



What To Know About APOL1 Kidney Disease

A Resource for Healthcare Professionals

What is APOL1 Kidney Disease (APOL1 KD)?



APOL1 KD is a **genetic form of chronic kidney disease (CKD)** that primarily affects people of African ancestry. Patients experience an increased rate of disease progression which leads to initiation of **dialysis almost a decade earlier** than patients without the high-risk variants.¹

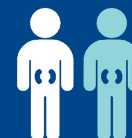
13%

of all African Americans have 2 copies of the *APOL1* gene variants.^{1,2}



50%

of African Americans with non-diabetic chronic kidney disease (CKD) have the high-risk *APOL1* genotype.^{2,3}



What is my role as a healthcare professional?

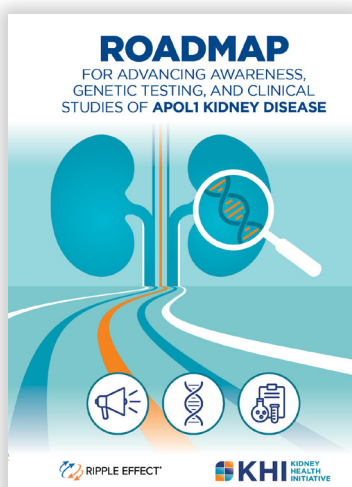
Those at-risk may not be aware of APOL1 KD. Inform your patients about APOL1 KD and how it might impact their families and communities.

Genetic testing is the only way to diagnose APOL1 KD. Healthcare professionals can talk to their patients about testing options and genetic counseling.

There are currently no treatments for APOL1 KD. Healthcare professionals should communicate with their patients about participating in clinical studies to develop treatments.

A Roadmap to Improve Patient Outcomes

The Kidney Health Initiative (KHI) has released a roadmap for APOL1 KD to support 3 goals:



Goal 1: Increase Awareness of APOL1 KD



Goal 2: Increase Access to and Awareness of Genetic Testing of APOL1 KD and Associated Counseling



Goal 3: Empower Patients to Make Informed Decisions Regarding Clinical Study Participation

¹ Elliott MD, Marasa M, Cocchi E, et al. Clinical and Genetic Characteristics of CKD Patients with High-Risk APOL1 Genotypes. *J Am Soc Nephrol*. doi:10.1681/asn.0000000000000094

² Dummer PD, Limou S, Rosenberg AZ, et al. APOL1 kidney disease risk variants: An evolving landscape. *Semin Nephrol*. 2015;35(3):222-236. doi:10.1016/j.semnephrol.2015.04.008

³ Pollak MR, Friedman DJ. APOL1 and APOL1-Associated Kidney Disease: A Common Disease, an Unusual Disease Gene—Proceedings of the Henry Shavelle Professorship. *Glomerular Dis*. 2023;3(1):75-87. doi:10.1159/000529227



What to Know About APOL1 KD Diagnosis

While CKD may be diagnosed by a urine test and biopsy, a **genetic test is required to diagnose APOL1 KD**.

Since APOL1 genetic testing is not routinely done, an **APOL1 KD diagnosis may be delayed for many patients with CKD**.

It is likely that by the time APOL1 KD is diagnosed, a patient's kidney function has already been adversely affected.

Why is the Roadmap Important?



The roadmap provides information on APOL1 KD and disease risk from the *APOL1* gene.



The roadmap provides information about *APOL1* genetic testing and associated counseling.



The roadmap provides information about APOL1 KD clinical studies.



What Actions Can I Take?

- Learn more about APOL1 KD to understand the risks of your patients.
- Learn and understand communication strategies to talk to at-risk patients about APOL1 KD.
- Learn more about the *APOL1* gene and inform patients about genetic risk factors.



What Actions Can I Take?

- Learn about genetic testing options, payment, and policies.
- Learn about communication strategies and tools to talk to patients about options for *APOL1* genetic testing.
- Establish relationships with genetic counselors in order to facilitate referrals.



What Actions Can I Take?

- Learn about the current APOL1 KD clinical studies.
- Inform patients about opportunities to participate in APOL1 KD clinical studies.
- Establish relationships with clinical study investigators to stay informed about the clinical study landscape.

How Can I Get Involved?

Read the *APOL1 KD* roadmap.

Share the *APOL1 KD* roadmap with your colleagues.

Connect with KHI. Become a member of KHI. Through KHI, you can get involved with initiatives to drive progress in kidney care.

Website: <https://kidneyhealthinitiative.org>

Email: khi@asn-online.org

Key resources on APOL1 KD:

- [How are variations in the APOL1 gene linked to risk of kidney disease?](#)
- [Understanding APOL1 Kidney Disease Among Black Americans](#)
- [Black Health Matters: Kidney Disease](#)
- [American Kidney Fund: APOL1-Mediated Kidney Disease](#)