Is talking about health equity translating into action? Plus: discussion about the Transplant Workup.

Featuring kidney transplant surgeon Dr. Velma Scantlebury.

In this episode of Kidney Transplant Conversations, we are joined by history maker Dr. Velma Scantlebury, who became the first Black female transplant surgeon in the US in 1989.

In a wide-ranging discussion we ask whether all the current talk about health equity is resulting in real action, and we explore several current examples of intentional change. Firstly, the "Boldly Against Racism" Campaign at the American Society of Transplant Surgeons (ASTS); secondly, the updated Hippocratic Oath at Columbia University Vagelos College of Physicians and Surgeons, clearly centering health equity, diversity, and inclusion; and thirdly the recent recommendations affecting the way that kidney function calculations (eGFR) are made. Dr. Scantlebury also shares her concerns that patients with fewer resources are being disadvantaged by the burden of appointments required in preparing for a transplant and this may extend how long patients are kept on dialysis, acting as a potential barrier to transplantation.

We also discuss ways that consideration of social determinants, along with a more diverse healthcare team, can help improve the quality of care for kidney disease patients, and help to increase the number of kidney transplants received. With podcast host Rolf Taylor.

Kidney Transplant Conversations is underwritten by Veloxis Pharmaceuticals, Inc. All views and opinions expressed in the podcast reflect those of the participants and do not necessarily represent the views and opinions of Veloxis Pharmaceuticals, Inc.

Resources and links

ASTS Boldly Against Racism Campaign
https://asts.org/about-asts/boldly-against-racism-campaign#.YZKxAL3MLa4

Columbia University Vagelos College of Physicians and Surgeons Hippocratic Oath
https://www.youtube.com/watch?v=AujwxJNZtp8

Time to Eliminate Health Care Disparities in the Estimation of Kidney Function
https://www.nejm.org/doi/full/10.1056/NEJMe2114918

TRANSCRIPTION

Host: Welcome to another episode of kidney transplant conversations. A podcast dedicated to the kidney transplant journey, exploring quality care delivery, inclusion, diversity, health equity, access, and allyship. I'm Rolf Taylor, your host and series producer. All views and opinions expressed in this podcast reflect those

of the participants only. If you find this of interest, you can subscribe on all the leading platforms and please do share links to friends and colleagues. Today's conversation is with history maker, Dr. Velma Scantlebury who became the nation's first black female transplant surgeon in 1989. Dr. Scantlebury joined our advisory committee representing the American Society of Transplant Surgeons whose, Boldly Against Racism campaign stands against racism of any kind that is affecting underrepresented minorities and especially Black Americans. A graduate of Columbia Medical School. Dr. Scantlebury has accomplished extensive published research and accolades. Welcome Dr. Scantlebury to Kidney Transplant Conversations.

Dr. Scantlebury: Thank you so much for having me on this podcast. I'm excited to be here and I want to say a shout out to all the listeners and hope that our conversation will be something that you will find meaningful, worthwhile and something you can tell your friends and family to come back and listen to again and again. So, thank you so much.

Host: So, we've had a lot of great conversations already on the podcast and you can't help but listen to the conversations and get the feeling that in general, we're moving towards more inclusive and culturally competent care. At least, you know, it seems like people are talking about it more. To what extent do you think that really is translating into actual action?

Dr. Scantlebury: Well, one of the things that 2020, I think especially with COVID, and we know that COVID unmasks so much inequality or inequities of healthcare when it comes to not only social but certainly medical injustices. And so, we've gotten to a place where we know that healthcare inequities exist, and we knew that for many generations. We've talked about it, but what has happened in 2020 is, it caused us to really buckle down, admit that there are disparities and what can we do about eliminating those disparities? Because when we look at COVID, we realized that there were certain minorities or people of color who were most effected when it came to being sicker, hospitalized, as well as dying. And a lot of those patients were people of color. And so, those disparities, what it comes to is really healthcare disparities in terms of the diseases they have that put them more at risk for even renal failure and the need for dialysis as the result of COVID. Many of this was not really understood in the beginning and not talked about really but patients who have underlying problems tend to be impacted more or have been impacted more by COVID. And so yes, it does translate into us saying, what can we do about it? How can we address the social and health inequities within our system to begin to level the playing field when it comes to appropriate healthcare?

