. Progression of this disease is relentless, but I have faith in the creator. Faith helps me move forward with our lives.

Now on that issue of faith preventing research participation, let me be clear. For us, it is not a competition. The research game is too important for our community to sit on the sidelines. If participation in a study will help anyone, then it is worth it. Leonard and I did not hesitate when asked to participate in a PD research study. My faith supports helping others. Participation in research is a way to gain some control when things feel uncertain and out of our control.


Holy
Bible

"A Seat at the Table as a Researcher because participation in Clinical Trials is personal to me."

ALYSSA O'GRADY

BERNARD: Alyssa, you made an intentional decision to engage in clinical research. Since trust and concordance (healthcare by someone that shares your ancestry) seem to be cited frequently by members of the Black Community, let's hear your thoughts. Especially in recognition of your role in helping shape Parkinson's Disease research, what is your take?

ALYSSA: I'm a member of our impacted PD community just like any other PD Mover, not just a Parkinson's clinical researcher. I know you know that our Black community is represented throughout the research community in many roles, but I recognize that this fact is not widely known or publicized. And yes, we need more Black researchers and clinicians, but we are not absent, as some people might think.

BERNARD: Can you reflect on the importance of increasing Black PD Community participation in clinical research trials from your vantage point as Vice President, Head of Clinical Research?

ALYSSA: This disease is personal for my family and so is research participation hesitancy. My cousin on my Austrian-Jewish father's side had Parkinson's, and my Jamaican mother's family and I need to share more conversations about research participation. We are not all alike in our feelings and views about research participation. Our barriers are historical, logistical, and emotional. A lot of information and education is needed by our community to build trust in clinical trial research. Broadening research participation among the Black community will take time and listening. I'm risk adverse, but I took to clinical research because it balances risk and hope. My work gives us a critical seat at that table.

STARTING THE COMMUNITY DIALOG

BERNARD: PD Movers alluded to not seeing people who look like us participating. Can you help us understand this better?

DR SHAH: Bernard, thank you for asking. A group of researchers examined representation of different racial and ethnic minorities in Parkinson's research, and they found that the African American/Black community was the least represented, representing 1.9% of participants [Di Luca DG, et al. Racial and Ethnic Differences in Health-Related Quality of Life for Individuals With Parkinson Disease Across Centers of Excellence. Neurology. 2023 May 23;100(21)]. As a researcher, this is so disappointing.

MS PARKER: Wow. The people they have researched do not look like our missing communities. So, the side effects and safety issues may not be the same, given that our ancestry is different - some of us have Native or indigenous roots, Caucasian roots, Caribbean roots, Asian roots, as well as our African roots, so one person and one family may involve multiple races and cultures - we are multi-cultural. Also, we don't have enough information about how Parkinson's manifests in Black communities and impacts families.

DR SHAH: What we do know is that Black patients face delays in diagnosis and are less likely to visit a Parkinson's specialist. These issues make research participation even more complicated, as people are systematically excluded from specific studies that are looking for those with early stages of disease, or before they start PD treatment. Or, people are unable to access a clinical trial if it is not nearby, or their health providers are unaware of the opportunities.

MS PARKER: The lack of access is partly due to lack of community education and awareness of early signs of Parkinson's, too.

DR SHAH: That's why your voices, and the community's voice, are so important. When Black patients and families help design studies, choose locations, and shape how we talk about research, we can reach so many more – and it also demonstrates the research community values your input, and builds trust between researchers and the community.

MS PARKER: Bernard, you should speak to Phil and Julia next. Julia once told me, "if there are people who look like us talking about research, explaining the benefits, and sharing their challenges and experiences in research, the studies would be easier to participate in and I think families would at least consider participating."

DR SHAH: It should be our goal as researchers to not just to invite Black communities into research, but to make them partners in it—so the science finally reflects everyone it's supposed to serve.

MS PARKER: Let's break down some of the myths that the Black PD community and research community hold about research.


WE PARTICIPATE IN RESEARCH

EDUCATION

BREAKING DOWN THE BLACK PD COMMUNITY
MYTHS OF CLINICAL TRIAL PARTICIPATION

MYTHS	FACTS
Researchers can't be trusted because of past abuses such as the Tuskegee Syphilis Study (effective treatment not provided), the Vertus Hardiman case in the US Government Radiation Study (10 school children irradiated in experiment disguised as ringworm treatments, Lyles Station School in Indiana), or the Henrietta Lacks Case (human cells taken from her body and grown in a laboratory as a profitable enterprise without her or her family's knowledge, permission or compensation).	Historical mistreatment is real, but modern research has multiple layers of oversight, mandatory informed consent, and community accountability to prevent any similar abuses. While there is a history of exploitation, modern research adheres to ethical standards that prioritize informed consent and participant welfare.
Participation in clinical trials is unsafe and experimentative.	Since the 1980's, in the US and Canada, human clinical trial participation is strictly regulated with safety protocols now in place to protect participants. The study protocols undergo extensive reviews by Institutional Review Boards before proceeding with the clinical trial. Participants must be fully informed.
Clinical trial results do not include racial data, so my participation won't make a difference.	Increasingly, clinical trials are designed to ensure diverse participation across different demographic groups to improve health outcomes for all.
I can't participate in a trial if I am on medication or have other medical conditions. Besides, clinical trials are only for people who are very sick.	Eligibility for research varies widely. Many trials include participants with pre-existing conditions or those on medication, as long as they meet specific eligibility criteria. Modern clinical trials are including individuals with various health statuses, including those who are well and looking for preventive care. One of the first factors to consider in looking into clinical trial participation is the inclusion and exclusion criteria.
If I join a trial, I'll be treated like a guinea pig. Clinical trials only give placebos, not real treatment.	Placebos are now used only when ethical and when no proven therapy exists. Many participants receive high-quality, closely monitored medical care, and often more frequent health checks than in standard care.
My information won't be kept private.	Clinical trials follow strict privacy and confidentiality laws that protect medical and personal information.

