

# HEALTH AND HUMAN SERVICES (HHS)

Resolution HHS-24-14

## SUPPORTING THOSE WITH CHRONIC KIDNEY DISEASE/AMKD

WHEREAS, more than 1 in 7 (15% of US adults or 37 million people) are estimated to have Chronic Kidney Disease (CKD) and as many as 9 in 10 adults with CKD do not know they have CKD;

WHEREAS, kidney disease disproportionately affects communities of color;

WHEREAS, African Americans are almost four times more likely, and Hispanics are 1.3 times more likely to have kidney failure compared to White Americans;

WHEREAS, although they make up only 13.6% of the population, African Americans make up more than 35% of dialysis patients;

WHEREAS, 90% of patients with CKD stages 1-3 are undiagnosed and less than 3% of Black patients believe that they are at high risk for CKD;

WHEREAS, CKD, when diagnosed, is often diagnosed in late stages of the disease, when irreversible damage to the kidneys has already occurred;

WHEREAS, 15% of people diagnosed with CKD are unaware of the cause of their disease;

WHEREAS, the overall Medicare costs for people with CKD were \$87.2 billion and the total Medicare fee-for-service spending for patients with ESRD or kidney failure reached \$37.3 billion in 2019;

WHEREAS, recent scientific advancements have shown that some of the health disparities associated with CKD have a genetic basis;

WHEREAS, this genetic risk factor for CKD was discovered in 2010 when scientists learned that people who inherit two variants of the APOL1 gene are at significantly increased risk of developing kidney disease;

WHEREAS, these APOL1 risk variants are found exclusively in people of sub-Saharan African ancestry, including people who identify themselves as African American, Afro-Caribbean, and Hispanic, as the risk variants originally offered protection from a parasitic disease known as African human trypanosomiasis;

WHEREAS, 13% of people of African descent carry two APOL1 risk variants, and estimates suggest that up to 1 in 5 people with two APOL1 risk variants will develop kidney disease; WHEREAS, APOL1-mediated kidney disease causes high levels of protein in the urine, or proteinuria, and can lead to various symptoms, including swelling in the legs and/or feet, fatigue, and weight gain;

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WHEREAS, research has also shown that the course of kidney disease is more rapidly progressive in individuals with two APOL1 risk variants than in patients without them;

WHEREAS, the disease may eventually lead to kidney failure, requiring dialysis or a kidney transplant;

WHEREAS, there are simple tests to diagnose chronic kidney disease, including blood and urine tests, and a genetic test exists to identify presence of APOL1 risk variants; and

WHEREAS, it is imperative to improve diagnosis and treatment of CKD in African Americans through community-based programs that address racial and ethnic disparities in the awareness, diagnosis, and treatment of chronic kidney disease.

THEREFORE, BE IT RESOLVED, that the National Black Caucus of State Legislators (NBCSL) urges state and federal policymakers to ensure that high risk individuals are screened for chronic kidney disease, and that genetic testing and counseling services are offered to at risk individuals diagnosed with CKD as recommended by the best scientifically validated data;

BE IT FURTHER RESOLVED, that state Departments of Health should develop and fund chronic kidney disease screening programs that provide for referrals for follow up care, including genetic testing if appropriate;

BE IT FURTHER RESOLVED, that in developing chronic kidney disease screening programs, the state Department of Health and/or the appropriate state agency shall solicit and consider input from the general public, with specific emphasis on attempting to receive input from persons or groups with knowledge and experience in the area of chronic kidney disease, including, but not limited to, patients, caregivers, patient advocacy organizations, nephrologists, and primary care providers;

BE IT FURTHER RESOLVED, that in planning CKD screening the Department of Health shall identify opportunities where disease education, CKD disease services, access to care, access to information and resources for CKD patients can all be improved;

BE IT FURTHER RESOLVED, that state Medicaid programs should work to ensure that high risk patients in state Medicaid programs are fully screened for CKD, including genetic testing if appropriate;

BE IT FURTHER RESOLVED, that state and federal policymakers take all necessary actions to identify and remove other impediments on CKD patients and their families, such as logistical and financial challenges, including access to genetic counseling services, time off from work, childcare, transportation, and other related expenses, that may prevent or otherwise impede all patients including CKD patients from accessing needed care;

BE IT FURTHER RESOLVED, that payers should encourage and fund CKD screening and diagnosis, including appropriate genotyping, as part of appropriate preventive care; and

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BE IT FINALLY RESOLVED, that a copy of this resolution be transmitted to the President of the United States, the Vice President of the United States, members of the United States House of Representatives and the United States Senate, and other federal and state government officials and agencies as appropriate.

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**Sponsored by: Rep. Terry Alexander (SC)**

**Policy Committee: Health and Human Services (HHS)**