

Kidney Transplant Conversations, Podcast series

Episode 1: [Impact of Pandemic, & Meeting People Where They Are](#)

The COVID-19 pandemic has everyone asking a lot of questions, especially transplant recipients, and those waiting for a transplant. In this episode we discuss the impact of the pandemic, talk about masks and vaccines, and how the pandemic is impacting people with immunosuppression. To explore these subjects, we welcome two guests to the podcast. Firstly, living donor recipient Risa Simon, who will share insights from the transplant patient's point of view, and then Daryle Blackstock, PA-C, who will talk about the importance of meeting people where they are.

Host:

Hello, welcome and thank you for joining us for the first episode of our Kidney Transplant Conversations podcast. I'm Rolf Taylor, your host, and series producer, and having been involved with health advocacy for many years, I'm honored and excited to be joining you on this journey of discovery. We'll travel across the world of kidney transplantation, through conversations with all kinds of healthcare professionals, and most importantly of all, with all kinds of people who experience kidney conditions. This podcast is a collaboration between several kidney patient organizations, professional organizations, and committed individuals, who together all share a passion for working to make kidney transplantation more accessible, more equitable, and as successful as possible in the long term.

Throughout this podcast, we're going to be exploring stories and perspectives that reflect the amazing diversity across this country so whoever and wherever you are, if kidney transplantation is important to you, then we hope you'll find conversations that are meaningful and relevant inside this space. Each new episode will feature interviews with patients, caregivers, advocates, donors, healthcare providers, and community leaders. We'll explore all the stages of the kidney transplant journey and invite our guests to share their experiences and insights as well. We'll also look at things like health disparities and identify where and why some groups don't do as well when compared to others and discuss what we can do to close the gap.

Our discussions will be purposefully focused on inclusion, diversity, equity, and access. Also known by the acronym *IDEA*, which are all subjects central to the purpose of this podcast. So, we hope you will subscribe and let kidney transplant conversations keep you connected, informed, and inspired with a constant flow of new thoughts and ideas. And so, for today, the COVID-19 pandemic has everyone asking a lot of questions, especially transplant recipients and those waiting for a transplant. So, today we'll discuss the impact of the pandemic, talk about masks and vaccines, and how the pandemic is impacting people with immunosuppression. To explore these subjects, we'll welcome two guests to the podcast. Firstly, living donor recipient, Risa Simon, who share insights from the transplant patient's point of view, and then Daryle Blackstock, PAC, who will talk about the importance of meeting people where they are.

All views and opinions expressed in this podcast reflect those of the participants.

So, our first guest on today's podcast is a kidney transplant patient, an author, an advocate, a mentor to other kidney patients in association with several organizations, and CEO and founder of Transplant First Academy. She's passionate about sharing her own experiences

as someone who received a new kidney from a living donor. And she has helped many people follow that same path. Welcome Risa Simon.

Risa Simon: Thank you so much for having me on the podcast, it's truly an honor. And while I feel like I'm one of the lucky ones, believe me, it didn't start out that way and it doesn't start out easy for any kidney disease patient. Sadly, my father died in his early forties, struggling on dialysis. He was told in his early twenties, he had about 20 years to live. As a child I wasn't given that information. My brother ended up on dialysis after, in between, I should say two transplants. And that's why I say I feel like I'm one of the lucky ones and the path that I discovered really needs to be elevated to a position where other patients who deserve to live a better and longer life can tap into the resources that can change their life, if they're willing. Make no mistake, this does take work and a commitment, but all you have to do is talk to somebody on the other side of this equation that said, "Hey, look at the life I'm living and possibly you could live this life too, but here's what you need to do," and a lot of it is patient engagement.

Host: Well, thanks for sharing that I'm sorry to hear that your father passed away so young. How long is it since your transplant now?

Risa Simon: It's an 11-year kidneyversary coming up in about six days, Rolf. It'll be June 8th. On June 8th, 2010, is when I received that magical gift that truly, changed my life.

Host: How, are you feeling now?