BREAKING DOWN THE RESEARCH COMMUNITY
MYTHS OF CLINICAL TRIAL PARTICIPATION

EDUCATION

MYTHS	FACTS
There aren't many Black participants because the Black community is just not interested in research.	Interest is high, but lack of adequate outreach, few invitations, and limited awareness of available trials are major barriers—not lack of interest. Most Black individuals want to help advance medical knowledge and may participate if given proper information, respect, and trust. Structural and societal barriers often exclude underrepresented groups.
There are plenty of trials available—Black people just don't join.	Many trials are not located near Black communities, have restrictive criteria, or lack access support (transportation and financial support). Generally, unaddressed structural barriers, not personal reluctance, limit enrollment.
Past abuses in medical research are the primary deterrent to Black participation in clinical research and trials; this cannot be overcome.	Studies do not support this view. Education is one of the keys to overcoming this manageable hesitation. Often, clinical researchers are not adequately aware of the legacies of Black participant research abuse, and study teams are not equipped to address these beyond asserting the safety of informed consent and Institutional Review Boards.
Black individuals have access to numerous, accessible resources about Parkinson's Disease and research participation.	Significant Parkinson's Disease content is available, but often is not representative or culturally affirming,and is not disseminated in culturally and socially effective ways for the Black Community to access it. There are digital divides, outreach focused on public and private spaces infrequently or not used by the PD Black Community, stigmatizing communications, and specialist who rarely service the Black PD Community.
Underrepresented communities don't need to be represented because PD treatments work the same for everyone.	There is a dearth of research to support this proposition. Diverse participation improves safety and effectiveness for all ethnic groups. Drugs may work differently across populations; ethnic representation of researchers enhances accurate data and equitable outcomes.
Black individuals lack understanding of research.	This myth can be traced to the systemic burying of Black researcher contributions to science in the US. This has been to the detriment of Black Community trust in the research community and lack of visible Black credible messengers.


THE PO MOVERS WE KEEP AROUND

“I do not Qualify, but there is a Role for everyone in Research.”

PHIL GEE

BERNARD: What’s in it for the Black Community? Phil, you have faced a lot of clinical research study rejections, but you still keep advocating for our community’s participation. Why?

PHIL: Well, Alyssa is right that for many of us, this is personal. However, I believe that there is a role for everyone in our community in PD Research, we have to tell our lived experience stories. I, like many of you, had been very frustrated trying to find a study for which I was qualified. I was diagnosed 10 years ago. I became disheartened and lost. Of course, I had been taking PD medication for years to live with this disease, so medication-based rejection was hard to take.

Then, Julia and I got an opportunity from a pharmaceutical company who was looking to do a feature for Parkinson’s Awareness Month for their employees. They asked Julia and I to tell our story. They sent a film crew that spent two days filming our daily routines. They were so happy with the results that they flew us to Boston for a screening of the 10-minute film at an all-company meeting. Julia and I thought we were going to learn from their researcher, but instead, we spent 40 minutes on stage with researchers firing questions at us. They were eager to learn as much about our experiences as they could. There were lines of super intelligent researchers waiting to talk to us after our time on stage ended. There is more to research than pills and shots. I felt a lot better about my contribution to research and realized that there is a role for people with Parkinson’s even if we do not qualify to be a participant in a clinical study. You know Julia was also a researcher, and we both believe it is important for Afro-Americans to participate in research.

"This is how we do it; I need to Protect My Husband."

JULIA GEE

BERNARD: Julia, you and Phil are quite the love story. With your research background, how does your expertise impact your assessment of the research participation benefits?

JULIA: Phil and I have been together since elementary school. Our foundation is built on love and supporting each other. Part of my role as his wife is to protect my husband Phil with his Parkinson's diagnosis. The pharmaceutical company's PD Awareness panel moderator asked me: "Why do you think Black people do not participate in clinical research?" I told the audience that day that I cannot speak for all Black people, but I believe that we are not made aware of the fact that our participation is needed or the consequences of us not participating. Having said that, I would advise my husband not to participate in any early-stage drug trials. There are just too many unknowns. After years of watching Phil decline with PD symptoms physical and mental, we were ecstatic when finally, the right combination of medications brought Phil back. So, I would veto any trial that required him to come off of his medications.

BERNARD: I guess researchers need to pay more attention to the care partner views as they recruit participants.

JULIA: My husband has a different view of clinical trials; he wants to make a difference. If my people see people that look like them and to whom they can relate, it could make a difference in their participation decisions. So, I decided to go along with Phil's wishes. You know I am committed to supporting him. For years it was difficult as he was rejected in clinical trial after clinical trial because he was already taking Parkinson's Disease medications. His outlook declined. We were so pleased when that opportunity to promote Parkinson's Disease awareness came along from the pharmaceutical company. We allowed them to film us in our home for two days. They flew us to Boston to be on that panel I talked about. Phil made me realize that Care partners have a lot of impact on research participation decisions. The Huckabee's are a great example of this.

EDUCATION

MEDICAL RESEARCH TYPES

ANITA: Occasionally, we have observed that there is some confusion about types of research studies. Thank you for putting together this list of definitions, Bernard, so our community can refer to these as they consider research participation.

TYPES OF RESEARCH STUDIES

1) OBSERVATIONAL STUDIES
Researchers observe what happens to people without changing anything about their care.

A) Cohort Study
A group of people are followed over time. Researchers see who develops a condition and what factors might be linked to it.
Example: Following smokers and non-smokers for 10 years to see who develops lung disease.

B) Case-Control Study
Starts with two groups: people who already have a condition (cases) and those who do not (controls). Researchers look back in time to find differences between the groups. Example: Asking people with and without a rare cancer about past chemical exposures.

C) Cross-Sectional Study
Looks at a group of people at one moment in time. Measures what's happening right now.
Example: Surveying a population once to find out how many people have high blood pressure.

2) EXPERIMENTAL STUDIES
Researchers actively change something—such as giving a treatment—to see what happens.

A) Randomized Controlled Trial (RCT)
Participants are randomly assigned to different groups (e.g., treatment vs. placebo). This is the strongest way to test if a treatment works.
Example: Half receive a new drug; half receive something that looks like the treatment but does not contain any medicine (a placebo).

B) Non-Randomized Trial
Like a randomized controlled trial, but people are not assigned to groups randomly.
This can introduce bias, so results are less strong than a randomized controlled trial.

3) OTHER IMPORTANT STUDY TYPES

A) Systematic Review
Researchers collect and analyze all high-quality studies on a specific question.
This provides a big-picture summary of what the total evidence shows.

B) Meta-Analysis
A type of systematic review that uses statistics to combine data from multiple studies.
This creates a stronger conclusion than any one study alone.

C) Case Report / Case Series
A detailed description of one patient (case report) or a few patients (case series).
This is useful for spotting new diseases or rare side effects but cannot prove cause and effect.

