2026 | COMMUNITY TOOLKIT

Be APOL1 Aware

Join in AMKD Awareness Day

APRIL 28

American Kidney Fund®

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Introduction

APOL1-mediated kidney disease (AMKD) is a rapidly progressive genetic kidney disease. Each of us has two copies of the APOL1 gene, but people born with variants (changes) in both APOL1 genes are at higher risk for kidney disease and kidney failure. AMKD disproportionately affects people of Western and Central African descent, including those who identify as Black, African American, Afro-Caribbean, and/or Latina/Latino.

Led by the American Kidney Fund (AKF) since 2024, **AMKD Awareness Day is observed annually on the last Tuesday of April** during National Minority Health Month and serves as an opportunity for communities, organizations, and families to learn how genetics impact kidney health. By becoming APOL1 aware and sharing this knowledge, individuals can take proactive steps to protect their health, spark meaningful conversations and help prevent kidney disease.

AMKD Awareness Day is not just about commemorating a day—it's a call to close the gaps in awareness, diagnosis, treatment and support. Together, we can raise awareness, support our communities and advance kidney health equity.

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

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Become an Official AMKD Awareness Day Partner

Partners play a vital role in spreading accurate, culturally relevant information about AMKD by engaging their communities in meaningful conversations and activities. We encourage interested organizations and individuals to use and share this toolkit to amplify awareness on AMKD Awareness Day and throughout the month of April. By actively participating in these nationwide efforts, your organization will be recognized as an official partner on our website.

Officially recognized partners take part in awareness day activities such as:

- **Promoting AMKD Awareness Day throughout April and on AMKD Awareness Day.** Partners are encouraged to use and share this toolkit to educate their communities, and spark conversations about AMKD within your community
- **Hosting awareness activities,** such as educational events, social media campaigns, community discussions or interactive challenges
- **Sharing trusted AKF resources** to help people understand how genetics impact kidney health and why being APOL1 aware matters

To learn more about becoming an official partner, email partnerships@kidneyfund.org.

How to Use this Toolkit

We are pleased to share this toolkit to encourage widespread participation in **AMKD Awareness Day on April 28, 2026.** 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, advocacy information and more.

In addition, you'll find actionable steps, such as interactive challenges and outreach strategies to support community engagement and outreach to populations at higher risk for AMKD. These resources may be used independently or can be integrated into existing programs and initiatives focused on health and wellness.

Our toolkit can be considered a starting point for your AMKD Awareness Day plans — we encourage you to personalize your outreach, which will help bring visibility to a disease that does not yet have widespread recognition.

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

Each of us has two copies of the APOL1 gene. If you're Black, African American, African, Afro-Caribbean, or Latina/Latino, you're more likely to have inherited variants in that gene. And if you have variations in both copies of the gene, you're at greater risk (1 in 5) of developing APOL1-mediated kidney disease (AMKD), an aggressive form of genetic kidney disease. These inherited variants can cause kidney disease to start earlier and damage your kidneys at a faster rate.

- The APOL1 gene evolved over the past 3,000-10,000 years in people who lived in Western and Central Africa. The variant that evolved is associated with protection against a certain type of parasite that causes African sleeping sickness.
- AMKD stands for APOL1-mediated kidney disease. AMKD is a form of rapidly progressive kidney disease caused by having two risk variants of the apolipoprotein L1 (APOL1) gene.
- Many people living with AMKD do not know they have it. Common symptoms of AMKD may include:
    - Protein in your urine (pee)
    - Swelling in your legs or weight gain
    - Feeling weak and tired
    - High blood pressure
- AMKD can lead to serious kidney problems, including kidney failure.
- People with AMKD can progress to kidney failure an estimated 9-12 years earlier than those without APOL1 risk variants.
- In the United States, an estimated 13% of Black Americans have two of the APOL1 genetic variations.

Discover the powerful stories of people living with AMKD at KidneyFund.org/APOL1Aware.