Risa Simon: You know, every day is filled with gratitude for the one day that gift was not only offered, but of course, you know, you take it full steam ahead from where that particular donor was approved. I had a total of six individuals come forward, the sixth one was the magic one. And that's on June 8th, that's when I received MAK. I have named my kidney from day one to 11 years out MAK stands for, it's an acronym Melissa's Amazing Kidney and boy, has it been amazing. So, yes, I'm feeling well, but once again, I need to say that it takes work. It's a daily commitment, there are immunosuppressive drugs that we will be on for the rest of our life or the rest of our functioning kidneys life, and there are certain disciplines that we need to follow if we want our kidney to last as long as possible and function as well as it can possibly function.

Host: Well, you look wonderful, you sound great, you're full of energy and you've been so helpful as we've been planning this podcast and, you know, thinking about the things that we're going to talk about. So, appreciate you sharing your story and joining us. I want to switch topics a little bit if I may because I think what's front of mind for everybody right now is the COVID-19 pandemic. And especially its impact on people who are taking immunosuppressants to protect their transplants. So, could you share a little bit about, you know, what is your experience been in terms of thinking about vaccination, thinking about taking a medication, how has that felt in this time?

Risa Simon: Such great questions! When the vaccines finally became available in our area, even if I was ready to jump forward and I'll tell you what a little bit of hesitancy I had, it was very hard to get in. I was, you know, dialling for an injection. I was just dialling here and dialling there and getting online. And so, there was that barrier. Inside, full confession, I was thinking, do we know enough about our immunosuppressed population? And that little voice in my head said, "I don't think we know enough." And when we, as transplant recipients, hear anything

to do with antibody, that word before transplant and after transplant is somewhat alarming. We don't want to develop the donor-derived antibodies, which could cause rejection and I have known and met a number of folks on dialysis for years, hoping to get a transplant, but they're highly sensitive because they have a lot of antibodies.

So, that was the other thing I was like, "Oh, what about that?" You know, yes, I finally did, yay got vaccinated. And I was curious, you know, am I going to show some immunity and am I going to respond? But I did test post-vaccine first dose and second dose, and after the first dose zero detection of any reaction to the spike protein. And after the second one, I expected, because the scale starts at like 0.08 and I was below that on the first one. The second one, I actually had a pretty high number. I would've been happy with a full one digit, and I ended up in three digits. The problem is though, since we don't know that much, communicating with my transplant nephrologist I said, "Hey, you know, what do you make of this? We didn't think that I would have any protection." He said, "Well, I think it's a good sign that you have a high number. We just don't know enough, yet.

And you're reminding me, Rolf, as far as what we're hearing out there in the field, there's a number of articles you've probably seen a few of them, but a couple of these studies that have been run on the mRNA, one out of New York-Presbyterian, another one out of Columbia that revealed 75% of those who have been vaccinated with the mRNA did not respond. And then, there's another study out of Johns Hopkins that only 54% did respond. So, it depends on what study you're looking at. You know, again, I call myself one of the lucky ones. I'm not quite sure why it happened, but I still have to be careful. I am not letting my guard down.

Host: It's an evolving situation and I'm sure that there is a lot of research starting up, but in the midst of a pandemic, everything feels like it comes too late, right? It's like we want clarity, and we don't have clarity. We have lots of mixed messages, but I think it's really helpful that you shared that experience. And hopefully, as time goes by, we'll have a better picture of what's really going on.

Risa Simon: Exactly. I think some of us just have to leap into that void, which I ended up doing because I have to protect MAK. I mean, somebody did this amazing sacrifice for me, and then I've got to do whatever I can.

Host: I think the other thing that's been happening is that right now, you know, this is the beginning of June and people declaring victory on the pandemic. And, of course, it's a rush to remove mask mandates. Everybody wants to get back to normal, which is understandable, but in light of how many people are on immunosuppressant medication or maybe receiving other treatments that are affecting their immune system, you know, a lot of cancer patients, then it seems a little insensitive that everybody's so preoccupied with I want to take off my mask and I want to have my reward for taking the vaccine, but at the same time, it's a little insensitive to people who are vulnerable.

Risa Simon: Absolutely, you know, it's funny when we turn the clock back and everyone was wearing masks, as an immunosuppressed individual who wore masks quite often, I was like, "Hey, welcome to my world." I didn't look so strange anymore. Everybody pretty much looked the same. And now, based on what you've just shared because of the liberation of masks and the insensitivity to it, you know, we don't expect everybody to be thinking about us as a community, as a society, as you know, just doing the right thing for, not just yourself, maybe

you don't care about yourself, but how about, you know, your family, your friends, and strangers.

