





What is APOL1-mediated kidney disease (AMKD) and who does it affect?

- Everyone has two APOL1 genes, but people of certain African descent are more likely to have APOL gene variants (mutations).
 If you're African, African-American, Afro-Caribbean or Hispanic/ Latino and you inherited certain variations (mutations) of the APOL1 gene, there is a greater chance of having APOL1-mediated kidney disease (AMKD).
- AMKD is a rapidly progressive genetic kidney disease that can cause kidney failure. It can develop even at a young age, and it can advance faster than other kidney diseases.
- People who inherit a mutation in both copies of the APOL1 gene have a higher chance of developing kidney disease, including, but not limited to, focal segmental glomerulosclerosis.
- 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.





AMKD Awareness Day

Held annually 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. For more information on AMKD Awareness day, visit KidneyFund.org/APOL1Aware.

The American Kidney Fund (AKF) is pleased to share this toolkit to encourage widespread participation in AMKD Awareness Day on **April 29, 2025**. This toolkit is designed for individuals, organizations, communities, partners and other stakeholders to help amplify AMKD Awareness Day. You'll find suggested 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. Social assets from our toolkit may also be easily downloaded and shared at socialpresskit.com/amkd. For your convenience, this year we have developed editable AMKD Awareness Day partner logos and social graphics, to easily allow you to add your organization's logo alongside the AMKD Awareness Day logo.

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 2025 and beyond.**





AMKD Awareness Day Logos



In addition to our standard logos below, we have also developed partner lock-ups, so if you choose to, you can easily add your organization's logo alongside the AMKD Awareness Day logo.

STANDARD WITH DATE



STANDARD WITHOUT DATE



PARTNER LOCK-UP WITH DATE



AMKD AWARENESS DAY PARTNER

(Add your logo)

PARTNER LOCK-UP WITHOUT DATE



AMKD AWARENESS DAY PARTNER

(Add your logo)





Suggested Social Media Posts

For 2025, AKF has also made available suggested social media posts on the <u>socialpresskit.com/amkd</u>, a user-friendly way of downloading images and social copy. If you are an organization, editable assets are also available for you to add your logo.

Pre-Event Sample Posts

FACEBOOK:

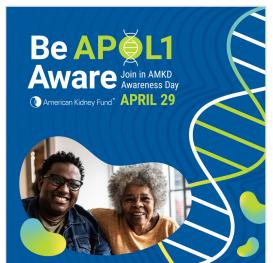
AMKD Awareness Day is coming up on April 29! Did you know your genes can influence your kidney health? Black Americans are more likely to have APOL1 gene mutations that increase the risk of developing APOL1-mediated kidney disease (AMKD), a rapidly progressive form of kidney disease that can occur at a young age. We're joining @American Kidney Fund on AMKD Awareness Day and encouraging others to become #APOL1Aware kidneyfund.org/APOL1aware

INSTAGRAM:

AMKD Awareness Day is coming up on April 29! Did you know your genes can influence your kidney health? Black Americans are more likely to have APOL1 gene mutations that increase the risk of developing APOL1-mediated kidney disease (AMKD), a rapidly progressive form of kidney disease that can occur at a young age. We're joining @AmericanKidneyFund on AMKD Awareness Day and encouraging others to become #APOL1Aware. Learn more at the link in their bio.

X OR BLUESKY:

AMKD Awareness Day is coming up on April 29! Become #APOL1Aware with @KidneyFund and learn more about APOL1's connection to kidney disease. Spread the word: kidneyfund.org/APOL1aware













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Suggested Social Media Posts (continued)

Day-of-Event Sample Posts

FACEBOOK:

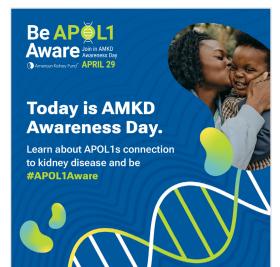
Today is AMKD Awareness Day. APOL1-mediated kidney disease (AMKD) is a genetic kidney disease that can start at a younger age and advance faster than other kidney diseases. Early diagnosis of AMKD can delay the need for dialysis or a kidney transplant, so it's important to become #APOL1Aware. People of certain African descent, including those who are Black, African-American, Afro-Caribbean, or Latino/Latina, are more likely to have APOL1 gene variants (mutations), that in turn put them at higher risk for AMKD. Learn more about AMKD and join the @American Kidney Fund in AMKD Awareness Day: kidneyfund.org/APOL1aware.