07

Assets and Resources

AKF has made all shareable assets available for download at socialpresskit.com/amkd, a user-friendly way of downloading all our AMKD Awareness Day tools and resources. If you are an organization, editable assets are also available for you to add your own logo.

AMKD Awareness Day Logos

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AMKD AWARENESS DAY PARTNER

Email Assets

DOWNLOAD NEWSLETTER/ EMAIL COPY AND GRAPHICS

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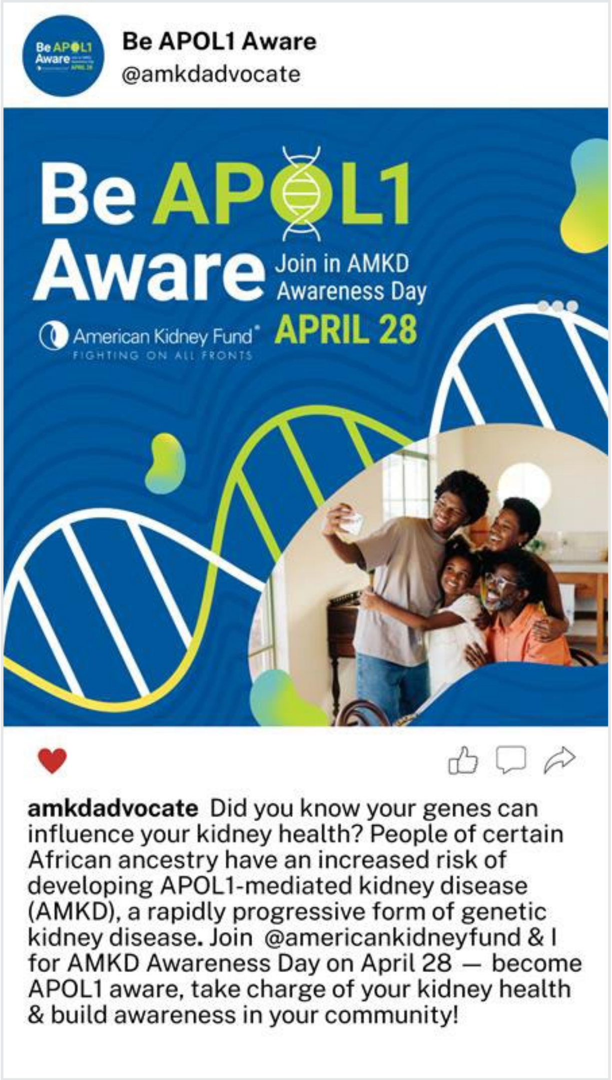
Social Media Assets

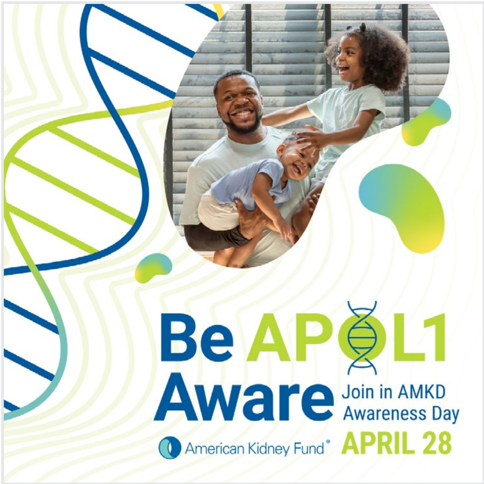
We request you add #APOL1Aware to your posts and tag AKF so that we can re-share.