We as transplant recipients that have received a kidney from a living donor, we're kind of spoiled because that is to me and I think many of my compadres that have gone through this experience that is like the ultimate, ultimate, heroic, altruistic thing, the highest achievement anybody could achieve in the level of human kindness. So, we've experienced that, we've witnessed that, and it's such a small sacrifice. If you even want to call it a sacrifice, it's really an inconvenience, but when the CDC says... So, we just have to continue to protect ourselves again, my own physicians at the transplant center saying, you know, you basically need to act as if you were still in that period of time where you needed to follow all the protocols because you're immunosuppressed and nothing's a hundred percent.

Host: Don't feel pressure to take off your mask because people are expecting it.

Risa Simon: Exactly.

Host: You're not making a political statement by keeping a mask on its necessary self-protection.

Risa Simon: Absolutely. No regrets, you know, there are no regrets. There's silliness when we just, you know, throw caution to the wind, but each to his own. We can't make people do that, but it would be nice, as the days go on, that some thoughts occur. Maybe it's a grandmother or grandfather, a child, you know, just maybe just some thoughts occur to these individuals that are thinking, you know, it really isn't that much for me to protect myself so that I can help protect others.

Host: And what about people who are actually waiting for a transplant right now?

Risa Simon: You know, it's interesting, there's a number of thoughts that are running through my mind on that question. The highlight, the silver lining in the pandemic is that we all of a sudden have access to telemedicine and I've been taking full advantage of that. Rolf, you know, there's no ifs and buts about it as soon as somebody is scheduling an appointment, I try, unless it's, they've got to draw blood or take an image, I'm having a tele-visit. And so that is really a positive, as far as getting a transplant, getting tested for transplant that as you said, has been slowed down, they're back up again, but they're still playing catch up right now, right?

So, and then there's the fear. A number of my mentees were going in to be evaluated or having donors evaluated, hoping they could get their transplant soon, and then the pandemic hits, and then there's the shutoff, no living donors are being evaluated, right now, and the whole thought process, which goes through my mind as well, would have gone through my mind. Eleven years ago, I'd be going okay, I'm already nervous in a hospital, I'm like, "Oh my gosh, you know, is it safe?" And for donors that want to help truly through their heart, want to help someone live a better and longer life, we can't put them at greater risk. So yeah, there were a lot of legs to that stool if you will.

Host: So, we're living in a time of greater complexity for everything, but particularly when it comes to healthcare. And so, people have a lot of questions. Where would you point people who were looking to kind of answer these difficult questions, where are the best information resources for this kind of thing?

Risa Simon: The way that I was able to get across the finish line and receive a transplant before I required dialysis all started when I attended a patient conference and I was attending conferences, not just for patients, for physicians too because I'm just curious. So, I'm a sponge. I love to learn.

And I think number one, patients need to reach out, access as much content as they can from an educational standpoint, they're probably not going to find a lot of it in their outside nephrology office, they may have some, but if we're talking vaccinations, they're probably going to be looking to some of these patient organizations, there's a handful of them, you know, three big ones for sure that have webinars. It seems like every other week you could get on a webinar with updates. The key here is, even as a mentor, you can learn a lot from your mentor as a mentee, you can learn a lot talking to your mentor, but we don't give medical advice.

So, we can only share our own experience and so making a point to bring your voice and your questions to the table with your own physicians and especially your transplant center, my outside nephrologist to me doesn't have the experience that the transplant center has because they're more up to speed on immunosuppressed patients. So, getting together with those organizations and really reaching out and doing your own research, make it a point to sign up for as many courses as you can.

Host: I guess what you're saying is that regardless of what stage you're at, whether your pre-transplant or post-transplant, it's your transplant center that's going to have the answers to your questions. So, engaging there is key, and then doing the research.