INSTAGRAM:

Today is AMKD Awareness Day. APOL1-mediated kidney disease (AMKD) is a genetic kidney disease that can start at a younger age and advance faster than other kidney diseases. Early diagnosis of AMKD can delay the need for dialysis or a kidney transplant, so it's important to become #APOL1Aware. People of certain African descent, including those who are Black, African-American, Afro-Caribbean, or Latino/Latina, are more likely to have APOL1 gene variants (mutations), that in turn put them at higher risk for AMKD. Learn more about AMKD and join the @AmericanKidneyFund in AMKD Awareness Day at the link in their bio.

X OR BLUESKY:

Today is AMKD Awareness Day. People of West or Central African ancestry who inherited certain variations of the APOL1 gene are at higher risk for 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 APOL1 gene have a 1 in 5 chance of developing a rapidly progressive form of genetic kidney disease. We are supporting the American Kidney Fund in its efforts to raise awareness about APOL1-mediated kidney disease (AMKD) through the second annual AMKD Awareness Day on April 29, 2025.

Everyone has the APOL1 gene, but people of West and Central African ancestry, including people who may be Black, African American, Afro-Caribbean and Hispanic/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 29, join the American Kidney Fund and be APOL1 aware.

FOR PROFESSIONAL AUDIENCE:

We are proud to support AMKD Awareness Day on April 29.

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 29, [ORGANIZATION NAME] is joining with the American Kidney Fund to support AMKD Awareness Day so that we can increase awareness of the connection between APOL1 gene variants and kidney disease.

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 progressive form of kidney disease. People who are from or have ancestors from West or Central Africa (including those who are Black, African American, Afro-Caribbean and Hispanic/Latino) are at increased risk of having a mutation in one or both of the genes that causes APOL1-mediated kidney disease (AMKD).

Knowing if you have the APOL1 mutations that cause AMKD could keep your kidneys working longer, someone's kidneys working longer, delaying the need for dialysis or a kidney transplant.

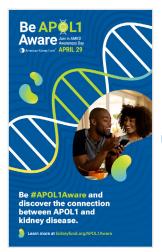
Please visit the American Kidney Fund's AMKD Awareness Day website at KidneyFund. org/APOL1aware to find resources to share with your networks, including social media posts, facts about AMKD, and information about genetic testing. Thank you for joining us to spread this important message.





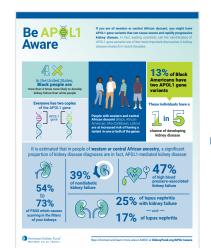
Printable Assets

AMKD Awareness Day Poster



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Understanding AMKD Infographic









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Other Digital Assets

Video Meeting Backgrounds

STANDARD VIDEO BACKGROUND:





PARTNER VIDEO BACKGROUND:





PowerPoint Templates

STANDARD DECK:





PARTNER DECK:





Social Media Cover Image









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Additional Educational Resources

AKF's Kidney Health Coach

If your organization is interested in learning more about AMKD, a Kidney Health Coach may be able to help. Kidney Health Coach is AKF's free community health education program. AKF has developed a presentation aimed at educating communities about AMKD and being APOL1 aware. Contact AKF at education@kidneyfund.org to learn more about virtual presentations that may be available.

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





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Additional Educational Resources (continued)

Genetic Testing Information

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





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









Advocacy Opportunities - Your Advocacy Toolbox

People living with AMKD play a vital role in advocacy efforts. The role of APOL1 gene mutations in kidney disease was not discovered until 2010, so AMKD is an underrecognized disease that policymakers may not be aware of or understand.

Your experience with AMKD can have a strong impact on lawmakers, providing them with a personal connection to this genetic kidney disease. In this section of the AMKD Awareness Day Community Toolkit, we'll provide you with tips on becoming an effective advocate, which you can apply to express your support for legislation such as bills that expand access to genetic counselors, biomarker testing and more.