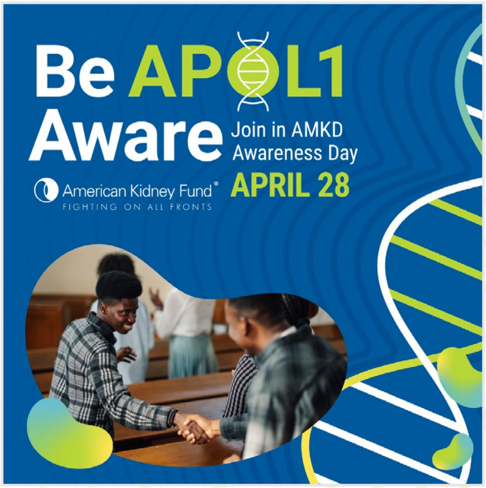


Be APOL1 Aware
@amkdadvocate

amkdadvocate Did you know your genes can influence your kidney health? People of certain African ancestry have an increased risk of developing APOL1-mediated kidney disease (AMKD), a rapidly progressive form of genetic kidney disease. Join @americankidneyfund & I for AMKD Awareness Day on April 28 — become APOL1 aware, take charge of your kidney health & build awareness in your community!

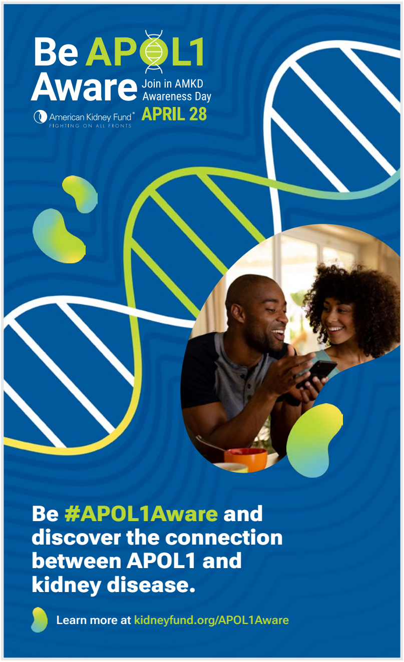
DOWNLOAD SUGGESTED SOCIAL POST AND GRAPHICS





Print Materials and Fact Sheets

AMKD Awareness Day Poster



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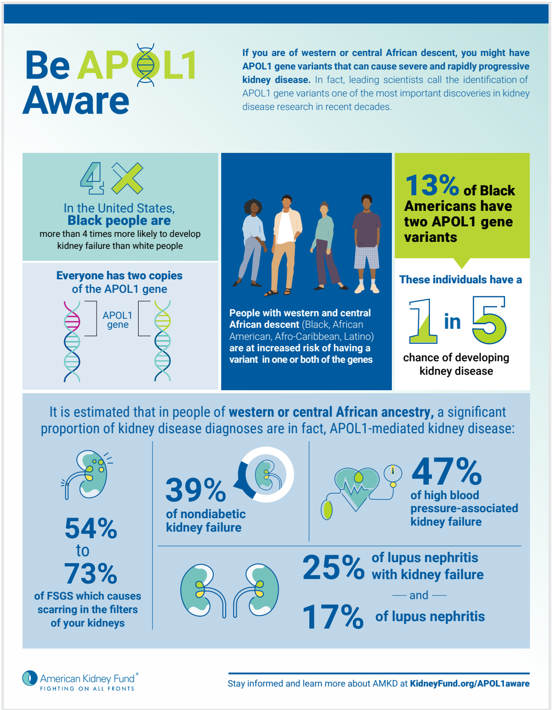
Be #APOL1Aware and discover the connection between APOL1 and kidney disease.

Learn more at kidneyfund.org/APOL1Aware

DOWNLOAD

Understanding AMKD Infographic



Be APOL1 Aware

If you are of western or 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.