Host: So, would you say that even though we have all this knowledge, there's still a kind of certain reluctance from some physicians to really embrace the idea of things like cultural competency?

Dr. Scantlebury: Well, certainly, the younger the physicians are the more likely they are to see that this is really the backbone of adequate healthcare and to begin to dismantle the structural and institutional racism that are built into our system that unfortunately translates into inequities. And yes, there are those who don't see it and don't get it, but we are counting on the majority of our healthcare professionals that say, yes, we do have these problems. Yes, we do need to focus on culturally competent healthcare professionals because that is our community. Our communities are becoming more diverse.

USA, as far as population, we have more and more people of color and ethnic backgrounds continually showing up in our practices. And so, we have to be knowledgeable when it comes to different cultures, integrating that culture and understanding human behavior, not just from the language perspective, but understand the customs and the beliefs and how they integrate their families into religious and social groups. And so, a lot of that can affect healthcare and how they view healthcare professionals. Are they understanding them? Do they really know about their background? Are they understanding the dynamics of the family unit? So, when you ask to speak to a patient of a certain cultural difference, in their eyes, it's a family problem. So, you don't ask the rest of the family to leave. They see that as an insult. They want everyone to hear. So, while you may be saying, well, you know, this is not HIPAA. This is not according to HIPAA, but to them that's their culture. So, speaking to the grandfather and the grandmother is as important as speaking to the patients. So, I think it's important that we understand that we all need to be culturally competent. And competence is having that ability and capacity to function effectively within that context of that culture and the beliefs so that you can effectively deliver appropriate healthcare.

Host: And I think what we do see is that the more challenging or the more complex the medical situation, the more likely it is that disparities can creep in that disproportionately impact communities of color. And so, I think an example that we had discussed that's very relevant to that is the workup ahead of transplantations. So, we know candidates for renal transplantation need to undergo an extensive evaluation or workup to understand suitability and identify factors that may have an adverse effect on outcomes. And the workup requires significant attention from the patient and also where applicable, the donor. And so, because patients are very

different and patients are very diverse, not every patient completes this on time, maybe risking delaying, or even losing their opportunity for transplant. So, what's going on there?

Dr. Scantlebury: I think it's important to realize that, you know, you have different patients, different backgrounds, different socioeconomic status. And so, when you see a patient and understand that every patient is different and therefore not every situation is going to apply to every patient. So where is this patient coming from? So, this patient missed their appointment or didn't show up. So, you don't think of them as, okay, they're non-compliant in not keeping their appointments. But you then have to look, take a step back and look at their situation. Why did they miss two appointments? Perhaps they have childcare problems. Maybe they have problems paying for the bus ride or those transportation issues. They didn't call in time to have the bus pick them up, or the public transportation that may be able to take them from point A to point B or maybe their car broke down. So, when you think about whether someone is meeting what you see as your requirements for completing that workup may drag on because there are inequities within this patient's social background that makes it a little bit harder for them to get there on time or to decide whether or not they save that money for that bus ride tomorrow or buy lunch today. So, I think we need to dig a little bit deeper and make sure that as a healthcare team, that we are providing the appropriate resources for all our patients and that some patients are facing many more challenges than others.

Host: So, we could right now have some prospective transplant recipients listening to the podcast and they've tuned to the podcast because they know that kidney transplant is perhaps on the horizon. Maybe they're having some challenges with the workup, with the evaluation. We've already heard on previous episodes about people experiencing delays in getting through the process that has really extended the amount of time that they were on dialysis. What's your advice to people in terms of how can they get more help? How can they get more understanding? How can they get some facilitation of that process?

Dr. Scantlebury: It's important to really discuss with the health care team at the transplant center, or even your dialysis unit who where there's a social worker, that's there a nutritionist people who can help you. But most importantly, if there are barriers that you're facing, don't be embarrassed about those things that you can't meet, because we are there to help you. There are services on every transplant team, that's there to provide all the necessary help, and each transplant team must have a social worker, a financial person to help you get through what's necessary, are the correct insurance that you need to help you with your medications and dietician to help

you, if you have to lose weight and you have challenges with that, who can give you some exercise or hook you up with some facilities that are sort of working hand in hand with the transplant center.

