Are there opportunities for patients to connect with others?

Members of the NKF Patient Network can connect with a supportive community that understands what it’s like to live with chronic kidney disease, so they can feel less alone.

What sort of platform will the NKF Patient Network use?

NKF has partnered with a technology firm, Pulse Infoframe, which has developed the healthie™ cloud-based platform, designed to extract, curate, analyze, and disseminate Real-World Evidence. All data collected through the NKF Patient Network will be stored on the healthie™ platform that is highly secure and meets all internationally established standards for security of health information. The healthie™ platform has the capability to connect to a myriad of health information systems safely and seamlessly.

What stage kidney disease patients will be eligible to sign up?

The NKF Patient Network welcomes patients at all stages of kidney disease, as well as dialysis and transplant patients.

How can I get more information on the NKF Patient Network?

Visit us at NKFPatientNetwork.org

You can also contact the NKF Cares Patient Help Line toll-free at 855.NKF.CARES (855.653.2273) or at nkfcares@kidney.org

Get to Know the NKF Patient Network

FAQS FOR HEALTHCARE PROFESSIONALS

A place to transform kidney care and research together

- Individualized education
- Peer support
- Easy way to get involved in research and innovation
- Access to clinical trials

NATIONAL KIDNEY FOUNDATION

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What is the NKF Patient Network?
The NKF Patient Network is the first nationwide kidney disease patient registry that will advance both patient education and kidney disease treatment. This powerful research tool can improve the lives of patients with kidney disease by better informing research, clinical care, drug development, and health policy decisions, as well as giving patients the tools they need to stay educated and healthy.

How does the NKF Patient Network plan to gather research data and why is it considered to be innovative?
The Network will collect both rigorous clinical and laboratory data from electronic health records (EHR), in addition to patient-entered data, which together allow for a “complete picture” of the patient. This model is considered innovative in that most research initiatives follow one path or the other—EHR or patient self-reporting. The NKF Patient Network will compile data on demographics, medical history, lifestyle, medications, blood and urine test results, in addition to extensive data on patient perceptions, challenges, and priorities.

How will patients be invited to participate?
Healthcare professionals are critical to the Network’s success—help introduce your patients to the NKF Patient Network and invite them to join by visiting us at NKFPatientNetwork.org

NKF will also collaborate with health systems to obtain both electronic healthcare records (EHR) and patient-entered data. In parallel, patient enrollment will be achieved through a comprehensive outreach program that includes links from various other NKF programs, local NKF field office recruitment, links from clinical trials for kidney disease treatments, referrals from other Network participants and partners, and a direct public relations campaign.

Why should I ask my patients to participate?
When patients participate in research, they are often required to share their medical history, which can be extensive. With the NKF Patient Network, it is simple for them to enter their health data through a secure patient portal, allowing researchers to quickly access and use it to develop new kidney disease treatments. Through the NKF Patient Network, your patients will be able to contribute data that will aid in the success of clinical trials and ultimately patient outcomes.

What are other benefits of the NKF Patient Network?
The Network offers a simple way for your patients to access a wide variety of individualized kidney care resources—all of which have been verified and vetted by NKF. In addition, through the Network, patients will be able to provide real-time feedback to the research community on their conditions and healthcare experiences. This information creates new opportunities for medicine and research that can target and help a wider range of patients, based on their perspectives, priorities, and activities.

To learn more, come visit us at NKFPatientNetwork.org