Introduction

Elected officials and their staff have many meetings throughout the day. When they are not in meetings, they are reading through mountains of letters and emails from constituents (people who live in their district) who are writing about numerous issues of importance. The best way to stand out from the crowd is by sharing your personal experience with them—this often has a lasting impact on elected officials.

Most elected officials will not act on an issue or sign onto a piece of legislation if their constituents do not let them know that the topic is important to them. In most cases, it just takes one person to call or email to move the needle in the right direction. We cannot let kidney disease-related legislation be ignored, and that is why we need your help to speak up.

This "silent" disease needs to be brought out into the light and that can only happen with your help. Your advocacy is extremely important and it does make a difference.

Identifying your Elected Officials

Click <u>here</u> and fill in your address to find out who your federal, state and local officials are.

How to contact your Elected Officials

There are many ways to contact your elected officials, but the reason for your communication will help you decide who you should reach out to.

If you want to ask a member of Congress to vote a certain way on a piece of federal legislation, or if you want to update them on an important issue, you should contact their office in Washington, D.C., because all voting and legislative work is done on Capitol Hill. If you need help dealing with a federal agency or want to simply connect with someone where you live, that is where the local district office comes into play. If



you don't know which office to contact, try the one you think fits best and the person you reach will direct you to the best office if it is not them.

If you are trying to reach your state lawmakers, contact their office in the state capitol. Most states do not have a year-round legislative session, but you can still contact your elected officials regardless of whether the legislature is in session or not. State lawmakers' staff check voicemails, emails and other correspondence all year long.

Effective Methods of Communication

Elected officials need and want to hear from their constituents. You vote them into office, so that means they are there to serve you. Your elected officials may not belong to the same political party as you, or vote the way you like every single time, but it's important to build relationships with their offices for the next time an important vote comes up.

Support for kidney disease-related legislation is typically bipartisan. Kidney disease affects people across all demographics in every congressional and state legislative district in America. The information below is an overview of various communications methods.

ACTION ALERTS

Action alerts are messages that ask an elected official to do something specific, like vote yes or no on a bill, or cosponsor legislation. Action alerts are important because they let lawmakers know how their constituents feel about a specific issue. Some members of Congress and state legislatures will not act on an issue, no matter how big or small, unless they hear from at least one constituent about it. Sending in just one action alert to an elected official can truly make a difference. Click here to view AKF's current action alerts.

CALLS

While technology has replaced the need for phone calls in many situations, it is still a very effective way to communicate with your elected officials. When you call an elected official's office, you will most likely not be able to speak with the lawmaker directly. You will often speak with a member of their staff who logs your comments and reports them back to a supervisor. Keep calls respectful and relatively short so that your point comes across.

EMAILS

Sending emails to your elected officials can be effective, if you send them to the correct person in their office. If you want to send an email to a member of Congress, we recommend sending it to the staff member who handles the topic you are inquiring about. For the issues AKF and our Ambassadors advocate for, that staff person will likely be the health legislative assistant for the congressperson's office. You can call the congressperson's office to find out the name and email address of the health legislative assistant.



Sending an email to a state elected official is a little different. State officials get far fewer emails than their federal counterparts, so there is a better chance that the legislators themselves will actually read your emails. However, it is still likely that an email sent to a state legislator's official email address will be read first by a staff member who will figure out how to respond. The lawmaker will be made aware of important or compelling emails, so your best bet would be to share your kidney disease story in your email to help it stand out in their crowded inbox.

SOCIAL MEDIA

Although the shortest of communications methods, social media, such as X, Instagram and Facebook, is one of the most effective ways to reach an elected official. This is because social media posts can be seen by lots of people, unlike an email that can only be seen by the recipient. It is rare for a member of Congress to be solely in charge of their social media accounts, but many are very involved in reading the messages they receive. If you choose to use social media, keep messages on point and respectful. You'll find more information about social media on page 14.

Attending an Event with your Elected Officials

Local town hall meetings (both in-person and virtual), constituent coffees, health fairs, parades and other events are a great and easy way to meet with your elected officials. The best way to find out what events your elected officials are hosting or attending is by following them on all their social media accounts.

