

BDO Podcast full transcript

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Adrelia Allen: Hello everyone. This is Adrelia Allen, executive director of clinical trial operations at Merck. A large part of my role is to lead the strategy and execution of clinical trial activities with an important goal in mind — increasing diversity and inclusion in clinical research. We know that treatments can work differently in different people, so it's important that we include volunteers from varying backgrounds in our trials, people of different ethnicities or nationalities, women, children, men, people of varying ages, people who are part of the LGBTQi+ community and people from different socioeconomic backgrounds. This is an area that I'm passionate about professionally, but also personally... from helping my father to consider taking an MRI that would eventually end up in helping to make the diagnosis of prostate cancer. I had to help him address the lack of trust that he felt for his health care practitioners. And with trust being at the center of many patients choosing to participate or not participate in clinical trials, I have found my passion to make sure that every patient has all of the information they need to make the right decision for themselves.

So today I'm so grateful to be joined by Dr. Renee Matthews, who is the director of live programming and production at BlackDoctor.org and Euvon Jones, who is a father, husband, and advocate for families navigating prostate cancer.

Thank you so much for joining us today to discuss a topic that's so important to both Merck and BlackDoctor.org. We're committed to helping people from all backgrounds address their health needs and ensuring that our research reflects the people we serve. So before we jump into things, can you both introduce yourselves, Dr. Renee, can you also tell us about BlackDoctor.org and your role at the organization?

Dr. Renee Matthews: Hi, I'm Dr. Renee Matthews. I am a medical doctor, and I do media for a living explaining to my community anything and everything about health and medicine. My role at BlackDoctor.org is the director of live programming and production.

Adrelia Allen: And thank you. Euvon, can you introduce yourself to us?

Euvon Jones: My name is Euvon Jones, and I was diagnosed with stage 4 prostate cancer. I am a father of four, grandfather of six. And I am a motivational speaker and artist and also a advocate on the Hill for cancer legislation, sponsorship, and also part of the Good Trouble group from the former John Lewis in reference to being a cancer advocate.

Adrelia Allen: That's a lot of great work that you're doing, Euvon, and we thank you for that. And so I want to start our conversation with Dr. Renee sharing how BlackDoctor.org is working to increase diversity in clinical trials. And we'd love for you to tell us more about what activities you've found to be most effective in forwarding that work.

Dr. Renee Matthews: BlackDoctor.org, is an online platform. And so we've been able to put clinical trials on our website and get our audience to sign up for the clinical trials. We also have partnered with lots of organizations such as churches and other nonprofit organizations. We've partnered with the Divine Nine, so the fraternities and sororities, just all these large groups, barbershop, schools that have been able to help us to garner more exposure to the information that we have, which of course includes clinical trial information.

Adrelia Allen: Well, thank you, Dr. Renee, for that information. It's definitely impactful work that is being done. Euvon, if you can share with us, how did you first become aware of the clinical trial that you participated in and how did you make the decision to participate?

Euvon Jones: I became aware of the clinical trial that I participated in through my oncologist. And it's amazing because you don't really study or become aware or consider a clinical trial unless you're sick or you're in the medical community. Other than that, as a patient, you are not focused on clinical trials because your life is good. I was relatively healthy for 59 years, and I was blessed to have an oncologist who, number one, I could trust, and that trust came because she was transparent and made me aware of the pros and cons of my options. And it's really interesting because it's hard to trust the process if you don't trust your HCP or the person recommending it. Good information might be provided, but you have to trust that the information is good for you. I also in her, knew that she had acumen.

She was a research oncologist with more than 30 years in the field. And then number three, she had devotion. Her devotion came because she had a father who had prostate cancer, so she had a connection. So trust, acumen and devotion helped me. And it ultimately helped me take part in it. And the decision came because my wife and I, Janet, we became students of my diagnosis. So it's amazing because once again, if I were not sick, I don't think I would've even cared about a clinical trial. And I also found out in that clinical trial that it could hopefully produce quality of life in reference to my cancer diagnosis.

Adrelia Allen: Euvon, you really touched my spirit with several pearls of wisdom that you shared. It shows that we have much more work to do because we really want patients to look at clinical trials as an option and not as the last resort. And my next question I'm going to ask both of you: Why do you believe that diverse representation in clinical trials is important?