PLAIN LANGUAGE CLINICAL RESEARCH TERMS

EDUCATION

RESEARCH TERM	DEFINITION
GENETIC TESTING	A medical test that could identify a health risk to a person or their biological family members by looking at their genes (DNA).
INFORMED CONSENT	The process of learning and discussing the details of a research study before deciding whether to take part.
INSTITUTIONAL REVIEW BOARD	A team of people who review studies to protect the rights and welfare of study participants. An institutional review board (IRB), also known as an independent ethics committee (IEC), ethical review board (ERB), or research ethics board (REB), is a committee at an institution that applies research ethics by reviewing the methods proposed for research involving human subjects, to ensure that the projects are ethical. The main goal of IRB reviews is to ensure that study participants are not harmed (or that harms are minimal and outweighed by research benefits). [FDA definition].
VOLUNTARY PARTICIPATION	Choosing to participate in research without feeling pressured.
CONTROL GROUP	The people in a study who do not receive the study treatment or do not have the condition being studied. A control group is used as a comparison to see the effect of the study treatment.
PRINCIPAL INVESTIGATOR	The main researcher who oversees a research study and makes sure it is done as planned.
PROTOCOL (OR STUDY PROTOCOL)	A complete description of the research plan and procedures.

"I am Terrified of Needles."

DENISE COLEY

BERNARD: Let's take a look at some of the barriers and challenges that we faced participating in clinical research trials. Denise, how about you starting?

DENISE: You all know that I am terrified of needles, so studies involving an IV blood draw are not on my desired list for research participation. But Bernard and I are out there advocating for our under-engaged communities to participate in Parkinson's Disease clinical research developing treatments and seeking a cure. If I am going to advocate for participation, then I'm going to have to participate myself. So, I told the study's principal investigator about my challenges and concerns after delaying participation for 5 years. The study nurse called me and assured me that they had heard my concerns and would come prepared. When she arrived, she sat with me and listened to my challenges. She was patient and empathetic, not just compassionate. She showed me what was going to happen and then waited until I was ready to begin. She was gentle and reassuring throughout the entire IV procedure.

It had taken years to find a clinical research study that I qualified for as taking PD medication disqualified me for many PD clinical research studies. I wish my neurologist had told me about this issue instead of rushing me into taking PD meds. My symptoms were concerning but not debilitating. I could have waited while participating in clinical studies. It was important for me to participate in clinical trials, as I learned after my diagnosis that two members in my maternal family line in addition to me had Parkinson's Disease. When I finally shared the news, my family wanted to know if they had anything to worry about. How did I get it? Where does it come from? We need accurate research to discover the answers to these unanswered questions. Bernard and I have been trying to explain this situation to researchers we encounter, but sometimes they are not interested in listening to us. You see, we are non-participants in their studies and non-medical professionals. If we cannot listen to each other, then why are we here?

"Participation burden, from whose Point of View – Different Perspectives or Perspective Difference."

BERNARD COLEY

BERNARD: It seems a common thread I keep hearing is that we have to speak up for ourselves when participating in clinical trials. Aside from the question of whether this is fair, after all we are volunteers, this just increases our burden. For one of the studies that I participate in, when we got to the MRI portion, the coordinator told me that I should allow one and a half hours and if necessary, they could compensate me for travel. All nice gestures, but they seemed to have underestimated the costs to the participants.

I insisted on explaining as this would be a deal killer for my participation. I explained that in contrast to their study design's 1.5-hour estimation, for me it would be 10 to 11 hours (basically, a whole day). She was befuddled. I said, "The devil is always in the details," I said. "Look, in order for me to participate in the MRI at the location that you require and times you have available, I would have to leave my home at 6 am for a 2-3 hour commute in traffic, 30 minutes for parking and medical center security check-in, then there's the 1.5 hour prep and MRI procedure, 30 minutes for redressing and restroom, a lunch stop, and finally, a 3 hour return commute home. I must arrange to get my grandchildren to school and be picked up since I will not be available." Then as I am the care partner for my wife Denise and she is my required study partner, she has to come along and be fed lunch, too. Also, I am claustrophobic, and I need to be sedated for MRIs. There is no chance I will be able to drive home safely for a while after the MRI procedure. Denise with her Parkinson's cannot drive 3 hours safely. "Can you agree to provide a driver in lieu of gas money?" I asked.

Finally, I had to be prepared for Denise's PD medication schedule, water to take her meds and her comfort following the long commute and wait time. To the study team's credit, they caucused and agreed to make accommodations annually. You see, I am a member of a highly sought-after constituency, a Black male able and willing to participate in a brain health clinical study. I often wonder when I see the low participation rates for our community, how many times failure to recognize realistic patient participation burden is a contributing factor.

I tolerate this burden because I realize how important our Black Community's participation is to the scientific accuracy of the research study findings and reports. The participation challenges for our under-engaged community are not always about the study leaders, sometimes it is about those who administer the study procedures.


PREP FOR PARTICIPATION
COMMUTE TO MRI CENTER
CHECK-IN ACTIVITIES
MRI PATIENT PREP
MRI PROCEDURE
PATIENT POST MRI ACTIVITIES
MEET DRIVER, EAT, TAKE MEDS
COMMUTE HOME
RETRIEVE KIDS, DINNER PREP
THAT'S 10 – 11 HOURS FOR ME!
1.5 HOURS
SIG

“Speak My Piece, Speak My Peace.”

ANGELA CRAIG

BERNARD: Angela, you’ve administered clinical trials before, would you share your perspective?

ANGELA: Well, not every study requires that you have never been on Parkinson’s medications. I remember that I only had to be off my medications before starting any study activities during my research participation. My medications were working, and my symptoms were under control, but we need to be represented, so I agreed to temporarily pause taking my medications for the purposes of the study.

It had been over 12 hours since I stopped my meds. I felt like my brain was losing control over my body. I was feeling anxious as I didn’t know what to expect as I sat there waiting for my name to be called. Finally, an evaluator said, “Angela please follow me.” I was out of sync as I completed the first half of study tasks. I was so relieved when told I could restart my Parkinson’s medication. I realized how dependent I am on my meds, and how diligent I had become on keeping up my medication schedule. Now, it would be 30 minutes before they would restart testing.

