What is APOL1-mediated kidney disease (AMKD)?

- APOL1-mediated kidney disease is a genetic condition that can cause kidney failure. It is a condition that occurs when a person inherits mutations (changes or variations) in both APOL1 genes.
- Every person has two APOL1 (apolipoprotein L1) genes. The APOL1 gene makes a protein in your immune system, which is your body's cells and tissues that fight infection.
- Typically, the APOL1 genes make a helpful immune system protein. But some people are born with mutations in one or both APOL1 genes that can raise the chance of kidney disease. This mutation is associated with increased protection from a parasite that causes African sleeping sickness. Unfortunately, while protecting from one disease, the APOL1 gene mutation has been shown to increase the risk for significant kidney damage in some.
- People who inherit mutations in both of their APOL1 genes have a higher chance of developing kidney disease (including, but not limited to, focal segmental glomerulosclerosis (FSGS)). 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. For example, if you inherit a mutation in both copies of the APOL1 gene, you have a 10x higher chance of having a type of kidney disease called FSGS than people without the gene mutation.

Who it affects:

- This is more common in people of Western and Central African descent (Black, African American, Afro-Caribbean or Latina or Latino).
- The APOL1 gene evolved over the past 3,000-10,000 years in people who lived in Western and Central Africa. The mutation that evolved is associated with protection against a certain type of parasite that causes African sleeping sickness. As a result, you are more likely to have APOL1 gene mutations if you are from Western or Central Africa or have an ancestor who came from these regions.
- If you have two of the APOL1 genetic mutations, you are at a higher risk for developing kidney disease and even kidney failure.
  - In the United States, an estimated 13% of Black Americans have two of the APOL1 genetic variations. However, not everyone who has two copies of APOL1 genetic mutations will get kidney disease.
  - If you have mutations in both copies of the APOL1 gene, there is a 1 in 5 chance that you will go on to develop kidney disease.
**The American Kidney Fund** is proud to launch the first ever AMKD Awareness Day on April 30, 2024. Held on the last Tuesday of April, during National Minority Health Month, AMKD Awareness Day serves as an opportunity for communities, organizations and families to better understand APOL1-mediated kidney disease and become APOL1 aware.

This toolkit is designed for individuals, organizations, communities, partners and other stakeholders to help amplify AMKD Awareness Day. It includes social media posts, key messages, content for newsletters, digital and printable assets, links to evidence-based educational resources and more, including suggested hashtags. **We request you add #APOL1Aware to your posts and tag AKF so that we can re-share.**

Our toolkit can be considered a starting point for your AMKD Awareness Day plans — we encourage you to personalize your social media posts and get the conversation started, which will help bring visibility to a disease that does not yet have widespread recognition.

You don’t have to be personally affected by AMKD to help bring attention to this disease. Thank you for helping to spread the word, in 2024 and beyond.

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**Suggested Social Media Posts**

**Pre-Event Sample Posts**

**FACEBOOK:**

Being #APOL1Aware means knowing how your genes impact your kidney health. For people of west or central African descent who inherited a certain variation of the APOL1 genes, there is an increased risk of developing APOL1-mediated kidney disease (AMKD). We’re joining @American Kidney Fund in recognizing AMKD Awareness Day on April 30 and encourage you to become #APOL1Aware: kidneyfund.org/APOL1aware

**INSTAGRAM:**

Being #APOL1Aware means knowing how your genes impact your kidney health. For people of west or central African descent who inherited a certain variation of the APOL1 genes, there is an increased risk of developing APOL1-mediated kidney disease (AMKD). Join AMKD Awareness Day on April 30 and become #APOL1Aware with @americankidneyfund.

**TWITTER:**

Become #APOL1Aware and join @KidneyFund for AMKD Awareness Day on April 30. Learn more about APOL1’s connection to kidney disease and spread the word: kidneyfund.org/APOL1aware
Day-of-Event Sample Posts

FACEBOOK:
Today we recognize the nation’s first AMKD Awareness Day! People who are from or have ancestors from west or central Africa are at increased risk of having a mutation in one or both of the genes that causes APOL1-mediated kidney disease (AMKD). It is estimated that 13% of Black Americans have two mutations of the APOL1 gene, and these individuals have a 1 in 5 chance of developing a rapidly progressing form of genetic kidney disease. Become #APOL1Aware by learning more about AMKD and join the @American Kidney Fund in AMKD Awareness Day: kidneyfund.org/APOL1aware

INSTAGRAM:
Today we recognize the nation’s first AMKD Awareness Day! People who are from or have ancestors from west or central Africa are at increased risk of having a mutation in one or both of the genes that causes APOL1-mediated kidney disease (AMKD). It is estimated that 13% of Black Americans have two mutations of the APOL1 gene, and these individuals have a 1 in 5 chance of developing a rapidly progressing form of genetic kidney disease. Become #APOL1Aware by learning more about AMKD from @americankidneyfund and join in AMKD Awareness Day.