Dr. Renee Matthews: It's very important that we have diverse representation in clinical trials because medications don't necessarily act the same way on every person. So it's really, really, really important that we make sure that we have a diverse pool. We have different races, different ages, different sexes and different any other, it could be height, it could be anything. Just make sure you have a diverse pool when you do these clinical trials because the medicines act differently in different bodies.

Adrelia Allen: Thank you, Dr. Renee. And Euvon?

Euvon Jones: Well, in reference to the clinical trial and even something really poignant, Dr. Renee said the response number one is permeated and foundationally supported because our DNA and our genetic supposition is different for everyone. So on a personal level, for me that diverse representation is so important because a consensus can't be established or found in research if you don't have participation. And if the demographics are missing, we have a hard time trying to get a baseline of how different groups would respond. And so, in reference to me, it's hard for me even before I know what the process is, and we're not included, it's hard to say I have an opinion. But then I have to also honestly say that many of us are afraid. And because we have that fear, there is inaction.

Adrelia Allen: We need to be able to really have more open conversations with our loved ones so that we can be able to share with them why it is important. A personal mission of mine is making sure that all patients know what is available for them and that clinical trial information, they have the option to choose and to make that decision for themselves. And as we've talked about, the lack of trust, that is very familiar to me. My father also was diagnosed with cancer, and for him it was a challenge to even agree to take an MRI just because the injection of the dye was a trigger for him. And he didn't feel that his health care practitioners had his best intentions in mind.

So I've had to have those conversations — I had those conversations with him — to build his trust and to help him with being hesitant about the misconceptions of what happened in the past and what laws were in place to protect patients. So with this having more conversations, Euvon, were you hesitant about starting and participating in a clinical trial? And if so, how did you overcome this? And did you have any concerns during the duration of the trial that your health care team had your best interests in mind?

Euvon Jones: I was totally hesitant. And one of the reasons is because once again, if you never have to deal with things in your life until you're sick, then all of a sudden you have to rally around all of the precepts in your mind to try to wrap your brain around, my goodness, I've been given a dire diagnosis. And with that, you're trying to do the best you can with limited options. Some people are hesitant because of a lack of understanding like me, limited trust like me. And the way to overcome that is through education and research. So for me, it was a family decision. So overcoming it came from involving our family. We provided our kids with information about the trials, and we could make sure that we were getting a concerted choice of also a group that we trusted would pray for us and pray for us succinctly.

And so in turn, we have to empower those around us that love us. We have to empower them. And it's not unusual as we look at it, to have concerns about whether the clinical trial will impact your condition, but you can't let those things stop you or permeate your mind. And my HCP, on a practical level, gave me — and this is how long ago it was that I had the clinical trial — she gave me and my wife a USB drive. You remember those, filled with information about the trial, and I'm dating myself here, at least it wasn't a floppy. And they helped me

understand, and my wife and I understand how that trial and that procedure could alleviate some of my concerns.

And we would be remiss if we did not acknowledge the elephant in the room. And I know everyone knows about the Tuskegee research and you end up being at a place you don't trust, but we have to move on and believe that somebody in the medical profession will allow you to trust them, be motivated by them. They will have the acumen and they'll have the devotion that's going to come alongside of you and give you good information. And I hope I'm not being too long-winded or passionate, but that's just the way I feel.

Adrelia Allen: No, you are right on spot and definitely bringing the right information that we really need to share to everyone. And again, as you've said, you became the student of your diagnosis and then also working alongside your family and your faith to help you make the decision to move forward with what was best for you. And so I'm going to ask Dr. Renee, have you heard similar concerns that Euvon has shared from others? And are there any other misconceptions you think it's important for us to address?

Dr. Renee Matthews: Yes, I have. And one thing that COVID did teach us was that, and I hope that it taught, was that the Tuskegee experiment, it wasn't anything with clinical trials. They withheld treatment from those people. So that's totally different than what we're talking about, which is what we kept trying to stress to people when we were talking about COVID vaccines and stuff. We are not trying to withhold treatment. So I think that yes, there's a lot of mistrust in the health field because unfortunately, there are those unconscious biases as they call them. And so unfortunately, people like us aren't necessarily treated the same as other people are. So I think that's where you end up getting the lack of trust.

And also, like Euvon said, it's very important you trust your caregivers. And so if you don't trust your doctor, then you need to switch doctors because you need to trust what's coming out of their mouths, and you need to trust that what they're telling you is in your best interest.

