HELP EDUCATE HIGH-RISK COMMUNITIES ABOUT APOL1-MEDIATED KIDNEY DISEASE (AMKD)

Please cosponsor a resolution that declares that last day of Tuesday as AMKD Awareness Day to help fight kidney disease in the United States.

What is AMKD?

AMKD is a genetic form of rapidly progressing kidney disease caused by variants (mutations) of the APOL1 gene. People of west and central African ancestry (Black, African American, Afro-Caribbean and Latino/Latina) are more likely to have the APOL1 gene variants. The identification of APOL1 gene variants offers an opportunity for early interventions, so that end-stage renal disease (ESRD) and dialysis may be delayed or avoided. **The Resolution will help educate the American public and raise awareness so that people in high-risk communities can be empowered to take action to protect their health, including talking to their health care provider about genetic testing.**

Kidney disease—one of the top 10 causes of death in the United States—is the fastest-growing noncontagious disease in the country. There are 37 million Americans living with it and millions more who are at risk. Of the Americans with kidney disease, 808,000 are living with ESRD, a life-altering condition that comes with enormous physical, financial and emotional burdens. People with ESRD need dialysis or a transplant to live. It is also a very costly condition for patients and society. An estimated one out of every eight ESRD patients cannot afford the cost of care.

In 2021, Medicare spent $52.3 billion (about $160 per person in the US) on ESRD beneficiaries, and these patients account for 6.8% of all Medicare costs.* Underlying conditions like diabetes and hypertension, which account for nearly 75% of all new cases of kidney disease, have led to more than 556,000 Americans with kidney failure currently relying on life-sustaining dialysis treatments. Studies project that the number of people living with ESRD will increase by about 200,000–500,000 by 2030, driving up Medicare costs further.*

The AMKD Awareness Day Resolution would:

1. designate the last Tuesday of each April as "APOL1-Mediated Kidney Disease (AMKD) Awareness Day;" and;
2. encourage everyone in the United States to become better informed about and aware of kidney disease and AMKD;
3. encourage people from or with Western and Central African ancestry to talk to their health care provider about genetic testing for APOL1 gene mutations, especially if there is a history of kidney disease in the family.

What is the APOL1 gene and how does it cause kidney disease?

Everyone has two copies of the APOL1 gene, which typically makes a helpful immune system protein, but people of west or central African descent are more likely to have a mutation, or variant, in one or both APOL1 genes. If someone inherits mutations in both APOL1 genes, they have an increased risk of developing kidney disease. The inherited APOL1 mutations can:

- Cause damage to parts of the kidney that filter blood
- Sometimes cause cells in the kidney to die, which leads to damage and scarring in the kidneys and can lead to kidney failure

An estimated 13% of Black Americans have two of the APOL1 gene mutations. About 1 in 5 of these individuals will go on to develop kidney disease.

To cosponsor, please email Shinnola Alexander in Congresswoman Stacey Plaskett's office at Shinnola.Alexander@mail.house.gov

* *2023 USRDS Report*