TWITTER:
Did you know that those of us with ancestors from west or central Africa & a certain variation of the APOL1 genes have an increased risk of developing APOL1-mediated kidney disease (AMKD)? Become #APOL1Aware & join the @KidneyFund in AKMD Awareness Day: kidneyfund.org/APOL1aware

Suggested Newsletter Copy

For patient audience

Be APOL1 Aware This AMKD Awareness Day

Are you at an increased risk for developing kidney disease or kidney failure? Your genes could provide the answer. People with two mutations of the apolipoprotein L1 (APOL1) gene are not guaranteed to develop kidney disease or failure, but there is a 1 in 5 chance they will. We are supporting the American Kidney Fund in its efforts to raise awareness about APOL1-mediated kidney disease (AMKD) with the launch of the first annual AMKD Awareness Day on April 30, 2024.

Everyone has the APOL1 gene, but people of west and central African ancestry, including people who are Black, African American, Afro-Caribbean and Latina/Latino, are more likely to have mutations of the gene. In fact, it is estimated that 13% of Black Americans have two of the genetic variations that put them at greater risk of developing kidney disease or failure. Find out more about AMKD by visiting kidneyfund.org/APOL1aware. On April 30, join the American Kidney Fund and be APOL1 aware.
For professional audience

We are proud to support the country’s first AMKD Awareness Day on April 30.

The American Kidney Fund is raising awareness of APOL1-mediated kidney disease (AMKD), a spectrum of kidney disease associated with variants in the apolipoprotein L1 (APOL1) gene that is linked to an increased risk for rapidly progressing kidney disease in people of west or central African ancestry. Find out more about AMKD and how you can get involved with AMKD Awareness Day by visiting KidneyFund.org/APOL1aware.

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Sample Community Email/Letter

On April 30, [ORGANIZATION NAME] is supporting the nation’s first AMKD Awareness Day so that we can increase awareness of the connection between APOL1 gene variants and kidney disease, and we invite you to join us in sharing information about this new effort.

It is estimated that 13% of Black Americans have two mutations of the APOL1 gene, and these individuals have a 1 in 5 chance of developing kidney disease. People who are from or have ancestors from west or central Africa (including those who are Black, African American, Afro-Caribbean and Latina/Latinos) are at increased risk of having a mutation in one or both of the genes that causes APOL1-mediated kidney disease (AMKD).

Knowing whether one has the APOL1 mutations that cause AMKD could keep someone’s kidneys working longer, delaying the need for dialysis or a kidney transplant.

Please visit the American Kidney Fund’s AMKD Awareness Day website at KidneyFund.org/APOL1aware to find resources to share with your networks, including social media posts, facts about AMKD, downloadable posters and information about genetic testing. Thank you for joining us to spread this important message.
If you are of western and central African descent, you might have APOL1 gene variants that can cause severe and rapidly progressive kidney disease. In fact, leading scientists call the identification of APOL1 gene variants one of the most important discoveries in kidney disease research in recent decades.

In the United States, Black people are more than 4 times more likely to develop kidney failure than white people. It is estimated that in people of western or central African ancestry, a significant proportion of kidney disease diagnoses are in fact, APOL1-mediated kidney disease:

Everyone has two copies of the APOL1 gene. People with western and central African descent (Black, African American, Afro-Caribbean, Latino) are at increased risk of having a variant in one or both of the genes. These individuals have a higher chance of developing kidney disease. For example:

- **FSGS**, which causes scarring in the filters of your kidneys:
  - 39% of nondiabetic kidney failure
  - 25% of lupus nephritis
  - 47% of lupus nephritis with kidney failure

- **Lupus nephritis** with kidney failure:
  - 17% of high blood pressure-associated kidney failure
  - 54% to 73% of FSGS, which causes scarring in the filters of your kidneys

Stay informed and learn more about AMKD at KidneyFund.org/APOL1aware.
Additional Educational Resources

Genetic Testing

APOL1-mediated kidney disease and Genetic Testing: learn more about connecting with a genetic counselor and about genetic testing.

- If you are thinking about genetic testing or have learned that you or a family member have the APOL1 gene mutation, a genetic counselor can be a great resource.

Guide: APOL1-mediated kidney disease: Connect with a genetic counselor

Patient Stories:

Emani’s Journey | Caring for APOL1-mediated kidney disease

Therochelle’s Journey | Caring for APOL1-mediated kidney disease

Kevin’s Journey | Caring for APOL1-mediated kidney disease

APOL1-mediated kidney disease | Rare Kidney Disease
Tips for talking with your doctor about APOL1-mediated kidney disease (AMKD)

**Ambassador Opportunities**

**State Proclamation Drive**

In our efforts to raise awareness about AMKD nationwide, we are embarking on a national proclamation drive. These proclamations will be authored by governors throughout the country and will help raise the profile of this issue in every state. We are asking AKF Ambassadors and all interested advocates to request a proclamation in their state.

If you’d like to get involved, visit [https://www.kidneyfund.org/amkd-day-proclamation](https://www.kidneyfund.org/amkd-day-proclamation)

**Share Your Story**

The most powerful way of raising awareness of a disease is by sharing personal experiences, which can provide insights that go beyond statistics and fact sheets. AKF is working to collect personal AMKD stories to illustrate the patient journey and draw much-needed attention to this disease.

If you are personally impacted by AMKD and are willing to share your story, simply fill out this form and record your video to share your story with us. Please feel free to forward this link if you know someone affected by AMKD.

KidneyFund.org/APOL1aware
AMKD Awareness Day is supported by KidneyFund.org/APOL1aware.