One of the things that we used to have at our center was that the nearby university offered what we call renal rehab, which allowed for patients who had renal disease on dialysis or waiting transplantation to come to their center. They evaluate them to see if they need more help in terms of being able to get to the point where they're more independent or they need to build muscle strength and all those kinds of things they are there to help for. So be sure to reach out to your transplant coordinator, as well as the social worker, the dialysis nurse, as well as their social workers also have information available to help you. So, it's important to say, I need help getting from point A to point B and what can I do? How can you help me get there? And we can't help you or the team can't help you if we don't know what your issues are.

Host: So clearly one of the solutions is to have more diversity in healthcare teams.

Dr. Scantlebury: It's essential and it's an important aspect because sometimes if we oftentimes say for instance, we take our Hispanic communities, we make sure we try to have a translator there to make sure some of the information isn't lost in the interpretation. Oftentimes, even in situations where they may say, well, I don't need a translator, I'm good, and you find that if I have a healthcare professional who is able to speak their same language or dialect puts it to a new level and they walk away with totally understanding that they misunderstood what you just said. A lot of you think we may be able to, they're understanding. They're not, they're telling us they understand, or they nod the head and so we misrepresent them, they may misrepresent us. So having someone who is able to speak their language, is familiar with their background, their culture and the practices and you know, the things that they do, can relate to them to say, okay, this patient cannot come on this particular day because this is what they do on that day. And this is understanding their practices as opposed to saying, well, why did you not show up? Now you gain a little bit more into the background and having that cultural ability to understand that patient and their family and move that to a different level. And I think that's some patients feel comfortable. I know many times I walk into a room and the African American patients, they're like, “Oh, I'm really glad you're here, that you're my doctor today because I feel so much better. You know, I can trust you a little bit more. I know you have my back.” So, those are things that if they can relate to you, not to say that it doesn't work the other way around. But yes, there's that level of comfort that that person really understands and gets them.

Host: And when it comes to diversity in healthcare teams, would you like to share a little about some of the challenges you faced and, also things that helps?

Dr. Scantlebury: Well, certainly, you know, for me, in my training, for instance as the only black female or the only person of color on the team, it was sometimes challenging. Sometimes the majority patients are a little bit, they're uncomfortable with me as an African American or they're in that place where they would rather have someone else or they're uncomfortable with me as a female. And so, those are challenges that I have to deal with, understand that people come from different places. Some people carry their own biases and their own levels of racism, and we each carry our own biases from that perspective. But I think it's important for me, it was important for me to get to the place where I do not see that as a personal insult, but more a level of ignorance on their part and not willing to embrace my difference. And you know, it's not just seeing someone is different, but be able to embrace the differences. And that's how we begin to bridge that gap in being able to say, no, I can learn about you, I can learn about your culture because now I'm inquisitive. I want to know more about you. The same thing with patients and physicians. You know, oftentimes patients will say to me, well, you know, that doctor really talked down to me, like I was a child. Almost like I didn't understand what he was saying, or he's speaking so loud like if he speaks louder, I can't hear what he's saying, and if they speak louder, perhaps they feel like I get it more. So, it does help in some ways to be able to be in that position where patients can air things to me from a perspective that they don't feel comfortable with other physicians. But certainly, for me, it's about having people respect who I am and the care that I'm able to deliver. Not everyone has to like their physician, but you really want to be able to say I trust you and I'm really coming from a place where I know you're going to do the best for me. And I want patients to be able to feel at the end of the day that I'm here for them, and I'm doing my best to keep them healthy.

Host: You feel like you actually benefited from specific diversity and inclusion initiatives during, you know, likely early career?

Dr. Scantlebury: Well, early in my career, there were no DEI initiatives. That was a long time ago. And so, then it was more or less, you know, sometimes I got the, we don't want you here. I got the patient who wanted me to leave the room and not be part of the team. And so those were things that you sort of look to your upper level for support. And that was something that I think for me at my level, understanding as the residents go into the room or people of various backgrounds, that when patients come forth with their, I should say, with their biases to be able to support those healthcare professionals of diverse backgrounds and to embrace that they're here to

help you. They're not here as a threat and they're going to deliver appropriate service. So, it really helps to have advocates who are behind and there to support you and are willing to stand up for you and your presence as a healthcare professional.

