

American Kidney Fund’s New APOL1-Mediated Kidney Disease Campaign Aims to Educate and Increase Awareness About APOL1 Gene Mutations

Campaign resources will include a video series and information on genetic counseling and materials for health care professionals

FOR IMMEDIATE RELEASE

ROCKVILLE, Md. (Sep. 27, 2022) – The American Kidney Fund (AKF) today launched its [new APOL1 campaign](#), which aims to educate and increase awareness about APOL1-mediated kidney disease, a spectrum of kidney diseases that is associated with mutations or variants in the apolipoprotein L1 (APOL1) gene and are linked to an increased risk for kidney disease in people of African and Caribbean descent. AKF’s [new educational materials](#) were developed with support from Vertex Pharmaceuticals Inc.

In the United States, Black people are almost four times more likely to have kidney failure than white people. While diabetes and high blood pressure are the leading causes of kidney disease, social determinants of health, inequities in health care and genetic factors are understood to contribute to the disparity in kidney failure among populations. One such genetic factor is mutations in the APOL1 gene, which makes a protein in the immune system. These mutations are mostly found in people of African, Afro-Caribbean, or Latino ancestry, with approximately 10-15% of the Black population having high-risk APOL1 genotypes. People diagnosed with focal segmental glomerulosclerosis (FSGS)—a rare kidney disease that causes scarring on the kidneys’ filters—are 17 times more likely to have APOL1 mutations. This new campaign will boost awareness and education about the connection between APOL1 and kidney disease and the need for increased genetic testing.

“Despite the clear link between APOL1 gene mutations and kidney disease, awareness of this association and the risks the mutations pose to people of African and Caribbean descent is relatively low,” said LaVarne A. Burton, AKF President and CEO. “People who have kidney disease and APOL1 gene mutations may see their disease progress more quickly than other causes of kidney disease and turn into kidney failure. The APOL1 campaign’s educational materials will help those affected and at risk gain a clearer understanding of these mutations and empower them to seek assistance from their kidney care team so they can take charge of their health and lives. We thank Vertex Pharmaceuticals for their support of this crucial work.”

For the campaign, AKF has developed an APOL1 “brain trust” consisting of a group of people with kidney disease attributed to APOL1 variants and a health care professional expert on the subject. Through individual interviews, the brain trust informs the campaign’s strategies and tactics to ensure education gaps are being adequately addressed. Throughout the course of the campaign, new resources for patients will include a digital resource to guide people who may want to talk with a genetic counselor, a [dedicated webpage with enhanced educational materials](#), an animated explainer video and a patient experience video series.

Because APOL1 mutations as a genetic marker for kidney disease risk remain a topic new to many health care professionals, [AKF’s campaign](#) will also educate them about the role of variants in kidney genetics and the impact of APOL1-mediated kidney disease on people of color via a professional-facing webinar and educational materials.

"Vertex is committed to developing medicines that treat the underlying cause of APOL1-mediated kidney disease and increasing awareness of this disease," said Amit Sachdev, Chief Patient Officer at Vertex Pharmaceuticals. "We're proud to support AKF and this effort to provide education and resources to those living with kidney disease."

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About the American Kidney Fund

The American Kidney Fund (AKF) fights kidney disease on all fronts as the nation's leading kidney nonprofit. AKF works on behalf of the 37 million Americans living with kidney disease, and the millions more at risk, with an unmatched scope of programs that support people wherever they are in their fight against kidney disease—from prevention through transplant. With programs that address early detection, disease management, financial assistance, clinical research, innovation and advocacy, no kidney organization impacts more lives than AKF. One of the nation's top-rated nonprofits, AKF invests 97 cents of every donated dollar in programs, earning the highest 4-Star rating from Charity Navigator for 20 years in a row as well as the Platinum Seal of Transparency from Candid, formerly GuideStar.

For more information, please visit [KidneyFund.org](https://www.kidneyfund.org), or connect with us on [Facebook](#), [Twitter](#), [Instagram](#) and [LinkedIn](#).