Then, it happened. One of the evaluators said, “take an addition half pill.” This seemed strange to me as it was not in my script. So, I asked, “why?” I was told that it was because the neurologist said so, and that he was the head of the department. I asked to speak to him, but was displeased with the response from the evaluator, “He’s busy.” Eventually, the neurologist entered the room, and I asked why he would increase my medications. He responded, “Do you know who I am? I ask the questions.” How dare he! You see I was raised in a democratic household and taught that I always have the right to speak my piece. I immediately turned into that little girl who was taught to speak up. I looked directly at him and stated: “They must not have told you who I am, because I am the one who asks the questions!” He smiled and answered my questions. As he left, he said, “I’ll always remember you.” Unfortunately, this is not a case of “one bad apple” as we often hear when participants share these experiences in our community. Michael, why don’t you share your experience.

"Why was he telling me to sit still? He knew I had Parkinson's and was there to take part in this clinical trial."

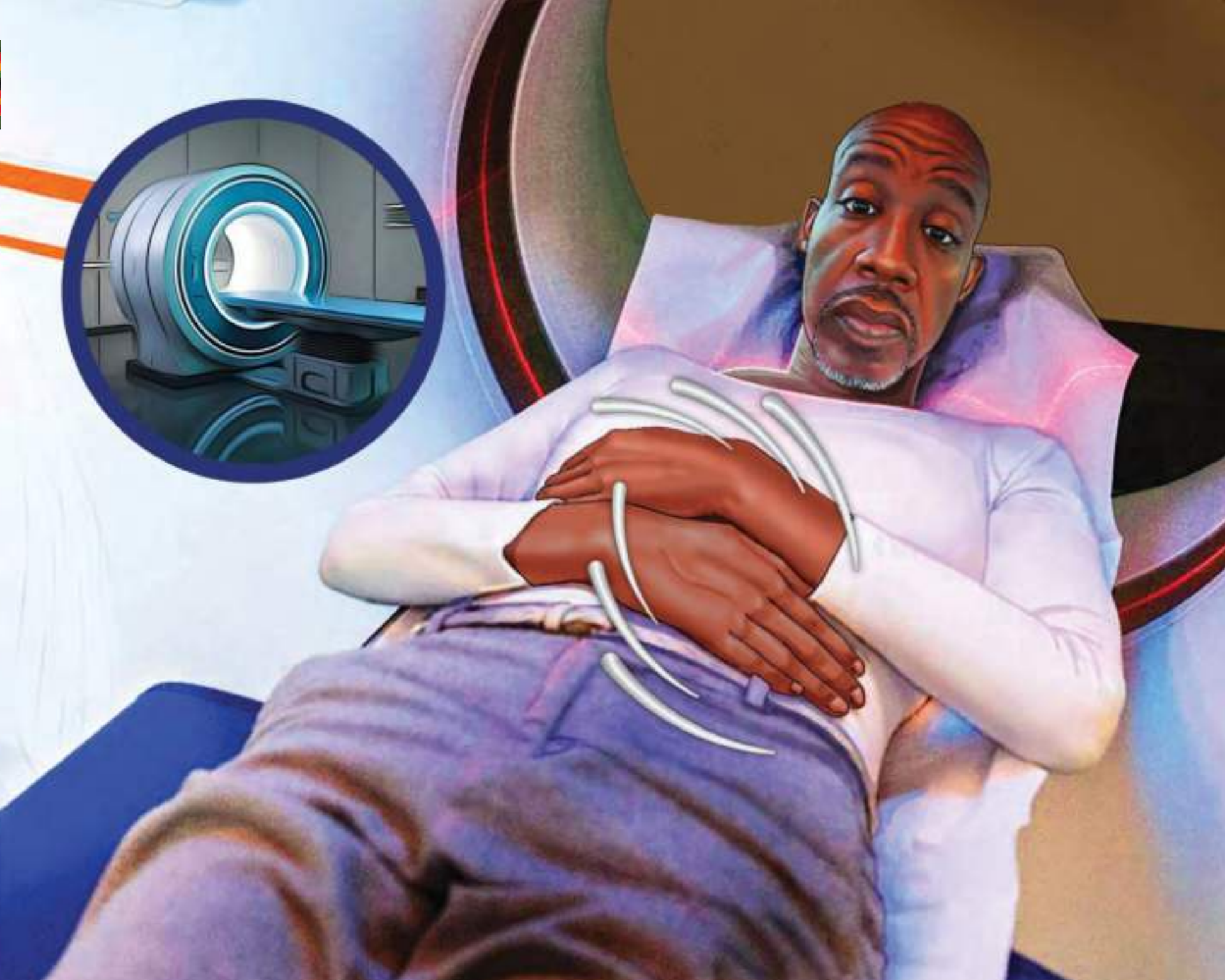
MICHAEL FITTS

MICHAEL: Well, all I have heard since my diagnosis is how important it is to participate in clinical trials. "You need to participate in clinical research. Clinical research, clinical research, clinical research!" Then, I spent the next five years being told that I do not qualify. It literally took me years before I found a clinical trial that I was eligible for. First, I was too young. You know that I am in the category of "Young Onset Parkinson's Disease" having been diagnosed at age 38. They wanted newly diagnosed, but I had Parkinson's for five years. Then it was the medications that I needed to take for my tremor symptoms that disqualified me from so many studies. I had been on meds since I was diagnosed! It is so frustrating!

Finally, I found a study, but this is still ringing in my ears: "sit still," I was told by the clinician. Why was he telling me to sit still? He knew I had Parkinson's and was there to take part in this Parkinson's clinical trial. It brought back recollections of the day I received my diagnosis. The neurologist just nonchalantly blurted out, "You have Parkinson's." There was no feeling, no emotions, no support, no nothing. My mind was racing. I was at a loss for words. I asked about getting a second opinion. "Suit yourself," he said, "They are just going to tell you the same thing." When I asked for an MRI, he told me it was out of the question. "Waste of time, waste of money," he said.

It's funny how God placed a mechanism of sorts in my DNA. When someone says something really crazy to me, I blackout for a couple of seconds, just long enough to avoid saying something crazy back to them or doing something crazy. I found this useful in avoiding even more unpleasant situations. What I wanted to say to the clinician, I cannot repeat here. I kept my cool and went on completing this appointment. I know how important clinical trials are, and especially for Afro-Americans and other underrepresented communities. It is challenging enough to get into these trials. When the researchers treat me like this, I really want to walk away. So, I'll just sit here, quietly for a while.

BERNARD: Okay, Michael. We know that these memories can be very emotionally challenging.



EDUCATION

EMPOWERING YOURSELF FOR CLINICAL TRIAL PARTICIPATION

DENISE: It has taken me years and many encounters to get comfortable and feeling empowered during clinical trial participation and investigation. Ms. Parker and Dr. Shah, I have heard you reference the power imbalance between the patient participant and the clinician. Can you please share more?