Risa Simon: One other point here that we should underscore is if the individuals feel that it's not a good fit, that they're not being listened to, their questions aren't being answered, there's not a portal, and the portal can be extremely valuable I use that all the time, asking those questions. The answer may be, we don't know enough yet. I get that often, but still, at least, I'm asking, and I'm engaged. And I feel a little more confident knowing that, well, my doctor is going to let me know when they do know more. But yeah, patients really need to spread their wings and make sure that they are connected in any way that they can and find other sources. This isn't a good connect. Let's find out who might be a better connect, might be a better provider for me.

Host: Just in closing could you just share one thing that you wish you had known when you were first diagnosed when you were in that early stage?

Risa Simon: Well, there's probably a number of things, but the one thing that was the most impactful, you may know that there's an initiative that's been around for years. It's called Fistula First. Had I known transplant could come first, most patients think dialysis has to come first, had I known that earlier my path would have been that much easier. Yeah, I was able to pull this off, but I could have pulled it off a lot easier, had I known the route and had I known the opportunity, and thank goodness I got it in time, and I activated it. Yeah, so truly if the patient is given that opportunity to seek information outside the sacred walls of that exam room, I didn't know I could do that either so, it all is connected and it all started at a patient conference.

Host: I think what I'm hearing you saying is you can't start pushing for a transplant too early.

Risa Simon: No, it's never too early. We're really the driving force. We have to get the information, you know, that old saying information is power. It couldn't be any truer for me and everyone, because sometimes you have to be hit full-on in the face with perhaps your scariest fear, but fear can be a motivator. It was for me, and it is for many. And if we can embrace that fear and take it by the reins and go, okay, what can I do to change my trajectory? That's really what it's all about.

Host: Risa, thank you so much. It's great to see you, it's great to hear your story and it's also great to witness how you're taking everything, you know, and sharing it with so many people including us. So, thank you so much and we hope to see you again very soon.

Risa Simon: Thank you so much, truly an honor, to be on your show.

Next Interview with Physician Associate Daryle Blackstock, PAC

Host: Okay, so now it's my pleasure to welcome Daryle Blackstock, PAC. He is the director of clinical transplant operations transplant services at New York-Presbyterian hospital, Columbia University, Irvine medical centre, and New York Presbyterian Weill Cornell Medical Center. So, that is two campuses that together represent one of the largest transplant programs in the United States. But somehow Daryle has found some time to be with us today. Welcome, Daryle Blackstock to kidney transplant conversations.

PA Blackstock: Thank you so much, Rolf, but it's really a pleasure and when you say somehow, I've found the time, listen, this is built into my schedule, and I absolutely am honoured to be here, and I am so grateful that we have this time together. And to just reach out to your listeners.

Host: Really appreciate your enthusiasm for the whole project. And today we're going to talk about some COVID-19 related things, which are kind of front of mind at the moment, particularly navigating the ever-changing mask guidance's, I think it's important we talk about that. We're also going to have a discussion about meeting people where they are. And I think that's all about being intentional about putting the patient at the centre of care and I'm excited to hear your thoughts on that. I know it's something that you're passionate about. But before we move on to those topics, Daryle, could you tell us a little bit about your role as a physician assistant director of clinical transplant operations and also your focus in your career on transplant patients?

PA Blackstock: Absolutely. So, you know, it's funny. I didn't choose transplant, transplant chose me I started off my career in wow, '97. I graduated from PA school and started off in the operating room as a surgical PA. Really and truly loved being in the operating room. I transitioned to Westchester Medical Center working trauma, critical care, and it just happened there was an overnight position and it was the largest transplant program, kidney transplant program in the region. And I had the pleasure of meeting [Dr. Khalid Butt](#), phenomenal world-renowned transplant, kidney transplant, surgeon, God rest his soul. And he just taught me so much about transplant and I got bit by the bug. You know, these patients are truly, truly unique. We get to, as a provider, we're often taught, you know, you have to maintain your distance in order to be objective.

And with the transplant, you have to get to know not just the patient, but their family and their support system, because that's when you, that's where the magic happens. That's where you get that additional information that you just really can't get from asking questions. You know, how are you, looking at vitals, looking at labs, you really get to know the patient. And that's when I fell in love with the field of transplant because you really get to know the patient and it's okay to cross that boundary.

