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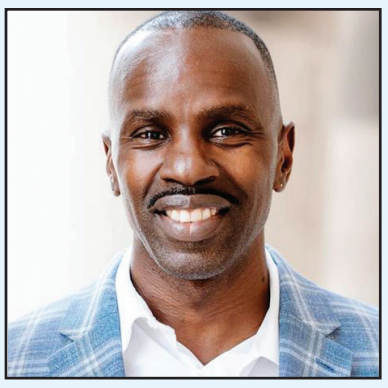
Precision medicine and chronic kidney disease

Precision medicine is unique in that it safeguards both individuals and communities. Precision medicine's mission is to move away from a one-size-fits-all approach and towards personalized healthcare. One of the cornerstones of precision medicine is genetics and genetics are highly individual. We all possess our own unique genetic blueprint that can inform our health decisions. Such information can serve as a user manual when it comes to understanding our own health and what choices to make to optimize it. One such example relates to chronic kidney disease (CKD). When a patient discovers that they have the APOL1 genetic variation that increases the risk of CKD, they can prioritize lowering their blood pressure. This kind of health information empowers and equips individuals in a way that the one-size-fits-all approach has never been able to accomplish.

While genetics is a key factor in precision medicine, it is not the only one. Precision medicine considers social determinants of health, environments, and exposures. Our communities are our contexts. Understanding what happens in our communities and how those things affect health and wellness is squarely within the realm of precision medicine. More than anything, precision medicine offers a glimpse at a future where our neighbors are well-supported and receiving care and treatment that is made for them.

In recent years, social determinants of health have garnered recognition for their incredible ability to predict and



CARLOS T. CARTER

affect health outcomes. Social determinants of health include the following categories: education access and quality, health care access and quality, neighborhood and built environment, social and community context, and economic stability. Precision medicine asks the right questions with social determinants of health in mind. Does this person have access to quality health information? What is the air quality or water quality like in this person's home? Does this person have robust social supports? These questions are examples of how precision medicine and its reliance on the social determinants of health analyzes the whole person and their whole situation.

CKD serves as an excellent example of how precision medicine is going to address community-based needs. CKD disproportionately affects the Black community. Its root causes are not only genetic—they are social. Diabetes and high blood pressure, both risk factors for the development of CKD, are triggered in part by lack of access to nutritious food. Because Black communities are more likely to be situated in food deserts, it is often difficult or impossible to sustain a nutritious diet leading to higher rates of CKD-causing conditions. Precision medicine does not ignore that reality. Instead, it centers and elevates it.

Our hope is that precision medicine will usher in an era of healthcare representation for all. One-size-fits-all approaches based on standards that have historically excluded the Black community will no longer be the default. This great promise of precision medicine is emphasized by its recognition of oppression, injustice, and inequality as factors of health.

Carlos T. Carter is President & CEO, Urban League of Greater Pittsburgh

Fighting chronic kidney disease disparities with genetic know-how

More than any other group, Black people suffer from chronic kidney disease (CKD) and are more likely to develop kidney failure, according to the American Kidney Fund.

Based on the most recent U.S. data about end-stage CKD, there were 5,855 cases per million for Black people vs 1,704 cases per million for White people (Harvard Health).

Kidneys are important organs that keep a person healthy. They come in pairs, with one kidney on each side near the spine and below the rib cage.

Kidneys, which are each about the size of a fist, clean blood, keep bones in good shape, make red blood cells, and help to control blood pressure among other tasks.

High blood pressure makes kidneys work harder

When a person has uncontrolled high blood pressure, blood vessels can be weakened or damaged. That damage increases the risk of heart attack and stroke — and forces the person's kidneys to work harder.

Over time, overworked kidneys can't do their job well and may eventually fail.

For white people, kidney function typically declines naturally as age increases, especially at 60+ years. But for Black people, the leading cause of kidney failure isn't age. It's having diabetes or high blood pressure.

Not only do Black people have higher rates of diabetes and high blood pressure than white people, but also less access to health insurance and medical treatment due to systemic racism.

To complicate matters, CKD is known as a "silent killer" because patients often show no outward symptoms.

All of these factors can result in delayed diagnosis of and treatment for CKD. In some cases, by the time a doctor discovers a Black patient has CKD, the disease is already advanced.