MS PARKER: We often talk about the importance of our community feeling comfortable when considering research, and I believe that is intertwined with being empowered and using one's voice.

DR SHAH: I agree; this is why we have partnered to host dialogues in the church, a safe space, to normalize these conversations, and invite the community to ask their questions without reservation. In the doctor's office, power dynamics can sometimes make it difficult to feel confident when asking questions. Even I get frazzled when I see my doctor; I may forget to ask a pressing question!

MS PARKER: That's right. This is where preparation can be key. I advise my community to write down their questions in advance so they can be informed before deciding to participate in research. For example: What is the purpose of this study? How much time is involved? Will it affect my regular care? Are there any costs or compensation? What are the possible risks? Can I bring someone with me?

I remind them that exploring research doesn't mean you have to say yes. Learn about your options. Then you decide what is best for you and your family. We want our community to make informed, confident choices. Once you identify something interesting, you should feel free to ask anything.

There are no stupid questions. Hold onto your Participant Bill of Rights and show it to the study team.
Empowerment also means remembering you have choices. You can ask for printed information. You can bring a family member to appointments. You can take your time before deciding. No rushing.

When our community understands this, they don't need to feel intimidated. They feel invited and powerful enough to say yes or no on their own terms. And that's the heart of it: real empowerment is knowing your voice matters and that asking questions is not only allowed, but also essential.

WHAT ARE PARTICIPANT RIGHTS FOR CLINICAL RESEARCH PARTICIPATION

MS PARKER: I am a patient advocate. Many of the PD Movers are research advocates. We want to empower our community to become familiar with our participant rights so when faced with a challenging situation, like Michael's or Angela's, they feel comfortable speaking up and asking for their needs. I would recommend that all individuals become familiar with what participants should reasonably expect and feel empowered to ask for when considering or participating in research. Specific protections, supports, and resources may vary by study, institution, and funding source. Participants always have the right to ask questions and discuss what is possible within a given study. I would recommend telling Kermit to ask his research institution for their "Participant Bill of Rights."

BERNARD: Based on our participation experience and participation research, PD Movers recommends that you consider that if you take part in a research study, as a participant you have certain rights. Those rights are here to protect your safety, privacy, and dignity. You can always ask questions or talk to the study team if something is not clear, or to express any concerns, problems, or side effects. You can also contact the research ethics office or institutional review board (IRB) with complaints or questions by having the information listed below:

- Study Team: [Contact Name / Phone / Email]
- Research Participant Advocate: [Advocate Name / Phone / Email]
- IRB: [Contact Name / Phone / Email]

MS PARKER: The PD Movers have developed our version of the "Participant Bill of Rights" that you can use for discussion or present to the study research team as a research participant.

PARTICIPANT BILL OF RIGHTS FOR CLINICAL RESEARCH PARTICIPATION

EDUCATION

SAFETY

- A participant has the right to close monitoring of their health and well-being.

VOLUNTARY

- A participant has the right to choose to participate in the study or stop at any time.

PRIVACY AND SECURITY

- A participant has the right to have their personal identity and medical information kept private.
- A participant has the right to be made aware of any disclosure of their name and personal information.

COMMUNICATION

- A participant has the right to be communicated with in a manner that is respectful, kind, compassionate, and meets them where they are.

BE INFORMED AND EDUCATED

- A participant has the right to understand what the study is for, what will happen during the study, and their role.
- A participant has the right to understand why they do, or do not, qualify for a study.
- A participant has the right to ask for information and communication in words they understand.
- A participant has the right to ask questions at any time, and responses that reinforce the understanding that there are no stupid questions.
- A participant has the right to know the possible benefits, risks, side effects, or discomforts to the extent they are known or learned in connection with the research study.
- A participant has the right to know if they will be paid or reimbursed for travel or any expenses associated with study participation.

PARTICIPANT BILL OF RIGHTS FOR CLINICAL RESEARCH PARTICIPATION

QUALITY CARE

• A participant has the right to be treated by trained team members who are familiar with the signs and symptoms of Parkinson's Disease.

EQUITABLE ACCESS

• A participant has the right to ask whether insurance status or income affects access to study participation or related care, and to understand what support or alternatives may be available.

• A participant has the right to share any challenges that make it hard for them to take part in research—such as childcare, medication scheduling, transportation, or care partner scheduling—and to have the research team work with them to find solutions to enable study participation.

PRIVACY AND SECURITY

• A participant has the right to have their personal identity and medical information kept private.

• A participant has the right to be made aware of any disclosure of their name and personal information.

DIGNIFIED CARE

• A participant has the right to be treated with kindness, compassion, and respect at all times.

• A participant has the right to have their time be valued and respected.

• A participant has the right to bring along someone they trust as they participate in research during all procedures and processes.

COMPASSIONATE SUPPORT

• A participant has the right to receive emotional, spiritual, and social support during and after the study.

• A participant has the right to have the research team acknowledge and respect the real-life burdens—such as practical, emotional or logistical challenges—that come with participating in the study research.

• A participant has the right to understand how their participation today can help shape better care, knowledge, and opportunities for future generations.

“The Beat of the Drum; I Participate in Lots of PD Fitness Studies.”

RICHARD HUCKABEE

BERNARD: Richard, you’ve gotten a lot of benefit from participating in clinical studies, can you share some of your experience?

RICHARD: For years something felt off. I couldn’t explain it. For nine years, I searched for answers, then finally a neurologist diagnosed me with Parkinson’s. A physical therapist recommended that I join a dance and drumming study. While participating, I found a sense of joy and community; things began to change. That study didn’t just get me moving, it brought my spirit back to life. Not long after that I joined a cycling research study for Parkinsons. Every pedal on that bike helped me reclaim something that the disease had taken away: my energy, my balance, and my confidence. I was even able to drive again. I wasn’t alone as my wife Angela joined me in some of the studies as a “control group member” and care partner. We grew stronger together. We became research advocates, and I began to encourage others to join research studies. Research has given me purpose and hope. Research has shown me that progress is possible and that everyone who participates helps move us all forward. The beat of my drum goes on. Let my wife and care partner Angela share her story as she has some benefits as well.

"A Hopeful Fight; I Participate because We are in this Together."

