In February 2021, the National Kidney Foundation (NKF) launched the NKF Patient Network, the first national registry for people with all stages and types of kidney disease that links patient-entered data with clinical and laboratory data from electronic health records (EHR). This novel infrastructure enables individualized educational resources, research, clinical care, and health policy decisions to be centered on patient perceptions, priorities, and activities. The Network is now well positioned to grow and expand to advance patient-centered kidney research, care, and treatments.

**THE NETWORK BY-THE-NUMBERS** (Patient-entered data as of February 1, 2022)

- **1,200+** participants enrolled from 47 states
- **58%** are women
- **57%** are age 60–79
- **19%** with history of a kidney transplant

**RACE**
- White - 87.6%
- Black or African America - 6.7%
- Asian - 2.9%
- Prefer not to answer - 1.5%
- American Indian or Alaska Native - 0.8%
- Unknown - 0.3%
- Native Hawaiian or Pacific Islander - 0.2%

**ETHNICITY**
- Not Hispanic or Latino - 90%
- Hispanic or Latino - 4%
- Unknown - 3%
- Prefer not to say - 3%

**CKD STAGE**
- CKD Stage 1 - 3%
- CKD Stage 2 - 2%
- CKD Stage 3 - 46%
- CKD Stage 4 - 13%
- CKD Stage 5/ESKD - 23%
- Don’t know - 13%

**HISTORY OF DIALYSIS**
- Never been on dialysis - 71%
- Currently on dialysis - 16%
- Previously on dialysis - 13%
NEWS FROM THE NETWORK

- The first U.S. clinical site is Geisinger health system. If patients are receiving care in the Geisinger system, their providers will share information from their EHR with the Network upon receiving consent. NKF looks forward to partnering with more health systems and academic medical centers in 2022.

- NKF and the Alport Syndrome Foundation announced their partnership in the “NKF Patient Network—Alport Syndrome,” a new registry expansion devoted to Alport patients within the NKF Patient Network. The NKF Patient Network—Alport Syndrome will launch in early 2022.

- Participation in the Network will open to Canadian sites in spring 2022. NKF is seeking other global sites in 2022.

- The NKF Patient Network will launch in Spanish in 2022.

BENEFITS OF JOINING THE NETWORK

- Patients will become part of research projects around the world
- Support from a community who understands what it’s like to live with kidney disease
- Patient voices will be heard by scientists and doctors studying kidney disease
- Information on how to join the latest clinical trials
- Individualized patient education, unique to the stage of kidney disease, symptoms, and treatments
- Health tips based on the most recent studies.

PATIENTS

Join the over 1,200 participants already enrolled in the NKF Patient Network.

HEALTHCARE PROFESSIONALS

Share the NKF Patient Network with your patients and spread the word with your colleagues.

Join today at NKFPatientNetwork.org

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NKF thanks the NKF Patient Network partners (in alphabetical order): Alport Syndrome Foundation, Geisinger, Labcorp®, Pulse Infoframe, University of Manitoba. NKF would also like to thank all the members of the governance committees.

Foundational support for the NKF Patient Network was provided through a collaboration with Bayer AG. AstraZeneca and Novartis are platinum sponsors. Boehringer Ingelheim is gold sponsor.