And from there, I went on to be a transplant coordinator and eventually got back into the world of being an inpatient transplant PA working in lung transplant, working with a great team of other practitioner's providers, and took on some leadership in the world of transplant PA and then ultimately became a director of clinical transplant operations here at NYP. And that really allows me to just take a look at how we're operating clinically. What can we do better? What are we doing well that we should continue? And it's really, it's put all of my experience as being a PA and being a transplant coordinator to use to keep doing what we're doing and doing it well.

Host: It's really interesting that you mentioned about kind of to know the patient in a way where maybe in other disciplines, there's more of a boundary and I'm wondering and I think we'll talk about this a little bit later when we talk about you know, patient-centered care and meeting patients where they are, whether that approach within kidney transplantation should actually be a model for other disciplines.

PA Blackstock: Absolutely, a thousand percent, because you know, when we think about it, you know, what we're taught as providers is that you listen to the patient. The patient really is going to tell you what is wrong with them, what they're going through and that makes up the majority of your diagnosis. They're going to guide how you treat them and it really is a partnership. And so, absolutely we should have that bond with the patient. You know, if you think about the old-time medicine where you had that physician in the town, and they did the bartering, that physician was a part of the town and a part of everyone's family.

And that's how you truly make the diagnosis and that's where that, again, that magic that's where it happens. And think about our own personal experiences with our own providers. Again, I feel comfortable when I walk into my provider saying, "Hey, how is this? How's your family?" Something about me that's personal because then that builds that trust and, that's where again we're sharing information. I'm letting my provider know what's going on with me and getting the best outcome possible. So, absolutely it should be a model that everyone follows.

Host: Reminds me of a conversation I once had with a doctor who was on the verge of retirement. And he'd been practicing, I think he'd been practicing since the 1930s as a doctor. And he said to me, you know back in my time, he said we only had three things. We had penicillin, we had aspirin and we had the tone of our voice. That was it. That's how we did it. And he used to bemoan that, you know, kind of the art of the bedside manner had kind of gone away because medicine has become so very technical.

PA Blackstock: And, you know, medicine, it's a science as well as an art, right? And, you know, any new person coming onto the team and whatever discipline, I always remind them that, remember, this is very much science yes until you have your facts that you have to look at and you treat, but then there's that art piece of this. And, you know, I've had the pleasure of hearing Dr. John Amman talk about this. You know, when he gives his lectures on the

history of transplant, he brings up this beautiful artwork and he's giving a great message. But part of it is don't forget the beauty of the art in what we do. And the only way that we can truly create a work of art, and you know might be a little abstract. I know people are thinking art in healthcare, wait a minute, you know, I'm not thinking of blood and drawing pictures, but it really is about having the best possible outcome. And that can only be done in unison with the patients and not just patients, but their support system. It's extremely, extremely important.

Host: So, this time these days in healthcare, you know, no discussion is complete without mentioning the COVID-19 context. And this is particularly true for transplantation, I think. When we think about the different situation that we have for people taking immunosuppressant medication, and it's not a small group when you look at the numbers, you know, it's 35,000 people every year receiving a new transplant in the United States. So, I'm curious to learn about what kinds of concerns your patients are raising with you when it comes to the pandemic when it comes to COVID-19.

PA Blackstock: You know, Rolf, that's an excellent question. And you know, I also want to acknowledge those are the patients that are getting transplanted. You know, on the post-transplant side, let's just acknowledge those patients that we also take care of pre-transplant, you know, and there are some disciplines, for instance, liver and lung and different transplants such that different protocols, if you will, but they actually manage those patients. They become the primary care provider for those patients, depending on how sick they are. So, you know, you can, in addition to that 35,000, maybe we can even quadruple that number when you think about the quote/unquote transplant umbrella. So, you know, what are we concerned about? It's access to healthcare, access to the COVID-19 vaccine. Equally important is access to the correct information. You know, I think Rolf you and your listeners can all appreciate the wonderful world of Google. You know, we can go ahead and Google anything, but, you know, keep in mind that the information that streams into Google may not be a hundred percent accurate or just might be information overload. So, that's one of the main things I'll tell you that we heard about, it's one access to the vaccine and then two access to accurate information as it pertains to the transplant patient. And so, through the many different transplant societies and, you know, just a joint effort, they've been working, or we've been working to put out information specific to the transplant patient. I would say that information and the right information was the major concern of patients, both on the pre and the post side.