ANGELA HUCKABEE

ANGELA: For years something wasn't right with Richard. His gait changed, one arm didn't swing, and his steps got stiffer. He couldn't even smell the stinking chicken coop next door. He, unfortunately, lost his sense of smell. Doctor after doctor could not tell us what was wrong. Then finally the words that we didn't know we were looking for came: "Richard you have Parkinson's Disease." Now with this diagnosis, we had something we could work with, and things shifted. Richard's physical therapist suggested that he enroll in a dancing and drumming study. The results were significant as Richard began to improve after years of decline. Before long, his neurologist got involved and more fitness studies were part of our lives. Richard and I joined some studies with me being part of the control group. Our learnings grew. I became a research advocate because I saw what it was doing for Richard. Participation in this and other studies has brought us closer together. As Richard improved, he let go of his cane and saw a reduction in his medications. We had a visible reminder that the work we were doing mattered. With research as our guide and hope as our anchor, we walk this path together.

EDUCATION

HOW DID YOU FIND THE STUDY IN YOUR STORY?

MS PARKER: I'm curious, how did most of you find the study you mentioned in your stories?

RICHARD: I found most of my PD fitness studies through recommendations from my neurologist.

ANGELA H: I found my studies by accompanying Richard to his PD studies.

DENISE: I was asked at a PD outreach event we attended to learn more about Parkinson's Disease. The study's Principal Investigator was speaking and asked every PD patient to join. But, I remember, after talking to her, I put off joining for several years until I was ready to be involved in an invasive study.

BERNARD: I found my study at a PD outreach event. The study's outreach patient coordinator asked me from the booth next to where Denise and I were tabling for PD awareness.

ANGELA C: I was a research evaluator, so I heard about the study from my neuro/movement specialist.

MICHAEL: After 5 years of searching, I learned of my study from the University of Alabama at Birmingham Medical Center. It was a relief to finally get started.

GRACE: My husband Leonard's neurologist asked us to participate in the brain study.

YVONNE: I learned about boxing to mitigate symptoms by reading research reports following a TV new story on the Parkinson's symptom benefits of boxing and intense workouts.

MS PARKER: There seems to be a theme emerging as all of you learned about your studies through a personal one-to-one connection. So, word of mouth from someone connected to these studies was important for your successful engagement.

DR SHAH: This helps me understand how important the role of the treating physician is in bringing about research participation. The lack of PD specialist in the Black Communities is a barrier to increasing participation in studies.

HOW TO FIND RESEARCH STUDIES AND EXPLORE CLINICAL TRIAL OPPORTUNITIES

BERNARD: For now, finding PD Clinical Trials to participate in is still a challenge in the Black PD Community. However, PD Movers and Special Interest Group – Black Diaspora want to encourage members of the PD community to be persistent. Dr. Shah and Ms. Parker, could you provide some tips?

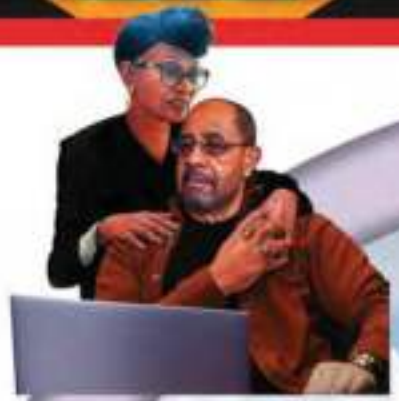
MS PARKER: Dr. Shah, a lot of people ask me, "Where do I even find research studies? No one tells us about them."

DR SHAH: One place to start is with your own neurologist or movement disorders clinic—they often know about studies happening locally.

MS PARKER: But what if someone's doctor never mentions research? Or, what if a primary care provider is not screening for PD or making a referral to the appropriate specialist?

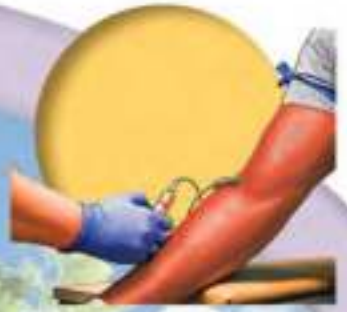
DR SHAH: We encourage the community to take control and advocate for themselves. First, be aware that community-based doctors or GPs are not often the ones doing research. Research tends to be conducted by specialists in academic or teaching hospitals, often in urban areas. So, start by looking into where the major academic centers are in your state or neighborhood that are providing Parkinson's Disease care. These centers are often identified as "Parkinson's Centers of Excellence" or "Movement Disorders Centers." Ask for a referral to a specialist or call one of these centers and ask, "Are there any studies I might be eligible for?"

CLINICAL RESEARCH PARTICIPATION LEVELS



FOCUS GROUPS

EXERCISE



BLOOD DRAW

SURVEYS

IV INFUSION

LEAST INVASIVE

MOST INVASIVE

CARE PARTNER ROLES

EDUCATION

THE RESEARCH STUDY LANDSCAPE – TYPES OF CLINICAL RESEARCH

TYPES OF CLINICAL RESEARCH	
RESEARCH TYPE	**WHAT IT MEANS (IN PLAIN ENGLISH)**
Observational Research	Researchers watch what happens naturally without giving treatments.
Interventional Research (Clinical Trials)	Researchers give a treatment or intervention to see how it works.
Diagnostic Research	Studies that test new ways to identify diseases or health conditions.
Treatment Research	Studies that look for better ways to treat a disease (medicines, therapies, devices).
Prevention Research	Studies that explore ways to prevent diseases (vaccines, lifestyle programs).
Screening Research	Research to find the best ways to detect diseases early.
Quality-of-Life Research	Studies that explore how to improve comfort, daily functioning, and well-being.
Genetic Research	Research that looks at how genes affect health, disease, and treatment.

MS PARKER: It is important to remember there are many ways to participate. I know a second resource for information to learn about your options is through PD support groups and local Parkinson's organization chapters. My community has not always felt comfortable joining support groups – but this is changing as more safe spaces for our communities are being established.

DR SHAH: For those with access to the internet, there are online tools. For example, Michael J. Fox Foundation has "Fox Trial Finder," which matches people to Parkinson's studies based on age, symptoms, and geographic location. There is also ClinicalTrials.gov which lists every registered study in the country—you can keyword search "Parkinson's" and your ZIP code. Navigating this resource can be challenging, but with assistance, it is can be useful. If you have questions or get confused, write them down and bring them to a trusted care navigator at your clinic—research coordinators and social workers are great resources. Finally, you can call PD community organizations like APDA or the Parkinson's Foundation, which have hotlines that can walk you through the search process. And if you're not comfortable using the internet, ask a family member, trusted friend, clinic staff, or even your local librarian for help.