Elected officials use social media to post about meet-and-greets and other similar events. Smaller events tend to fill up quickly, so be on the lookout for posts encouraging you to RSVP. You can also sign up for your elected officials' mailing lists to learn about events. Most elected officials have an email signup form on their website, but you can also call their office to let them know you want to be added. Many lawmakers have free open house-style events where you can show up and talk to them about anything and everything. These events tend to have very high attendance.

SAMPLE THANK YOU LETTER

When you have contact with a lawmaker's office, whether it be an in-person meeting, virtual meeting or phone call, it is important to send a thank-you email promptly. Not only does a thank-you show your appreciation for their time and consideration, it is also the perfect opportunity to provide follow-up information to the staffer you spoke with.



Feel free to use this sample thank you email or letter as a template to send after your meetings.

Dear [Staffer First Name],

Thank you for taking the time to [meet/speak] with me [today/ yesterday/recently].

We discussed [state the topic(s) you discussed]. I wanted to reiterate how much [the goal of the legislation] really means to [AMKD/kidney disease] patients. [Provide a concrete reason why it's important].

Attached to this [email/letter] are the documents I promised. If I can be of any further assistance to you, please don't hesitate to let me know. Thank you once again for your time.

Sincerely,

[Your Full Name] [Your Contact Information]

Using Social Media

Social media is a great way to stay up to date on what your elected officials at all levels of government are doing. Many elected officials use social media to share news, legislation they are working on and how they plan to vote on certain bills. You can learn a lot just by following them. If you don't already have Faecbook, X, Bluesky or Instagram accounts, you can sign up for free.

You can find your elected officials' social media handles (profiles) on their official websites. Every year social media grows in importance for elected officials. This is a big benefit to the public because it makes it much easier to interact with lawmakers. For the majority of issues, if 100 people email a Capitol Hill office and say they are for or against certain legislation, the member of Congress will likely just get a tally of the emails. If 100 constituents tweet about the same topic, it is more likely to be noticed.

By following a few simple rules, your social media posts can have a big effect on the kidney disease issues you care about.

AKF Ambassador Opportunities - Join our Advocacy Network

There is strength in numbers. More than 36,000 passionate patients, family members, friends and kidney care professionals serve as AKF Ambassadors. Join our Advocacy Network and be a voice for kidney patients. <u>Click</u> here to join.

TAKE ACTION

Add your voice to thousands of other voices in our Advocacy Network and help us make a difference! <u>Contact</u> your state and federal legislators by filling out an action alert about kidney related legislation.





CURRENT LEGISLATION

On Feb. 24, 2025, the New Era of Preventing End-Stage Kidney Disease Act of 2025 was introduced in the U.S. House of Representatives. This bill aims to help doctors and patients better understand rare kidney diseases better and help patients get diagnosed faster. Included in the legislation is the requirement of a federal study on testing, preventative care, precision medicine and treatment for rare kidney diseases, including testing for APOL1-mediated kidney disease.

Email your lawmakers and urge them to support more research into rare kidney diseases by filling out AKF's action alert for this bill.

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 kidneyfund.org/amkd-day-proclamation.

CONTACT US

AKF is always excited to work with patients, families, and caregivers all over the country. With legislation progressing in statehouses and on Capitol Hill, we need help from all of you. Politicians want to hear from their constituents and we want Ambassadors posting, calling, emailing and meeting with their elected officials.

If you are unsure about where to get started, we are more than happy to help guide you.

Ben Shlesinger
Associate Director of Government Relations
bshlesinger@kidneyfund.org

Advocacy Resources

AKF website: KidneyFund.org

Join our Advocacy Network: KidneyFund.org/join-our-advocacy-network

AKF's federal and state action alerts: KidneyFund.org/Act

AKF's public policy agenda: KidneyFund.org/policy-priorities

U.S. House of Representatives (find your rep): House.gov

U.S. Senate (find your senator): Senate.gov

Find your local legislator: pluralpolicy.com/find-your-legislator



KidneyFund.org/apol1aware

We are grateful to our corporate sponsors who support AKF's AMKD education programming.

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