



NephCure Allied Leadership Conference on:

Addressing the Unequal Burden of Kidney Disease on Black Americans

A New Era of Hope – Beyond Dialysis

Tuesday, September 19, 2023

8:00 AM – 4:30 PM ET

Park Hyatt, 1201 24th Street NW, Washington, DC

Conference background:

Chronic kidney disease (CKD) is a nationwide epidemic, with 1 in 7 US adults affected and one third at risk. Black and African Americans are disproportionately affected by chronic kidney disease and have higher rates of kidney failure. Although social determinants of health can play a role in an individual or community's risk for chronic illness, there is also a recently discovered genetic link to a progressive form of kidney disease, called APOL1, that specifically affects individuals of African descent. 1 in 8 individuals of African descent have the high-risk gene mutation, and about a fifth of those high-risk individuals will go on to develop APOL1 kidney disease.

Audience:

- Faith leaders
- Community leaders and heads of historically Black colleges and universities
- Members of Congress
- Primary care physicians and other frontline healthcare professionals
- Community nephrologists
- Allied health organizations
- Drug development industry
- Those with diagnosed kidney disease and those who are at risk

Conference objectives:

1. Increase awareness of both general CKD as a public health emergency and of APOL1 Kidney Disease in the African American community
2. Destigmatize both genetic testing and clinical research because:
 - a. Increasing genetic testing and participation in clinical trials may improve outcomes
 - b. African Americans should feel empowered to ask their healthcare providers about genetic testing and clinical research
3. Arm the African American community with education and tools to address APOL1 Kidney Disease

Conference Steering Committee:

Keisha Gibson, MD, MPH, FASN, UNC at Chapel Hill (Co-Chair)
Opeyemi Olabisi, MD, PhD, Duke University (Co-Chair)
Barbara Gillespie, MD, MS, UNC at Chapel Hill and Fortrea CRO
Reverend Leroy Miles, Enon Tabernacle Baptist Church
Kevin Mott, Edward Jones and NephCure Board Member

**NOTE - Working agenda – All sessions/speakers subject to change.
8/8/2023*

7:00 AM	Breakfast
8:00 AM	Opening Remarks and Meeting Goals <i>Opeyemi Olabisi, MD, PhD, Duke University</i>
8:15 AM	The Power of the Church to Impact Health <i>Senator Reverend Raphael Warnock, D-GA</i>
8:20 AM	Keynote
8:50 AM	Why NephCure: APOL1 History and an Overview of NephCure’s Health Equity Initiative <i>Joshua Tarnoff, NephCure</i>
	Fireside Chat: The Evolving Landscape of APOL1 <i>Martin Pollak, MD, Harvard University</i>
9:05 AM	CKD and APOL1 in Black and African Americans <i>Keisha Gibson, MD, MPH, FASN, UNC at Chapel Hill</i>
	Panel Discussion
9:30 AM	Voice of Patients: Journey, Perceptions, and Hopes <i>Panelists: Joshua and Jordan Albright, and AJ Coulter</i> <i>Moderated by: Montrez Lucas, LMSW, NephCure</i>
10:15 AM	Alonzo Mourning: How APOL1 Kidney Disease Changed My NBA Career and Life <i>Alonzo Mourning, NBA Hall-of-Famer and Olympic Gold Medalist</i>
10:20 AM	Break
10:40 AM	Genetics of CKD and APOL1 – Perspectives from a Scientist, Clinical Geneticist, and Clinical Nephrologist <i>Gentzon Hall, MD, PhD, Duke University</i>

Additional speakers pending

11:00 AM

Community Conversation on Genetic Testing

Panelists:

Reverend Leroy Miles, Enon Tabernacle Baptist Church

Kevin Mott, personally impacted by APOL1 kidney disease

Elizabeth Valenti, MS, CGC, Natera

Gentzon Hall, MD, PhD, Duke University

Moderated by:

Barbara Gillespie, MD, MS, UNC at Chapel Hill and Fortrea CRO

Lauren Eva, NephCure

12:00 – 1:00 PM

Lunch

1:00 PM

Dialysis No Longer the Status Quo: Generating Data and Innovations in Research

Kirk Campbell, MD, FASN, Icahn School of Medicine at Mount Sinai

1:25 PM

FDA Strategies to Encourage Drug Development and Ensure Equitable Representation

RDML Richardae Araojo, PharmD, MS

1:40 PM

Getting the Message Out: How to Create Awareness, Education, and Screening Opportunities

Moderated by:

Keisha Gibson, MD, MPH, FASN, UNC at Chapel Hill

Opeyemi Olabisi, MD, PhD, Duke University

2:45 PM

Break

3:15 PM

KHI APOL1 Roadmap: Increase Awareness, Genetic Testing, & Trial Participation

Barbara Gillespie, MD, MMS, FASN, UNC at Chapel Hill, Fortrea CRO, and ASN Kidney Health Initiative

3:40 PM

A New Era to Prevent End Stage Kidney Disease: Legislative Opportunities

Britta Dornan, MPA, NephCure

Roundtable Discussion with Congressional Black Caucus Members

4:20 PM

Closing Remarks

Opeyemi Olabisi, MD, PhD, Duke University