EDUCATION

CLINICAL TRIAL SAFEGUARDS

JULIA: People often worry that joining a clinical trial means they are going to be guinea pigs or be exposed to unsafe practices.

BERNARD: There are safeguards in place today to protect participants. Clinical trials should always be built on trust, transparency, and respect. The Belmont Report was developed by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in response to unethical human subject research and was published in April of 1979. The report focuses on the following principles: respect for persons, beneficence, and justice. Respect for people is reflected in the process of informed consent. Informed consent is not just a document, it is an ongoing process to ensure each participant understands the purpose of the study, its risks and benefits, and that you have the chance to ask questions. It also affirms that participation is voluntary. This understanding is then documented with signed written consent.

MS PARKER: Yes, I was in the medical field, and I am familiar with the consent process. But, many people who are living with various medical conditions and later develop Parkinson's Disease may not be aware of these processes. We, as credible messengers Bernard, we need to educate them and inform them to expect the consent process to be easily understandable and culturally appropriate.

BERNARD: Also, every study protocol has to be reviewed by an independent ethics board—called an Institution Review Board (IRB). Their job is to make sure the study is fair, conducted safely, and respectful. Patients and advocates can be members of IRBs to ensure that the patient perspective is considered. This board has the authority to stop a study at any time if there are safety concerns.

ANGELA C: Personal safety is a significant concern for the families I worked with, so it is important to educate people that there are in-depth safeguards in place beyond the study team, and outside of their realm.

DR SHAH: Clinical trials have very significant safety checks throughout and an increased amount of access to the study team. If you are in a study, you typically have direct access to the study team so that if you have any concerns, or experience any new symptoms, you can notify the Principal Investigator (me for example) right away. Throughout the trial, the doctors monitor you closely, and frequently, and any side effects are taken seriously. Some studies even have outside safety boards that review the data regularly.
To summarize, there are multiple layers of protection in research—from the ethics board, the study team, outside experts, and you as participants. Participants are partners in the process, not just test subjects. When people understand their role, I believe, they will feel more confident and empowered to participate.


WE KEEP MOVING
PD
MOVERS
WE KEEP MOVING

EDUCATION

THE PD MOVER GATHERING
FINAL THOUGHTS

BERNARD: Your stories and our discussions have provided a lot to think about on the topic of clinical research participation from the Black PD Community. Clearly this is a topic that will require more dialogue between our Black PD community and the PD research community. I've got lots of notes to carry forward in our advocacy work. I have one more request. What take aways from our clinical research participation experiences do you want to highlight, first for our PD community, then second, the research community. To give an example, I'll start.

For our PD community, participation is important to me for Denise, my other family members who have Parkinson's Disease, and all the younger generations, I have to volunteer. For the research community, why on earth do I have to drive at least an extra 2 to 3 hours if Denise and I are in the same study, just at two different institutions? It would help if you took the time to explain it to me.

GRACE: For both our community and the research community, Leonard and I didn't hesitate when asked to participate by the physician conducting the study. If participating in the study would help anyone with PD, then it was worth it. We both realized and agreed that the game was too important to sit on the sidelines.

YVONNE: Likewise, I became a woman on a mission, searching for a lifeline for both Fred and I, I became a tireless researcher, trying everything. Research provides us with the information we need to live our best lives. Parkinson's has taken so much, but this I know. I have Parkinson's, but it will not have me.

THE PD MOVER GATHERING
FINAL THOUGHTS

ALYSSA: For our community, I would add that research balances risk and hope. Without research participation, tomorrow's treatments stay in the lab. To my colleagues in the research community, I would ask how can we get cures for all communities if all communities don't participate in research?

MICHAEL: For researchers, I want to stress the importance of making sure that everyone on your team understands all it would take is to be nice and respectful. Ask me how I am. Ask me what I do. But whatever you do, don't ask me to sit still. For my PD community, please understand how important research participation is for us. Despite all my efforts, it literally took me years to find a clinical trial I was eligible for, but I was persistent. With early and consistent exposure, participating in research can be normalized.

JULIA: For the research community, I will state again, I was a researcher. However, due to the many unknowns, I would not advise my husband Phil to participate in any early-stage trials or any trials would cause him to discontinue his medications. Doing this might worsen his symptoms. It took too many years to get him stable with Parkinson's Disease. Now to my community, let me be clear, regardless, I will support my husband's decisions to participate. I realize the importance of my care partner role to his progress. We are a team.

PHIL: With Julia by my side, I can do anything. So researchers should appreciate and respect the role that a care partner plays in deciding to participate in research. To my PD community, I will repeat myself. There is a role for every one of us in PD research.

THE PD MOVER GATHERING
FINAL THOUGHTS

RICHARD: I want to go back to something Julia said. In my research participation, I was not alone. My wife often joined me as a control participant. She is an important voice in my consideration of research participation; she is my partner. Her concerns are my concerns.

BERNARD: Excellent point Richard. I have heard many in our community talk about consulting their family members and friends about the risks of clinical trials. Sadly, there is a lack of plain language explanations about what a given clinical trial means for our participants and the Black community. Advancing PD research or reimbursement of some expenses is just not enough information for them to decide on their participation, they are concerned about the safety of the study, trustworthiness and competency of the researchers they encounter, real burden of participation, the lack of our community being represented as researchers and participants, and often whether our community will actually see benefits.

ANGELA C: Remember, I was a research evaluator, but even I had to stand up for my right to have my questions answered by the lead researcher. So, it is not just before you decide to participate, it also while we are participating. For my community, I urge you to learn your rights as a clinical research participant. Things have and are changing with respect to information which should be provided to us about a research study. Advocate for yourself without fear.

ANGELA H: Thank you for giving me the last word. For the research community, I would give a thank you for allowing me, a care partner, to participate alongside my Parkinson's husband and to watch him improve in spirit and symptoms improvement. It gives our family hope and inspired me to become a research advocate.


DESIGN AND DISCUSSION FORUMS
EDUCATION AND DISCUSSION GUIDES
PD MOVERS RESEARCH PARTICIPATION BOOK
CREDIBLE MESSENGER DOCUMENTARY

EPILOGUE

MS PARKER: These are first-person stories from impacted members of the Parkinson's Disease community. They are the result of a collaborations of organizations and individuals seeking greater diverse Parkinson's Disease research participation and improved PD health outcomes for marginalized communities. Below is a list of the major themes that came out of the storytelling.

