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Underrepresented Communities in Rare or Kidney Disease Clinical Trials: Why Is This Important?

Announcer:
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Dr. Kovesdy:
Well hello, my name is Csaba Kovesdy. I am a Professor of Medicine in Nephrology at the University of Tennessee Health Science Center and the Memphis V.A. Medical Center. It is a pleasure to be here and to participate in this program entitled: Underrepresented Communities in Rare or Kidney Disease Clinical Trials: Why Is This Important? With me are my two esteemed colleagues, Dr. Adriana Hung, who is an Associate Professor of Medicine in the Division of Nephrology and Hypertension at Vanderbilt University and Hemodialysis Director at the Nashville V.A. Medical Center, and Dr. Martin Pollak, who is a Professor of Medicine at Beth Israel Medical Center and Harvard Medical School. Welcome Adriana and Martin.

So, let me start with a question about clinical trials in general in nephrology. Adriana, can you tell us are there adequate numbers of clinical trials for kidney disease, and specifically for chronic kidney disease?

Dr. Hung:
Hello. It's very interesting, and I think that the nephrology community is familiar with the fact that there's a lack of clinical trials in nephrology. This is extremely important, because clinical trials that are devoted to the kidney population is the only way that we can inform safety and efficacy of different drugs in this population, whether they are devoted to slow the progression of kidney disease, or to improve kidney - any outcomes actually, in general. And it's important to change this epidemiology because we know that CKD is a major public health problem.

Dr. Kovesdy:
Yes, it's like 15% of the population, right, suffering from a chronic kidney disease. Yet, in my experience, when we look at the number of CKD trials, they are really dwarfed by the numbers that we see in cardiology or in oncology, for example, and it really puts our patients at a disadvantage. So thank you.

And Martin, let me throw this question at you here. So talking specifically about certain populations with kidney disease, are there trials that are representative of underserved populations, for example?

Dr. Pollak:
Yeah, well, I think that the answer to that is highly variable. I mean, as you just pointed out, kidney disease does disproportionately affect underserved populations. And certain forms of disease seem to be somewhat more prevalent in certain populations than others. You know, for example, APOL1-associated kidney disease is more common in people have recent African ancestry. You know, it's a little tricky, because not everyone knows their ancestry. In the United States, most people who identify as Black or African American, have recent African ancestry. On the other hand, we have to understand that, you know, some things are really ancestry driven. They're not driven by race, per se, and so we shouldn't make that mistake. And we shouldn't assume that anyone in a particular population has

one disease or another certainly. You know, there are plenty of people who don't identify as Black may have APOL1-associated kidney disease. Someone of course who is Black may not have APOL1-associated disease, they may have polycystic kidney disease. So we need to be, I think - it's just very important to be accurate.

Dr. Kovesdy:
Nevertheless, I guess, you know, we know that APOL1 mediates at least kidney disease in a fairly large proportion of African Americans who are considered underrepresented in clinical trials. Am I correct?

Dr. Pollak:
Yes, I totally agree. I mean, I think, you know, we don't know if therapies that are going to be effective in kidney disease of one etiology are going to be also effective in diseases of another etiology. And so, you know, it's important that we, you know, intelligently, you know, lump and split populations for study. It's important that, you know, if we have a therapeutic that we think is going to be particularly effective in, let's say, APOL1-associated kidney disease, that the trial, you know, consists of people with that form of disease. So it's, you know, a variety of factors can contribute to kidney disease. And, you know, some trials may only be valid in the context of certain contributing factors. So we need to intelligently design our trials and include the appropriate populations.

Dr. Kovesdy:
And following up on that, Adriana, let's then think about what strategies could one use. Let's say, if you're a researcher, how could we improve access to medications to these underserved populations? And of course, if medications don't exist, then first we need to improve access to these clinical trials. Because without those, we won't have any medications. So what do you think? What would be some strategies to improve access to clinical trials or treatments?

Dr. Hung:
Absolutely. And I want to take a step back Csaba. I think in order to improve access to these populations, we have to develop, to dose medications, we have to develop those medications. And in order to do that, we really also need to increase the representation of a diverse population in current studies that are doing genetics and discovery and informing the interaction with the environment so that we can learn of new target therapies, new targets that we can aim with the medication. I think that's crucial. Then when we get lucky enough to recognize, and it can be in many dimensions, I can imagine even the response to MMF and lupus nephritis, how it is different in African Americans and Latinos compared to European Americans. Clearly, the disparity with APOL1, right? So we have to understand those disparities and to be able to offer them to those populations.

I think that engaging with the population is not as hard when they understand that they're differentially affected by a given disease. I have enrolled patients with APOL1 for studies, and they're truly invested in understanding how it affects them, their families, and I think, how that changes the care that is provided by their physicians.

So I think it's very important to enroll a diverse population into research studies in general, so that when we have the information, and the medications that can improve outcomes, can then be offered to them. I think these different segments of the population, whether they're African ancestry individuals, or individuals that are from the Caribbean countries, they are interested in participating in studies.

Dr. Kovesdy:
I guess you're pointing out the importance of education, which cannot be stressed enough, so that they become knowledgeable and engaged in their own disease state. So that's very interesting.

Martin, let me throw it to you now. So could you just share maybe some strategy or anything that you have found useful in engaging maybe underrepresented populations in research or in treatment efforts?

Dr. Pollak:
Yeah, well, I think outreach efforts are important, educational programs, and making sure your clinics are, you know, accessible to the broad population. I think education is really important. And I think, you know, trying to be really honest and accurate about the way that we convey information is critical. We, you know, want to be accurate. We should not, for example, you know, overestimate or underestimate the contribution of any particular factor to disease. We should not be paternalistic. We shouldn't assume that a person would or would not want to participate in a study. We shouldn't assume that a person won't understand the study. It's very important to be honest, to not be paternalistic. Ideally, to have diverse staff involved in running the study. All these things I think can help.

Dr. Kovesdy:
Yes, we bring up very good points there talking about the diversity of the staff, because patients are probably more open when the staff looks like their community.

And I found it very useful to work with community outreach organizations here in our area. There are efforts to improve blood pressure

control, for example, in the community, and these existing frameworks and networks can be utilized to engage these communities in clinical trials that are directly relevant to these populations.

Dr. Hung:
Absolutely. I think we need to incorporate our initiative for community engagement.

Dr. Kovesdy:
So we discussed today about the importance of having good numbers of clinical trials in nephrology. The fact that nephrology is underrepresented in the clinical trial landscape is really a disservice to our patients, especially to those patients who are difficult to reach and are underrepresented in even the smaller number of trials that we do. Because these are the populations that most suffer from kidney disease, especially, for example, we brought as an example, APOL1-mediated kidney disease, which affects a large proportion of our African American patient population. Yet they are typically underrepresented in clinical trials, as has been shown by recent high-profile trials of cardiorenal protective medications that now are available to patients with chronic kidney disease. So it is very important to educate our patients and to foster outreach efforts to diversify our own clinical practices to assure that our patients are knowledgeable, engaged, and willing and eager to participate in trials so that this will lead ultimately to the development of interventions that will directly benefit them.

I think we are in a good position in nephrology. There is an important movement towards increasing clinical trials of drug development, and I'm pretty certain that we will see an increasing number of therapeutics available to a large number of patients with CKD, which ultimately should lead to an improvement in their kidney outcomes. So, with that, I'd like to thank you for your attention, and have a great day.

Announcer:
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