A genetic discovery

In addition to social determinants of health and structural racism, genetics and biology play a role in CKD.

In 2010, researchers found a variation in a gene named APOL1 that increases the risk of developing CKD. The risk rises if an individual with a certain APOL1 variant also has high blood pressure

While every person has the APOL1 gene, not everyone has the variation. However, people with African ancestry have the

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variation more than any other group. Why?

Like the sickle cell gene, which helped to protect African ancestors from malaria, the APOL1 variation helped to protect against African sleeping sickness.

Sharing genetic knowledge with GUARDD-US

In an upcoming study at the University of Pittsburgh and other sites across the U.S., the APOL1 genetic variation may help to empower Black patients and their clinicians to safeguard their health. The study is named GUARDD-US.

"The GUARDD-US study at Pitt will focus on Black patients who have high blood pressure -- and their doctors," explains Dr. Philip E. Empey, Associate Professor, Pharmacy and Therapeutics, at the University of Pittsburgh and study investigator.

"GUARDD-US will use genetic testing to identify which patients have the APOL1 variation and whether that knowledge has an impact on high blood pressure and kidney health treatment," he adds.

If GUARDD-US participants and their health care providers are aware they carry the APOL1 variation, will they use that information to make positive changes that may improve their individual outcomes? "That's what we want to find out," Dr. Empey says.

Those changes may include helping a participant lower blood pressure by taking medications as directed, CKD screening, eating healthier foods, and exercising. "By treating high blood pressure with all the tools available, a person may lessen the impact of CKD," notes Dr. Empey.

GUARDD-US, which is part of a larger study supported by the National Institute of Health, will use a community-engaged approach to enroll up to 350 Pittsburgh patients of African ancestry.

The participants must have high blood pressure and no existing CKD. They'll be enrolled at community health centers, primary care facilities, and other locations.

"A special blood test will be given to participants to identify which people have the APOL1 gene variation," says Dr. Mylynda Massart, Assistant Professor, Family Medicine at the University of Pittsburgh and co-investigator. "Some of the participants will know right away and that information will be shared with their doctors. The rest will know at the end of the testing period at a 6-month follow-up visit."

All participants will be monitored and data will be collected at regular intervals throughout the study. This will include surveys, blood pressure monitoring, and electronic health record data analysis.

GUARDD-US will fundamentally help researchers better understand how to close the gap between what patients know and what patients do. This is known as "implementation science," with the ultimate goal of improving the health of our Black population and decreasing the burden of advanced kidney disease.

"In this example," Dr. Empey explains, "Black patients with high blood pressure will enroll in GUARDD-US and, through a blood test, some will learn they also have the APOL1 variation. With that information, patients know their chances of developing chronic CKD are high.

"Will that knowledge cause patients and their doctors to act differently than if they didn't know?

"Will they be more likely to engage in evidence-based, preventative behaviors?

"Will their doctors be more aggressive with treatment on their behalf? That's what GUARDD-US can tell us."

Even more important to Dr. Empey personally is the hope that GUARDD-US's genetic information will improve individual outcomes in a group of people who continue to suffer from large disparities and structural racism in healthcare.

"What I hope shines through from this study is that at Pitt, we're passionate about inclusivity. As health care providers, we want to improve everyone's health, but especially the health of individuals who've been historically underserved by the medical community. GUARDD-US is a step toward advancing precision medicine to all patients."

Precision medicine helps personalize healthcare patient by patient

In Pittsburgh, healthcare providers at the University of Pittsburgh and UPMC have teamed up via The Institute for Precision Medicine to advance the science of personalized medicine. The goal is to collaborate to advance research, education, and implementation of precision medicine to improve the health of our population.

This approach is called "precision medicine." It allows providers to consider more than just a patient's symptoms. Instead, researchers and providers study the patient's genetics, family history, and how and where they live to assess environmental influences like social determinants of health. The information is then used to better understand why certain individuals get certain diseases and what treatment will work best for each individual patient.

The goal is better preventative care and therapeutic treatment for everyone.

Active research and clinical implementation at Pitt and UPMC are applying precision medicine to deliver personalized care for diseases, such as breast cancer, chronic kidney disease, and vascular issues, as well as diagnosing newborn illness in the NICU.

Learn more about precision medicine research and clinical implementation by visiting ipm.pitt.edu.

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