Host: So, I mentioned earlier that ASTS has created Boldly Against Racism, a taskforce and called for membership votes to change bylaws. Could you share with us a little bit about what were the changes to the bylaws that were being called for?

Dr. Scantlebury: Well, let me say that, you know, for those on the call ASTS is the American Society of Transplant Surgeons. As a body, our goal with our previous president of the ASTS was to really, as you said early, to really address racism within our society and our taskforce, but boldly against racism was really to do that. And so, in order to address the needs of both with the field of transplantation and its members, the goal really was to be able to see that we need to institute changes that would allow us to embrace the diversity of the organization. And if you look at top leadership, there were basically all Caucasian backgrounds for the majority of those serving on the leadership position. So, basically part of the goal was to be able to say they've only had a few female presidents of the society, and they've only had primarily white males and women. So, the goal is how do we begin to embrace diversity? And part of that was beginning to be able to say, we need to bring in, for those who have on the level of leadership to be able to have positions that would allow for the chair of our Bold Against Racism Task Force be someone to be considered for a leadership position. How do you have organizations with people of color, have the ability to be part of leadership as well as to have a vote that counts, and I think that becomes important. So, in terms of instituting change, it's really about changing the bylaws and if changed the bylaws, we needed to have membership have their input into that. And so, if you're going to effect change and you lobby, and you really want to have people who are for these changes and to stand, begin to integrate and to have diversity in leadership positions, that's what we did.

Dr. Scantlebury: So, we didn't have a unanimous embrace by membership, but we certainly had an overwhelming majority to be able to bring about some changes in the bylaws. And yes, it's always going to be that part that's going to be resistant. But again, majority rules. And you want to make sure that even if there's only three or 400 people that showed up for the meeting, that that majority really made a difference. And, you know, with any voting process, as we see here in the United States, there's always going to be competition and there's always someone against a statement or proposition, or even the president of the United States.

Host: I think what I'm hearing is that that intentionality is being co-defined and enshrined in those bylaws and that results in a different framework and different decision-making and facilitate generally a more equitable climate and approach within the organization.

Dr. Scantlebury: Right. You know, and to take action with anything you need to institute something in your bylaws, and it has to be put in place so that you can change the old ways of the rules. Change the rules that were set 25 years, 30 years ago. And so, because your demographics have changed being able to look at the makeup of your organization and even just knowing who is in your organization. Who are you serving? Are you meeting the needs of the constituents? So that becomes important. As far as leadership, the same thing. Now we're more diverse, but how do we embrace our membership and begin to put laws in place, bylaws in place that allow for a diverse leadership coming down the pipeline in the next coming years.

Host: You sent me another really great example of intentionality. Something that's happened at Columbia University. What I found really amazing and inspiring was what you sent was a link to a video of the annual white coat ceremony for the class of 2025. So, this is the incoming class for the medical school and for the first-time students recited their own class oath. In fact, the oath had been rewritten by the incoming class and facilitated by senior students and faculty to better reflect the values they wish to uphold as they enter their medical training. And I think it captures, you know, the core intentions of cultural competency perfectly. So, I wanted to share this with the listeners and then give you an opportunity to respond to this from your old medical school. So, here's what they said, and it was just at the end of August 2021.

Recording: *We enter the profession of medicine with appreciation for the opportunities to build on the scientific and humanistic achieves of the past. We also recognize the acts and systems of oppression affected in the name of medicine. We take this oath of service to begin building a future grounded in truth, restoration and equity to fulfill medicine's capacity to liberate. I make this pledge to myself, my classmates and future colleagues and the individuals and communities I will serve. I acknowledge that my role is to inform my patients, accompanying them in moments of wellness and vulnerability and respect their privacy and autonomy while empowering them to flourish. I promise to take care of my future patients by engaging in dialogue, listening to their lived experience, and tailoring my recommendations to their unique circumstances. I commit to honor the relationship formed between patient and physician, by maintaining confidentiality at all times. I vow to contribute to the field of medicine through ethical studies and equitable evidence-based care, and to*

treat my patients and represent my profession with compassion, humility, and equanimity. I acknowledge the past and present failures of medicine to abide by its obligation to do no harm and affirm the need to address the systemic issues and the institutions I uphold. I promise to critically examine the systems and experiences that impact every person's health and ability to receive care. I vow to use this knowledge, to uplift my patients and disrupt the injustices that harm them as I forge the future of medicine.

