



NATIONAL KIDNEY
FOUNDATION®



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National Kidney Foundation Partners with Alport Syndrome Foundation to expand First-Ever National Registry for Patients at All Stages of Kidney Disease

August 9, 2021 — A new partnership between the [National Kidney Foundation](http://www.kidney.org) (NKF) and the [Alport Syndrome Foundation](http://www.alportsyndrome.org) (ASF) is designed to give hope to the thousands of patients, including children and their families, who suffer from debilitating Alport syndrome, a rare genetic kidney disorder.

NKF and ASF will collaborate on the NKF Patient Network – Alport Syndrome, a new sub-registry devoted to Alport syndrome patients within the [NKF Patient Network](#), a registry for people with all stages of kidney disease. The NKF Patient Network is the only kidney disease registry that has both patient-entered data combined with electronic health records (EHR). Patients with all stages of kidney disease can register and add their important health information. The unique digital platform is designed to improve the lives of people with kidney disease by better informing research, clinical care, drug development, and health policy decisions, as well as give kidney patients the tools they need to stay educated and healthy.

"We believe that this partnership, with the combined strengths of NKF's programmatic expertise and the Alport Syndrome Foundation's large, engaged patient community, will provide a powerful research tool, support clinical trials and help find new treatments," said Kerry Willis PhD, NKF CSO.

Alport syndrome is a rare kidney disease resulting from a defective collagen gene that is passed down in families from parents to children, although sometimes it can occur spontaneously. The disease causes kidneys to decline in function over time and frequently results in hearing loss and/or eye abnormalities.

"This sub-registry provides a valuable opportunity to capture critical data about aspects of our genetic kidney disease that are specific to Alport syndrome, currently understudied, and have been documented by the patient community as important in their experience living with this rare disease," said Lisa Bonebrake, Executive Director of Alport Syndrome Foundation. "Partnering with NKF, an organization with a long history of successfully investing in scientific, educational, and advocacy resources benefiting kidney patients, is a great fit for this registry."

It is estimated to affect 1 in every 5,000-10,000 people, which means that about 30,000-60,000 people in the United States are living with Alport syndrome, though recent research suggests that this number may be far higher.

“I am so delighted about this partnership,” said Lesley Inker, MD, Director of the Kidney and Blood Pressure Center and the Kidney Function and Evaluation Center at Tufts Medical Center. “As a member of the Medical Advisory Committee for ASF and as chair of the steering committee for the Network, I have great confidence that the information we learn from the patients with Alport syndrome will make a real difference in helping us to find, and ultimately implement, life changing therapies.”

The new NKF Patient Network – Alport Syndrome sub-registry will accelerate research focused on outcomes, perceptions, and experiences that are important to people with Alport syndrome and will facilitate the planning and implementation of clinical trials to help develop new treatments.

For more information about the new NKF Patient Network – Alport Syndrome sub-registry, go to nkfpatientnetwork.org.

Kidney Disease Facts

In the United States, 37 million adults are estimated to have [chronic kidney disease](#) (CKD)—and approximately 90 percent don’t know they have it. 1 in 3 adults in the U.S. is at risk for chronic kidney disease. Risk factors for kidney disease include: [diabetes](#), [high blood pressure](#), [heart disease](#), [obesity](#), and family history. People who are Black or African American, Hispanic or Latino, American Indian or Alaska Native, Asian American, or Native Hawaiian or Other Pacific Islander are at increased risk for developing the disease. Black or African American people are almost 4 times more likely than Whites to have kidney failure. Hispanic or Latino people are 1.3 times more likely than non-Hispanic or non-Latino people to have kidney failure.

About the National Kidney Foundation

[The National Kidney Foundation](#) (NKF) is the largest, most comprehensive, and longstanding patient-centric organization dedicated to the awareness, prevention, and treatment of kidney disease in the U.S. For more information about NKF, visit www.kidney.org.

About the Alport Syndrome Foundation

ASF is the leading patient-led, independent, non-profit organization in the United States educating and giving a voice to the Alport syndrome community. Their mission is to improve the lives of those affected by Alport Syndrome through education, empowerment, advocacy, and research. For more information about ASF, visit www.alportsyndrome.org.