Some doctors know about clinical trials, and some don't. Some know about some that others don't. And for you to find what works best for you, you might need to talk to a few people. So it's really important that communication is the thing. If you keep the lines of communication open, you can find out this information. And with the help of the lovely internet now, you can really get great information like visiting [BlackDoctor.org](https://www.blackdoctor.org) and clicking on our menu.

Adrelia Allen: I think both of you have really done a great job of really helping others to be able to have the conversation with their family members and helping them to really overcome the lack of trust and using resources that are available to get the right information. And so Dr. Renee, if there's someone out there who still has questions about clinical trials or is interested in participating in a trial but doesn't know where to start, what would you tell them?

Dr. Renee Matthews: I would definitely tell them to please visit [BlackDoctor.org](https://www.blackdoctor.org). Like I said, we do help to find people to match people up with clinical trials, but we also are a great resource

of honest, truthful, factual information. So we do a show usually once a month about clinical trials where we'll talk about clinical trials and the latest and greatest going on in clinical trials in the Black community. And talk to your doctor, ask your doctor if you like we said, you don't have to wait until you're sick, you can just ask about clinical trials. If you know have, I can say for me, I have severe asthma. I had a conversation and was like, are there clinical trials for asthma? There are. Okay. And so I participated. So you can ask the question. You don't have to wait until you are, like you said, this is the last resort.

You don't have to do that. You can ask. If you're diagnosed with diabetes even, you can say, are there any clinical trials on diabetes research? You can just ask the question. So ask your doctor and see what they say, and they might be able to lead you to something that's local to where you live. Nowadays, because of the wonderful internet, there are ways to do things even if you're not local to the hospital or the school that's doing the clinical trial. There are still ways to participate. But definitely visit BlackDoctor.org and click on clinical trials.

Adrelia Allen: Thank you for that. At Merck, we also have resources that are available and can be accessed at merck.com. And so Euvon, do you have any advice for others who are thinking about participating in a clinical trial?

Euvon Jones: I guess on a personal level, before I get to be analytic, on a personal level, the first thing I share is that I was diagnosed more than 13 years ago, stage 4 metastatic prostate cancer. And as Dr. Renee so eloquently said, I started off with a doctor that was in a rural area that to me, it looked like we did not have a lot of resources. And honestly, the facility seemed to be overladen with too much need and not enough people. And we ended up going to, once again, an oncologist. So my second line or second opinion was an oncologist that I, once again, we go back to the trust, acumen and devotion. And because of the trust acumen and devotion, I was able to move forward not only having some hope, but also believing that I could trust someone that was giving me information.

And because my personal diagnosis was so dire when she recommended a clinical trial for me, that was subsequent to something that it fringes on the fact that we, the patient is your greatest advocate. I am the best person to advocate for me. So that means that me, I need to study, study, study, I need to ask questions. I need to become a student of my diagnosis, and my wife and I did that.

When you're backed in a corner and you feel like you have no other way, you want to be a part of something that's going to be real. So it's important for us to try to absorb and explain the process to yourself, try to wrap your brain around the trial in a way that makes sense to you. And big time, you have to drop off the pride. Take pride that icon on your screen on your computer, and take it to the trash bin, deposit it, and it's okay to admit that you need help. And this, for being a Black man, is one of the toughest things we go through because we don't want to be that guy who looks like we can't handle it and keep it together. I'm saying that to say that I really appreciate all of you ladies, because you're being proactive. And I guess one of the things that is on my heart is that I find that in the community we do a lot of seminars. And in

the community, the caregivers scream much louder and are more cognizant about what needs to be done than the guys who come out. So I realize us men, we need to step up to the plate.

So I have life more abundantly as it says in our good word. I have kids who are just, when they look at me, they don't even think about cancer anymore. They think about life. We have a ball. So why clinical trials? Why? Because it's not just about you, it's about helping someone else. And BDO is a great place because it's good to be able to go to a place that looks like you, is for you, sponsored by you, talks to you, and will tell you what you need. For lack of a better word for it, I'm going to be quiet now.

Adrelia Allen: Euvon, thank you for really being a great gift here today and sharing the gift of your journey and with so much passion to really help others who may be in the same situation and wanting to understand even more and how they can receive the information needed for them to be able to make the decisions and to help them during their time of need. So I thank both of you for taking the time today to join us and for sharing your stories and perspectives. And I'm glad we had the opportunity to discuss such an important topic. Thank you, thank you, thank you.

Euvon Jones: Thank you.

Dr. Renee Matthews: Thank you. And you're welcome.