I acknowledge the background and experiences that enrich my perspective, while recognizing the limitations, shortcomings, and biases that I bring to each encounter with patients and colleagues. I promise to self-reflect diligently, to confront unconscious prejudices and to develop the skills, knowledge, and character necessary to engender an inclusive, equitable field of medicine. I commit to fostering empathy and a culture of care, not just for our patients, but for ourselves and our colleagues in healthcare.

I vow to remember the humanity and tolerability of myself and every member of the care team and to call upon my colleagues for assistance in recognition of the limits of my knowledge and skills. I acknowledge and embrace the diversity that exists within all communities and the formative influence that the Washington Heights community will have on my future as a physician. I promise to respect regardless of identity or socioeconomic status, the fundamental dignity of all patients, colleagues and community members and their right to quality care. I vow to restore trust where it has been broken and to inspire and nurture trust in the relationships I build with patients through collaborative effort with my colleagues and communities. Let us bow our heads in recognition of the gravity of this oath. We swear to faithfully engage with these ideals and obligations to the ongoing betterment of mankind and humanity.

It is now my honor to present the class of 2025. Please turn around to your families and friends.

Host: I'm struck by the humility of that updated oath.

Dr. Scantlebury: It is without question one of the most dramatic things that I have ever seen. I mean, you have to recognize that Columbia University was one of the first medical schools to have a white coat ceremony starting back in 1993. And it's important to know that for them, this class of 2025 has more students from underrepresented minority backgrounds than any other medical school class in the history of Columbia. So, here with the previous precedents that have occurred in 2019 and

2020, this is a class that was ready to begin to say, we see things differently. We need to make decisions differently. And because we're going to be taking care of patients and their treatments based on their disease and their individuality, it recognizes that the circumstances of these patients who their own circumstances that will, and by and large determine the outcome of the treatment. So, you have to not only care for the patient, but you also have to care about their circumstances. And that's why it's so very important to have that ability to confront your unconscious prejudices. And if you weren't going to be a medical student practicing in that area, you have to begin to embrace the neighborhood and the people in that neighborhood, whether they're of the Latin X community or African American community or Asian community, which for Washington Heights is tremendously diverse. So yes, this has been, I think a new look at a newer version of the Hippocratic Oath because it's not the old version, but it's their oath and the way that they want to be able to say, as a student, this is what I want to embrace and this is the way this is going to affect me as I continue my life experiences beyond medical school.

Host: Would you say this is a good example of talk becoming action because it really is. It's just such an explicit statement of intention.

Dr. Scantlebury: Exactly. Because one of the things that even has brought about the change in as far as nephrology of the changes and question of say the estimated GFR, glomerular filtration rate, was a medical student. Asking the question why does race have to come into this equation? And so, we see things and we take things, and we do things in a routine, but it takes someone looking at things from a different perspective to say, how does this play a role, why is this here, what can we do differently and does this really affect the outcome of our patients? And yes, it does and what does race have to do with this care of this patient? It shouldn't matter. And so, it's about those young people who you may say, you know, ask the whys, continue to ask those questions, and seek answers and begin to know that your goal is to do no harm. And like it says, is there to really affirm the need to address systemic issues that within our old institutions that we have put in place for years and years and haven't questioned.

Host: So, it was actually medical students that really called into question the whole way that there were basically two sets of outcomes depending on race. The potential or the reality is that that many black patients have had transplant delayed because of the way that that protocol works.

Dr. Scantlebury: Right because it was assumed that as a black person you have more muscle mass. So, we're going to create a formula that puts in race. So, when you get your blood work and you know, you do routinely, unfortunately this country has adopted that race is seen as you are black or non-black. What about people who fall between? So, you look at your blood work and you see, this is my creatine, my EGFR if I'm black, and this is my EGFR if I'm non-black. So, why should it matter? It matters if it's going to put you at a disadvantage and give you a higher EGFR, which then limits you from getting to the transplant waiting list, because now you need an EGFR of 20 to be on the list or below, but now this formula puts you at a EGFR of 23 or 24. It may sound good, but it keeps you from being listed. Then you get to that range where it really matters.

