



### Will I be able to learn about clinical trials and research?

Yes! Clinical trials play a big part in finding new and improved treatments. Kidney disease researchers need participants to help drive the success of the trials. Through the NKF Patient Network, you will be able to find new research opportunities and volunteer your time and experiences.

### Why should I join the NKF Patient Network?

There is power in numbers. By joining the Network, you'll become part of a community of people affected by kidney disease who want to improve care and treatments, now and in the future. By sharing your health data and life experiences you will help expand knowledge of kidney disease for yourself, scientists, doctors, and researchers. This data will inspire and inform research that will improve what is known about kidney disease and how it affects people's health and their lives. Improvements in treatment only happen when there's access to enough patient health information—you can help by joining today!

### How can I join the NKF Patient Network?

Visit us at [NKFPatientNetwork.org](https://www.NKFPatientNetwork.org)

Need help? Contact the NKF Cares Patient Help Line toll-free at [855.NKF.CARES](tel:855.NKF.CARES) (855.653.2273) or at [nkfcares@kidney.org](mailto:nkfcares@kidney.org)

National Kidney Foundation

## PATIENT NETWORK

**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



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[kidney.org](https://www.kidney.org)



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PATIENT NETWORK

## Get to Know the NKF Patient Network

FAQS FOR PATIENTS

**A place to transform kidney care and research together**



National Kidney Foundation

# PATIENT NETWORK

## What is the NKF Patient Network?

The NKF Patient Network is the first nationwide kidney disease patient registry developed with the overall goal of improving the lives of people with kidney disease through research, clinical care, drug development, and supportive health policy decisions. We believe the best way to achieve this is by partnering with kidney patients like YOU—the Network is a place to transform kidney care and research together!

## What is a patient registry?

A patient registry is an organized collection of information, or data, about people's health. It can be used to study groups of people with a similar condition or disease to increase our understanding of that disease, and how it affects people.

## I have heard of patient registries. How is the NKF Patient Network different?

The NKF Patient Network is not just a database, it is also a one-stop shop for kidney resources, focused on enhancing care through individualized education, tips, and support. The data we collect goes beyond numbers on a spreadsheet—we want to hear about your experiences living with kidney disease. The Network also allows you to connect with other patients and be a part of a supportive community that understands what it is like to live with kidney disease.

### What makes the NKF Patient Network unique:



Individualized education



Peer support



Easy way to get involved in research and innovation



Access to clinical trials

To learn more, come visit us at

[NKFPatientNetwork.org](https://www.nkfpatientnetwork.org)

## How does the NKF Patient Network work?

The NKF Patient Network offers a secure portal that you can log on to at any time to easily share your experiences and health data that, in turn, helps with research that supports the entire kidney disease community. You can choose to manually enter your information or link it, with permission, to your medical records.

By sharing your information and providing feedback through surveys about your condition and healthcare experiences, both doctors and scientists will be able to better understand your care and create research that focuses on what you need.

## How is my information kept private and secure?

Your information will be stored in an online platform by our technology partner, Pulse Inframe, which is highly secure and meets all internationally established standards for security of personal and health information. Access to the database containing protected health information is limited to select and qualified registry personnel.