



PRESS RELEASE

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KIDNEY HEALTH INITIATIVE UNVEILS APOL1 ROADMAP TO ADDRESS APOL1 KIDNEY DISEASE

APOL1 Kidney Disease (APOL1 KD) is a genetic condition that affects people who carry a high-risk APOL1 gene variant. Most people with those variants are of African ancestry.

Washington, D.C. (April 23, 2023)—The [Kidney Health Initiative \(KHI\)](#), a public-private partnership among American Society of Nephrology and the US Food and Drug Administration (FDA) has released an essential new resource, [Roadmap for Advancing Awareness, Genetic Testing, and Clinical Studies of APOL1 Kidney Disease](#).

What is APOL1 Kidney Disease?

African Americans represent 13% of the U.S. population, yet account for approximately 32% of patients receiving dialysis treatment. Of those receiving dialysis treatment, many have APOL1 variants. About 50% of African Americans carry at least one APOL1 variant, and 13% carry the high-risk variants. Despite this, there is little acknowledgment of APOL1 KD in kidney care, and only a few clinical studies currently seek to develop targeted treatments for this disease.

The APOL1 Roadmap serves as a guidance document for individuals who are actively engaged in establishing awareness of APOL1 KD, including care team, patients and their families, patient advocacy groups, leaders within communities of those at risk, and more. It includes crucial information to support the kidney health community. The document delineates three areas of focus or goals to address the challenges associated with APOL1 KD:

1. Improve awareness of APOL1 KD by focusing efforts on education.
2. Increase access and awareness of genetic testing and counseling of APOL1 KD by leveraging care team training and education on testing availability.
3. Empower patients to make informed decisions about participating in clinical studies with community outreach and engagement.

By leveraging the Socio-Ecological Model, a model based on the idea that a person's health outcomes are not isolated but rather connected to larger systems (e.g., family, caregiver, health care, community, etc.), the APOL1 Roadmap prioritizes health equity and patient-centered care as it works to address the challenges of kidney diseases and

improve health outcomes for those at risk or affected by APOL1 KD. The solutions presented within the roadmap will help reach patients and at-risk individuals and include engagement and culturally informed discussions with the care team.

Uptal D. Patel, MD, Chair of KHI's Board of Directors, stated, "This roadmap represents a critical step forward in our collective efforts to address APOL1 KD and its disproportionate impact on individuals of African ancestry. By fostering collaboration among our partners and implementing targeted initiatives, we can drive meaningful progress toward closing the gap in kidney health disparities."

For more information about the APOL1 KD Roadmap and the Kidney Health Initiative, please visit khi.asn-online.org.

About ASN

Since 1966, ASN has been leading the fight to prevent, treat, and cure kidney diseases throughout the world by educating health professionals and scientists, advancing research and innovation, communicating new knowledge and advocating for the highest quality care for patients. ASN has nearly 22,000 members representing 141 countries. For more information, visit www.asn-online.org and follow us on [Facebook](#), [X](#), [LinkedIn](#), and [Instagram](#).

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