

APRIL 30

# Be **APOL1** Aware



Join in AMKD  
Awareness Day

 American Kidney Fund®  
FIGHTING ON ALL FRONTS





## 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.**

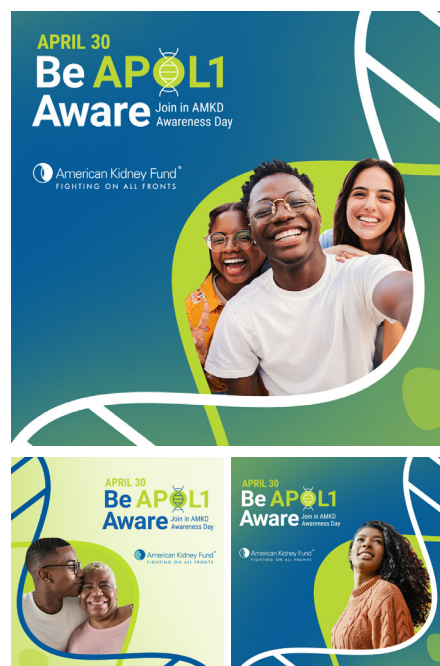
Our toolkit can be considered a starting point for your AMKD Awareness Day plans – we encourage you to personalize your social media posts and get the conversation started, which will help bring visibility to a disease that does not yet have widespread recognition.

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.



## 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](https://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](https://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 @AmericanKidneyFund in AMKD Awareness Day: [kidneyfund.org/APOL1aware](https://www.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](https://www.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](https://www.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](https://KidneyFund.org/APOL1aware).



eNewsletter  
Banner



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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](https://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.



Email  
Banner



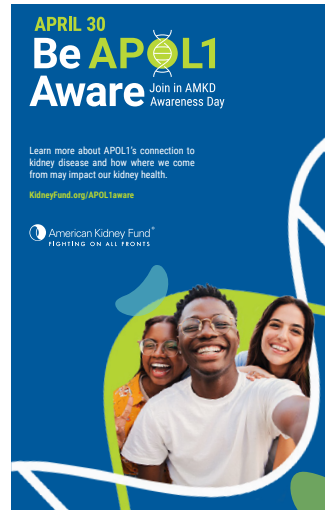
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[KidneyFund.org/APOL1aware](https://KidneyFund.org/APOL1aware)

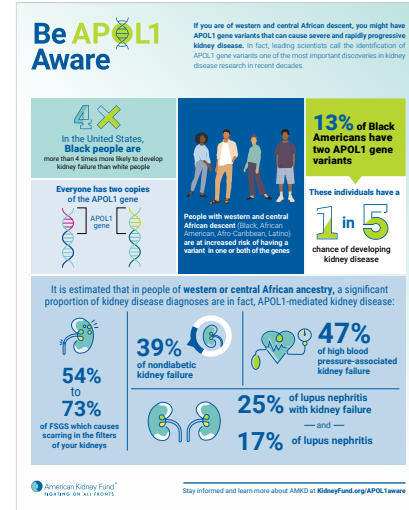
## Printable Assets

### AMKD DAY POSTER



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### UNDERSTANDING AMKD



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## Other Digital Assets

### LOGO



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### ZOOM BACKGROUND



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### SOCIAL MEDIA COVER IMAGE



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KidneyFund.org/APOL1aware

## Additional Educational Resources

### Genetic Testing

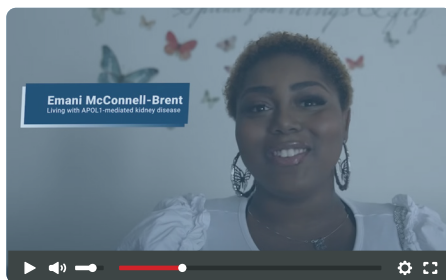
APOL1-mediated kidney disease and Genetic Testing: learn more about connecting with a genetic counselor and about genetic testing.

- 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](#)

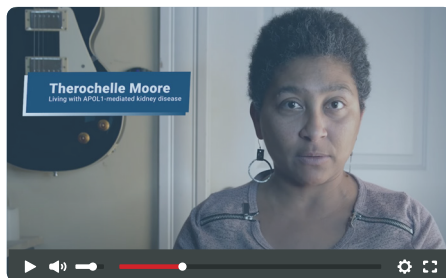
### Patient Stories:

#### Emani's Journey | Caring for APOL1-mediated kidney disease



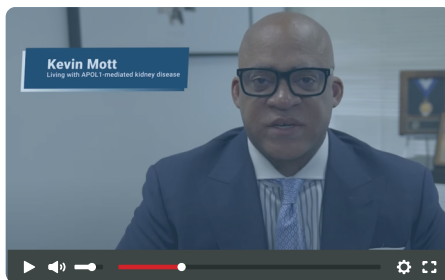
[CLICK TO WATCH AND SHARE](#)

#### Therochelle's Journey | Caring for APOL1-mediated kidney disease



[CLICK TO WATCH AND SHARE](#)

#### Kevin's Journey | Caring for APOL1-mediated kidney disease



[CLICK TO WATCH AND SHARE](#)

#### APOL1-mediated kidney disease | Rare Kidney Disease



[CLICK TO WATCH AND SHARE](#)



## Tips for talking with your doctor about APOL1-mediated kidney disease (AMKD)

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### Tips for talking with your doctor about APOL1-mediated kidney disease (AMKD)

If you have questions about **APOL1-mediated kidney disease (AMKD)** you should talk to your doctor. AMKD is genetic, the best way to manage it is to detect it early. Below are a series of questions to help guide your conversation with your doctor.

**QUESTIONS TO ASK YOUR DOCTOR:**

- From my family history and symptoms, do you think I am at risk for AMKD?
- How do I get tested for kidney disease?
- Can you tell me about genetic testing?
- Can you explain the process for getting tested for the APOL1 variant?
- If I do test positive for AMKD and I have both APOL1 variants, what are the next steps?
- Can you refer me to a genetic counselor who can answer my questions around genetic testing?
- Are there any things that I can do to keep my kidneys healthy?
- What signs/symptoms should I look out for if I am at risk of kidney disease?
- Are there any lifestyle changes I should make to improve my health?

**KEEP YOUR DOCTOR INFORMED:**

There are some specific characteristics of AMKD. Check  any that apply to you and share with your doctor.

- I have chronic kidney disease
- I have a family history of kidney disease
- I have family members who have one or more copies of the APOL1 variants
- I have African ancestry and/or identify as one of the following:  
Black, African American, Afro-Caribbean, Latina/Latino
- I have high blood pressure
- I frequently experience swelling in my hands/ankles/feet
- I have been feeling fatigued/weak
- I have foamy urine

**Medical Professionals:** learn more about APOL1-mediated kidney disease and implications for care.  
**Webinar:** [APOL1-mediated kidney disease: Overview and Implications for Care](#)  
**Guide:** [APOL1-mediated kidney disease: professional webinar summary](#)

This APOL1-mediated kidney disease education campaign is sponsored by **VEREEN**

**DOWNLOAD**

## 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>

### 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.





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