Host: So, where would you recommend people go to access information that they can trust?

PA Blackstock: A wonderful question. So, the American Society for Transplant Surgeons, ASTS, they have wonderful information. American Society for Transplantation, AST, has phenomenal information. You have the Kidney Foundation, the National Kidney Foundation, excellent information there, as well. The nephrology associations, wonderful information, but specifically for the transplant patient, I would recommend ASTS they have wonderful, wonderful information.

Host: Well, you know, what we can do is we can add links to the description of the podcast on our website. So, anyone who's listening, if you come back to our website, then you'll be able to access the resources that we're talking about in this conversation. What about things like vaccine hesitancy and, you know, I've got to say, I live in Baltimore. I follow the Baltimore Department of Health on Facebook, and they've had a great campaign. They've had a really

good strong campaign, a very inclusive campaign. But I'm amazed by the number of people who are piling it in the comments section every time they post with disinformation.

PA Blackstock: You know, we were just talking about this, what is a major concern of our transplant patients, both pre and post, and it's really, you know, access to the right information. And, you know, I like to think of hesitancy, and I've been walking away from the term hesitancy, right? And I'm just saying, you know what, its deliberation. Our patients need information to make up their right minds. I'm not calling it hesitancy in my head and I'm approaching it as, you know what, you deserve the right information, because why wouldn't you deliberate on this major, you know, issue that's happening that's, COVID-19?

I'd like to say, "Well, what's COVID?" We can't say that, right. So, yes, you know, folks who have been marginalized, meaning, you know, who have a distrust in the healthcare system, they have every right to deliberate, right, just a little bit longer because they don't trust the information coming from the academic institutions. They don't trust information coming from the hospitals. And, you know, there's so much right and wrong information coming at you through sources like Google, and it's, you know, what do I do? So, you have folks who are confused, or people just, I just don't believe this. And they know what's safe for them is to do what they can, they can control what's in their world, which is, you know, not get the vaccine, ignore what's out there and just say, "I'm going to stay away from folks." And so, that lends itself to that hesitancy that you see that deliberation.

And so, how do we combat that? You know, we just have to say, listen, like the Baltimore Department of Health, what they're doing is this is the right information. Go to trusted sources, go to the academic centers, you know, go to your physician, your NP, or PA, your nurses, go to your providers and say, where can I get accurate information that you trust? Or, you know, what I would even encourage your listeners to do is ask your provider, well, did you take the vaccine? And why did you take the vaccine? And pose those questions that you have because believe me, we all have those same questions for ourselves. Because I was sitting there and getting my shot, my two shots, I did some research I had to think about it I went through all of the anxiety. Ultimately, I had all of the right information. I made my decision to take the shot. And that's where I work now. I work on the speaker's bureau here at the hospital to just deliver the right information, to help people make their minds up about the vaccine.

Host: It sounds like the key to that is the opportunity to have a conversation where if you're feeling cautious and there are things that are giving you concern, you can voice those things. You can have them acknowledged and you can talk through those. That's key.

PA Blackstock: And you know, we talked about this. This is something that I didn't come up with this term but meeting the patient where they are. I love that term and I've adopted that. This is exactly, you know what I mean when I talk about that. Where are you in your point of deliberating? Where are you in this point of making a decision that's best for you, your family, your loved ones, your friends? Let's talk, where are you? What are your concerns? What have you been hearing? You know, and something that I've heard quite a bit we've talked about nanotechnology and people hear that and they're thinking, nanorobots, wait, what are we talking about? You're injecting these little technologically advanced creatures in my arm, and now I'm going to become a 5G antenna? Are you're going to be able to track me? You know, and I take that seriously I said, well, let's talk about that. Let's talk about what it means to use nanotechnology when delivering the vaccine. Yes, you're right. We are talking about

these small particles to deliver information. Are they robots? No, but that's what I mean by let's have that real conversation. Let's meet you where you are. And so that we can start to pull apart and get you the right information to things that concern you. I think that's only fair and as healthcare providers, we owe that to our patients as a physician assistant. Well, we've now changed from physician assistant to physician associate that's the hottest thing in the PA world.