4X

In the United States, **Black people are** more than 4 times more likely to develop kidney failure than white people

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**

13% of Black Americans have two APOL1 gene variants

These individuals have a 1 in 5 chance of developing kidney disease

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:

54% to 73% of FSGS which causes scarring in the filters of your kidneys

39% of nondiabetic kidney failure

47% of high blood pressure-associated kidney failure

25% of lupus nephritis with kidney failure

— and —

17% of lupus nephritis

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Stay informed and learn more about AMKD at **KidneyFund.org/APOL1aware**

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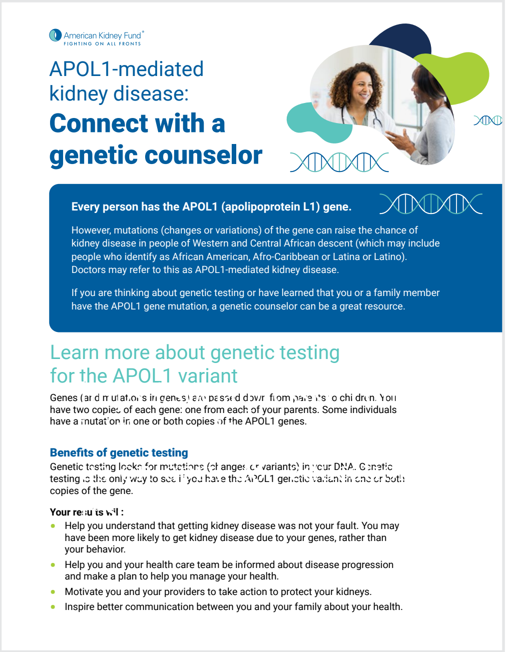
Print Materials and Fact Sheets (continued)

Genetic Testing Information



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

Every person has the APOL1 (apolipoprotein L1) gene.

However, mutations (changes or variations) of the gene can raise the chance of kidney disease in people of Western and Central African descent (which may include people who identify as African American, Afro-Caribbean or Latina or Latino). Doctors may refer to this as APOL1-mediated kidney disease.

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.

Learn more about genetic testing for the APOL1 variant

Genes (and mutations in genes) are passed down from parents to children. You have two copies of each gene: one from each of your parents. Some individuals have a mutation in one or both copies of the APOL1 genes.

Benefits of genetic testing

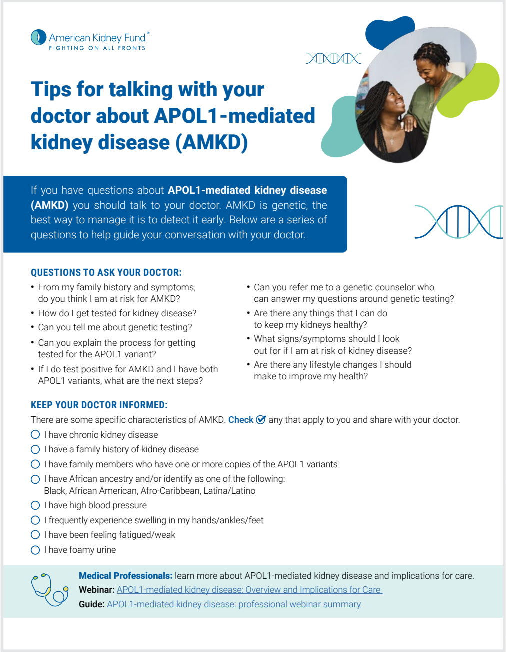
Genetic testing looks for mutations (changes or variants) in your DNA. Genetic testing is the only way to see if you have the APOL1 genetic variant in one or both copies of the gene.

Your results will:

- Help you understand that getting kidney disease was not your fault. You may have been more likely to get kidney disease due to your genes, rather than your behavior.
- Help you and your health care team be informed about disease progression and make a plan to help you manage your health.
- Motivate you and your providers to take action to protect your kidneys.
- Inspire better communication between you and your family about your health.

DOWNLOAD

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

DOWNLOAD

Presentation Tools

Video Meeting Backgrounds

STANDARD DECK:

PARTNER DECK:

DOWNLOAD

PowerPoint Templates

STANDARD DECK:

PARTNER DECK:

DOWNLOAD

Ideas for Community Events and Activities

Coffee and Conversations

Host a coffee and conversation. Conversations about health, especially chronic diseases such as kidney disease, can be tough to initiate, but coffee or tea can help foster an open and meaningful conversation.