Host: So that specific outcome means that you're less likely to be put onto the transplant wait list.

Dr. Scantlebury: Right. If you take equal across the board, black and white patient, height, weight, body mass index, all those stuff and creatine level and plug them in, let's say they both have a creatine of three, they weight the same, the EGFR for, let's say creatine five, and you expect that this is going to be a Caucasian person, then the formula may come up with a EGFRs of 18, but the black person may have an EGFR of 22.

Host: So that can explain why when you look at the data, there is a difference in generally how long black patients stay on dialysis compared to white patients, and it's longer.

Dr. Scantlebury: Well, it is from a different perspective because once you get below 20, one of the things that we're seeing, we see is that patients are diagnosed late in the course of their disease, and there may be only given the option of, well, you have to, you know, we're going to put you on dialysis. When a patient hears that, they don't hear well, you know, have you ever thought about transplantation? That comes way down the line. So, then they're on dialysis and they're dismissed because they may be overweight. They may not be seen as being compliant. They may not be the ideal candidate, so, they're put into the category of not being suitable for transplantation, as opposed to referral. But now we have, by the time they get to referral, they can still gain their wait in time that goes back to the date, the start referral. But I still questioned patients who have sitting in on dialysis five and six and eight years and try to say, well, are you just coming forward to get a transplant? Why did you not show up the first time you knew that you ended up on dialysis. Did you know of transplant in the beginning? And I think those are the things that begin to give us a greater understanding of why patients are delayed. I mean, they have one lady who's

been on dialysis for, she was on dialysis for 15 years and her physician told her that kidney transplant was still experimental. So, she never sought out getting to the waiting list. I'm like, who does that? So yes, information is key.

Host: And as we've seen with the COVID vaccination, using the word experimental makes it immediately a loaded term.

Dr. Scantlebury: Yes. I mean, if you're doing transplant since the first successful transplant in 1952, and, you know, granted we now have better medications to do a reverse rejection. We have better monitoring avenues to keep for longevity of the transplant. And so, the reason why it is the gold standard for treatment of end stage kidney disease is you live a better life, you live a longer life, and you have less complications as compared to patients who live on dialysis, who stay on dialysis with overwhelming heart disease and 50% mortality for some age groups.

Host: So, we will be returning to the subject of EGFR in future episodes, because I know that change is coming. So, we will be dedicating future episodes to the subject and I'm really glad we introduced it today for discussion. Dr. Scantlebury, do you have any closing comments that you'd just like to share with our listeners?

Dr. Scantlebury: Well, I would like to thank you very much for allowing me to be on this podcast and to talk about some of the racial and ethnic disparities as it relates to our patient population and that's kidney disease and dialysis patients, and getting on the waiting list and understanding that there are many barriers to patients who don't have the smooth course and access to be diagnosed early, to avoid dialysis and to have preemptive transplant. And while that is ideal, we can still begin to educate our patients, even within the healthcare community or your primary physician to understand that dialysis is not the only option and that there are better options out there. You just need to be educated about them. Ask more questions. Ask your physicians about what they can do to help you get there. And if you aren't in the system, reach out for help, so you can navigate the system better and get on the active waiting list and not be inactive. You don't want to sit there for not getting a call. You want to be able to say, I want to be active. I want to be able to not miss that call and not miss that kidney that is supposedly for me or my turn when it becomes available.

Host: Dr. Scantlebury, it's been such a pleasure to talk with you today. Thank you for joining us on the podcast and also, you know, thank you for all your help with advising on the podcast as well. It's a real pleasure. I look forward to us speaking once again about other subjects in the future.

Dr. Scantlebury: Thank you so much again, have a wonderful day.

Host: And thank you to our listeners for joining us today. If you enjoyed the podcast, please consider sharing it with others and subscribing on any of the leading podcast platforms and smart speakers. We also thank the participants and advisors who helped create this podcast and our underwriter, Veloxis Pharmaceuticals. Join us, again, soon for more kidney transplant conversations. Until next time, take care and be well.