Host: I was going to ask you about that because that's new news, isn't it?

PA Blackstock: It is. It's breaking news.

Host: Is it official?

PA Blackstock: Well, are the AAPAs, the American Academy of Physician Assistants, or should it be Physician Associates, now voted the house of delegates voted last week to officially change the name from physician assistant to physician associates. So, what's interesting, Rolf, is that in the past we were actually, you know, that term physician associate was out there and in England as the UK is, you know, they're known as physician associates. So, it's a new thing as far as our association goes now, it's just time to change the laws state by state.

Host: You're going to have to reprint everything!

PA Blackstock: Well, you know, we'll stick with PA.

Host: Yes. So, I love what you're saying about meeting people where they are in terms of mindset, where are people sitting in terms of deliberation, in that process of deliberation, and what I've also seen with some really great initiatives that are focused on meeting people where they are to get vaccinated is the physical location.

PA Blackstock: Yes.

Host: So, taking vaccination to individuals, to churches, to community centers, in addition to the mass vaccination sites that we all know about that are in these, you know, like in Baltimore here, it's in the convention center. It's thousands of people. But not everybody can go and stand in line for an hour before they get actually to see someone. And then, the other area for meeting people where they are is also maybe recognizing resource availability.

PA Blackstock: That's right. You know, we talk about access, and you know, this is where we talk about social determinants of health. I think we've heard that term over and over. And what does that mean healthcare disparities? We've known since the 1970s that black and brown communities, not just black and brown, but marginalized communities and groups in lower socioeconomic groupings here, crossing that transcends race and ethnic boundaries that there's just been a lack of access to healthcare and to good health care. And why is that? We know that policies that became laws excluded access for certain groups. And that's where I'm talking about the black, brown and marginalized and lower socioeconomic grouping. And so, what did COVID teach us? COVID has no respect for boundaries, it has no respect for race, for social class, for economic class. I mean, it has no respect for that meaning that it's going to hit everyone equally and therefore, we have to respond, and we have to address, we have to attack, and we have to fight back this COVID-19 on all levels. And so, that's why you know, those, you know, your listeners, what I want to let you know

is that we're not trying to just get this vaccine out to you just because we're because we want to inoculate you with some kind of antenna or make you a 5G device, but we have to fight this in every group, because guess what, if we ignore a certain grouping of this population, that virus is going to sit, it's going to become stronger, it's going to form different variances and guess what? That virus is going to go back into the general population and undo all of the work that we did.

Host: Right.

PA Blackstock: So, we have to address this as a community. It takes a village and it's taught us that only as a village, only as a big global community, will we be able to address this and get this under control? So, that's why it's about time that we see some of these social determinants of health. Some of these disparities that we knew existed, this is why we're working to correct it. And if we can work to correct this with COVID-19, that means we can work to correct this with other things such as hypertension, diabetes, you know, because we have to work as a community because we are all interconnected. And that's what COVID has shown us.

Host: So, it's showing us that there was already a pandemic in terms of diabetes and obesity, and other conditions. And we have to tackle those conditions in the same way that we've tackled the pandemic.

PA Blackstock: Absolutely, absolutely and, you know, we can just look at, you said it the pandemic and endemic. I mean, we can go into gun violence. We can look at, you know, it's just so much more that we can look at, and this, if we get this right, there is no reason why we can't translate what we've learned here with COVID-19, into all aspects of life. You know, we need each other to survive that's pretty much what this is teaching us.

Host: So, just a couple of final questions as we're coming to the end of our time. First of all, health disparities within kidney transplantation, what are a couple of key disparities that you are particularly concerned about that we can maybe return to have a deeper discussion in the future?