Walk and Talk

Host a community walk at a local park or trail to raise awareness about AMKD. This event encourages movement and conversation while educating participants about kidney health and genetic risk.

Community Presentations and Tabling

Partner with a local senior or community center to host an educational event focused on chronic kidney disease (CKD) and APOL1-Mediated Kidney Disease (AMKD).

Social Media Challenges

Encourage your community to learn, engage in conversations, take action, and amplify awareness throughout the month on social media. Consider sharing a photo of what you're protecting (your kids, family, community, career) and tag three friends to ask their doctor about AMKD.

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Other Ways to Get Involved with AKF

Become a Kidney Health Coach

Kidney Health Coach® (KHC) is the American Kidney Fund's free, peer-to-peer community health education training program. The program equips people with the knowledge and tools to educate and support others in preventing kidney disease and slowing its progression to kidney failure.

More than 8,200 patients, caregivers, advocates, healthcare professionals, and the lay community are a Kidney Health Coach. If you enjoy educating others about the importance of living a healthy lifestyle, then the KHC program is for you! Take the free course here.

As a KHC, you can help spread the word about AMKD by:

SERVING AS TRUSTED MESSENGERS IN THE COMMUNITY

- Hosting AMKD community conversations, workshops or information sessions both virtually and in person
- Sharing AMKD education through faith-based, civic and community partners
- Distributing AKF's AMKD resources and toolkits that can be found on the KHC portal

DRIVING MORE VISIBILITY TO THE AWARENESS DAY

- Leading #APOL1Aware social media push and using the log form to highlight your efforts
- Sharing the AMKD checklist

SUPPORTING EARLY DETECTION EFFORTS

- Encouraging blood pressure monitoring and kidney numbers conversation (Know Your Kidneys)
- Sharing the importance of knowing family medical history (Genes to Generation)

WORKING WITH LOCAL, REGIONAL, AND NATIONAL PARTNERS

- Encouraging organizations to participate and speak about how the yearly grants that AKF provides can be something they apply for in the upcoming year to advance their AMKD efforts year round
- Supporting partner-hosted AMKD Awareness Day activities

Advocacy Opportunities - Your Advocacy Toolbox

The kidney community plays a vital role in advocacy efforts. 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.

Identifying Your Elected Officials

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

How to Contact Your Elected Officials

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 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.

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]*

Guidance for Using Social Media

Social media is a great way to stay up to date on with your elected officials. 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 their social media accounts that you can find on their official websites. If you don't already have Facebook, X, Bluesky or Instagram accounts, you can sign up for free.

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 post on social media about the same topic, it is more likely to be noticed!

Take Action

Add your voice to thousands of other voices in our Advocacy Network and help us make a difference! Contact your state and federal legislators by filling out an action alert to ask your elected official to support kidney related legislation.

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.

CURRENT LEGISLATION

- **New Era of Preventing End-Stage Kidney Disease Act of 2025:** Aims to help doctors and patients better understand rare kidney diseases 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.

- **Access to Genetic Counselor Services Act (H.R. 6280):** Would authorize Medicare to reimburse licensed genetic counselors directly for their services. Under current policy, Medicare will only cover genetic counseling when a physician orders and bills for the service.

AKF is always excited to work with patients, families, and caregivers all over the country! There is strength in numbers. More than 50,000 passionate patients, family members, friends and kidney care professionals serve as AKF Ambassadors.

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.

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

Take Advocacy Action: KidneyFund.org/Act

Share Your Story: KidneyFund.org/ share-your-story

Thank You for Supporting AMKD Awareness Day

AKF appreciates the efforts of every individual and organization working to help raise awareness about AMKD in their communities. Whether you share information on social media, host an event in your community, advocate for policies that help improve health outcomes or post educational resources in your community or workplace, every action counts toward helping others become APOL1 aware.

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KidneyFund.org/apol1aware

We are grateful to our corporate sponsor who supports AKF's AMKD education programming.

LEAD SUPPORT IS PROVIDED BY

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