WE NEED TO BE RESPECTED

- Michael (Don't Ask Me to Sit Still, Ask Me How I Feel)
- Angela C (Speak My Piece, Speak My Peace; I Ask the Questions)
- Alyssa (A Seat at the Table as a Researcher Because This is Personal to Me)

REJECTION ATTEMPTING TO PARTICIPATE IS HARD TO TAKE

- Phil (I Do Not Qualify, but There is a Role for Everyone in Research)
- Michael (Don't Ask Me to Sit Still, Ask Me How I Feel)
- Denise (Journey into Research - I am Terrified of Needles)

WE PARTICIPATE BECAUSE WE LOVE OUR SPOUSE (CARE PARTNERS)

- Julia (This is How We Do It; I Need to Protect My Husband)
- Angela H (A Hopeful Fight; I Participate Because We Are In This Together)
- Bernard (Participation Burden, From Whose Point of View – Different Perspectives or Perspective Difference)
- Yvonne (Movement is My Medicine and I Learned This From Reading Research Studies)
- Grace (Participation is Too Important, Overcoming Quiet Denial)

WE PARTICIPATE OUT THE LOVE OF FAMILY/LEGACY (ALL)

- Denise (Journey into Research - I am Terrified of Needles)
- Bernard (Participation Burden, From Whose Point of View – Different Perspectives or Perspective Difference)
- Alyssa (A Seat at the Table as a Researcher Because This is Personal to Me)

EPILOGUE

FITNESS CLINICAL RESEARCH PROVIDES EASILY IDENTIFIABLE BENEFITS

- Richard (The Beat of the Drum; I Participate in Lots of PD Fitness Studies)
- Yvonne (Movement is My Medicine and I Learned This From Reading Research Studies)
- Angela H (A Hopeful Fight; I Participate Because We Are In This Together)

OVERCOMING HESITATIONS

- Denise (Journey into Research - I am Terrified of Needles)
- Bernard (Participation Burden, From Whose Point of View – Different Perspectives or Perspective Difference)
- Michael (Don't Ask Me to Sit Still, Ask Me How I Feel)

INSIDER PERSPECTIVES; I WORKED IN RESEARCH

- Julia (This is How We Do It; I Need to Protect My Husband)
- Angela C (Speak My Piece, Speak My Peace; I Ask the Questions)
- Alyssa (A Seat at the Table as a Researcher Because This is Personal to Me)

PD CLINICAL RESEARCH PARTICIPATION IS IMPORTANT

- Grace (Participation is Too Important, Overcoming Quiet Denial)
- Denise (Journey into Research - I am Terrified of Needles)
- Bernard (Participation Burden, From Whose Point of View – Different Perspectives or Perspective Difference)
- Phil (I Do Not Qualify, but There is a Role for Everyone in Research)

RESEARCH HAS HELPED PERSONALLY

- Richard (The Beat of the Drum; I Participate in Lots of PD Fitness Studies)
- Angela H (A Hopeful Fight; I Participate Because We Are In This Together)
- Yvonne (Movement is My Medicine and I Learned This From Reading Research Studies)

A SEAT AT THE TABLE: BEING ASKED/BEING INCLUDED/BE REPRESENTED IS IMPORTANT FOR OUR BLACK PD COMMUNITY

- Alyssa (A Seat at the Table as a Researcher Because This is Personal to Me)

EPILOGUE

CALL TO ACTION

BERNARD: **The full version of PD Movers' stories are in videos of their own creation and are available to explore in the documentary Credible Messenger. In addition, we have created educational guides focused on critical issues raised in these stories. It is our belief that future discussions between the PD Movers and members of both our Black PD Community and the PD Research Community can lead to practical and pragmatic solutions to remove barriers and challenges to research participation. We believe these discussions and the materials produced can lead to increased clinical research participation by members of the Black PD Community. Finally, I want to thank everyone for reading our stories. I would like to make sure that you hear coming through these presentations the calls to action.**

First, a call to my community for greater participation in clinical research, and Second, a call to the PD research community to enhance your efforts and work towards greater diverse inclusion in clinical trials. Now, we hope you are armed with a better understanding of some of the challenges and barriers for Black Community participation in Parkinson's Disease clinical research. We, PD Movers, invite you to sit down and have a conversation with us. Thank you.

EPILOGUE

CALL TO ACTION

DR SHAH: As my final words, I wish to encourage the PD research community and Black PD community to engage each other in critical dialogues aimed at developing local solutions to increase participation in research studies and especially in clinical research studies. To arrange for PD Movers presentations, please contact:

FOR PROFESSIONAL CONFERENCE PARTICIPATION REQUESTS:
Email subject line: Professional conference request
email to: neurorehablab@tc.columbia.edu or sig.blackdiaspora@aol.com

FOR SPEAKER ENGAGEMENT REQUESTS FOR PD MOVER STORYTELLERS:
Email subject line: PD Mover Storytellers speaker request
email to: neurorehablab@tc.columbia.edu or sig.blackdiaspora@aol.com

FOR RESEARCHER EDUCATIONAL TRAINING AND DISCUSSION GUIDES:
Email subject line: Education Guide request
email to: neurorehablab@tc.columbia.edu or sig.blackdiaspora@aol.com

RESOURCES

PD Movers – We Participate in Research e-book can be accessed here:
https://www.columbiadoctors.org/specialties/neurology/
our-services/movement-disorders/patient-family-support-services-and-resources/parkinsons-disease-storybook

PD Movers – We Participate in Research hardcopy book can be purchased from Amazon.

The Multi-Regional Clinical Trials Center of Brigham and Women's Hospital and Harvard (MRCT)
https://mrctcenter.org/glossary/

FDA's Institutional Review Boards Frequently Asked Questions
https://www.fda.gov/regulatory-information/search-fda-guidance-documents/institutional-review-boardsfrequently-asked-questions

RESOURCES

Please scan the QR code below to access the PD Movers website with current resources and additional educational materials that can help YOU live and thrive with Parkinson's Disease.

Please visit PD MOVERS online at:

- **@PD Movers**
- **@pdmovers**
- **@PDMOVERS**
- **@PD Movers**

NOTES

Currently, Black inclusion and participation rates in Parkinson's Disease clinical research are well below their census in the United States and in most PD research studies miniscule to nonexistent. Special Interest Group – Black Diaspora wanted to learn WHY from our Black community's view. So, we asked some community members to tell us their stories of clinical research participation: motivations, benefits, challenges, and barriers. These are their stories in their own words and images.

THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH
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