PA Blackstock: Wow, phenomenal. Right? That's a phenomenal question. So, access to transplant centers, you know. We, the government has now required that anyone who receives dialysis should have some kind of referral to a transplant center, regardless of where you're located. You know, we saw the disparities where you know, patients who sought care at specific dialysis centers were getting referred to transplant centers at a higher rate than those black, brown and in marginalized communities. That's a huge, huge problem and while the government did mandate it and we can put things into play, we need to maintain a certain level of quality, and we need to make sure that we're not just doing this to check off a box, but that we're doing this to make some kind of a long sustaining you know, initiative and it's a good quality initiative that these folks are going to get educated and they're going to be seen at a transplant center and it's not just, oh, I made the referral. Oh, they didn't go. We need to look into why they're having difficulties going. Where is the closest transplant center to them? And what does access, what does transport look like to get that patient from Point A to the transplant center so they can be evaluated and back? If there's a problem with getting that patient there, then the transplant center needs to look at setting up a location in the community to serve those at greatest risk. And we know it exists, we just need to address it. So, access, access, access, it's huge. You know, we can't help them if they don't have

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access. And so, that's an area that we need to definitely talk a little bit more about, and that's something we can talk about in future episodes.

Host: And then, finally, what are some words of encouragement, or maybe some resources that you would particularly like to highlight to our listeners?

PA Blackstock: Thank you for that. So, there's a book written by Nadine Morsi, and I know you will post that link for us thank you. It's "[Kinsey's Kidney Adventure](#)." It's a wonderful, wonderful book. She had a phenomenal experience with her transplant center, and you know, what she wanted to highlight, you know, some things that maybe parents who don't know the system, they may face some obstacles. She wrote a wonderful, I mean, it's a great book. It's great for the pediatric patient, as well as the parent or the advocate that's going through that. So, I think that's a phenomenal resource. Shout out to Nadine. I had a wonderful talk with her, and we'll be interacting with her some more.

The other book that I really think should be at the cornerstone, or should be a required reading for everyone to understand why is there this distrust in the medical system? The book is written by author [Harriet Washington](#), a phenomenal author, she's written several books, but this book, in particular, is called, "[Medical Apartheid](#)". You know, most people, when you talk about what did the African American community goes through and why do they have the distrust? Most people talk about the Tuskegee Experiment and, you know, shame on us for labelling Tuskegee, which is a phenomenal institution, and most people think of Tuskegee as, "Oh, the Tuskegee syphilis experiments." Tuskegee is much more than that, right? Similar to that in that vein, there's a lot more that went into the distrust that Black Americans have towards the medical system. And with that, we can talk about the same thing with folks who are in lower socioeconomic groupings. You know, we can talk about our Chinese Americans, our Latin X community as to why they have a distrust, but I think that one book really, it will open the floodgates for you to really understand why is it that our Black Americans have this issue.

Host: Speaking as a white person, who's come into this space and trying to understand terms like structural racism or systemic racism, I think these are the concepts that are difficult to grasp unless you do a little bit of work, and then you do the reading and you come to grips with just the immense scale of what's been going on for hundreds of years.

PA Blackstock: Yes, that's actually a great point. And, you know, something that we are learning again, we're not in this by ourselves, you know, and that's why I love to have these conversations with everyone. And I've always been open regardless of your background because we need these alliances, we need this companionship, we need to speak up for each other, and again, the point that I've been making, we are a village, we're a global village, and that's the only way that we're really going to get to that next level as a group, as a village, we need each other.

Host: Daryle It's been a real pleasure. Thanks for joining us today and thanks for being the first healthcare provider to come onto the podcast. So, you're blazing that trail.

PA Blackstock: I just can't believe the time flew by so fast. I could listen to your accent like all day. I don't know, I love talking to my family in England just because of this but thank you so much.



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Host: My pleasure, absolutely and yeah, please come back and we'll continue the conversation in the future. Daryle Blackstock, many thanks.

PA Blackstock: Thank you so much. Take care, everyone.

Host: This concludes our first episode of Kidney Transplant Conversations. It's been a pleasure to have Risa Simon and PA Daryle Blackstock visit with us today and we hope you've enjoyed joining our discussions. Links to resources mentioned in the podcast can be found on our website. We thank the participants and advisors who helped create this podcast and our underwriter, Veloxis Pharmaceuticals. Join us again soon for more Kidney Transplant Conversations. Copyright, Project Advocacy, 2021.

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Resources mentioned in this episode:

[TransplantFirst Academy](#)

[ASTS Patient Resources](#)

[AST Patient Resources](#)

[NKF Patient Resources](#)

[AAKP Patient Resources](#)

[Kinsey's Kidney Adventure by Nadine Morsi](#)

[Medical Apartheid by Harriet Washington](#)