

How is my information kept private and secure?

Your information is stored and protected in a highly secure online platform hosted by our technology partner, HHS Technology Group® (HTG). The KidneyCARE Study meets standards for security of personal and health information. All data is de-identified to maintain your confidentiality, which means your personal information is not connected to your answers. Only authorized staff can access the information.

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

Yes! Clinical trials play a big part in finding new and better treatments. Kidney disease researchers need volunteers to help drive the success of the trials. Through the KidneyCARE Study, you also have opportunities to join new research studies. These trials and studies can improve treatments for everyone.

Does the KidneyCARE Study cost anything to join?

No, there is no cost to join the KidneyCARE Study. You do not need a physician's referral and we do not contact your insurance to join.

How can I learn more about the KidneyCARE Study?

Visit us at KidneyCareStudy.org

Need help? Contact us at **212.889.2210 x134** or at **KidneyCareStudy@kidney.org**

KidneyCARE Study

Community Access to Research Equity

Join today and receive:



- Comprehensive, up-to-date education
- Information about peer support resources and NKF programs



Access to participation in clinical trials and research studies



30 East 33rd Street New York, NY 10016 **kidney.org**



KidneyCareStudy.org

A place to transform kidney care and research together.





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What is the KidneyCARE Study?

The KidneyCARE (**C**ommunity **A**ccess to **R**esearch **E**quity) Study is a nationwide research study for people with all stages and types of kidney disease. The goal of the KidneyCARE Study is to improve understanding of kidney disease, and how it affects people in the real world. People can share health information and answer survey questions about their kidney disease and lifestyle. Researchers use the information provided by you and others like you to improve kidney care. By joining, you can be part of creating better treatments and help us work toward a cure for kidney disease.

Is the KidneyCARE Study a patient registry?

Yes, the KidneyCARE Study is a patient registry. A patient registry is a collection of health information used for research. It includes groups of people with similar conditions. The KidneyCARE study is specifically for people with kidney disease. This includes all causes and stages of kidney disease, people on dialysis, and those with a kidney transplant. The information you share will help researchers better understand kidney disease and how it affects your daily life. This data helps researchers create studies on improving kidney care.

How is the KidneyCARE Study different from other patient registries?

The KidneyCARE Study is different because it focuses on your day-to-day life. We want to hear about your own experiences living with kidney disease and how it affects your daily life. The KidneyCARE Study also offers you:

- Comprehensive, up-to-date education about kidney health
- Information about peer support resources and NKF programs
- Access to participation in clinical trials and research studies

Why should I join the KidneyCARE Study?

We want you to be a part of a group of people who share a vision: a future with better treatments, earlier detection and, ultimately, a cure for kidney disease. Your participation will help answer questions about kidney disease and help improve treatments.

Once you share your experiences with kidney disease, researchers will be able to view answers from you and others with kidney disease. This collective process gives researchers a better understanding of patient needs. There is power in numbers and you can help by joining today!

How does the KidneyCARE Study work?

The KidneyCARE Study is a secure online portal that you can log into from any internet device. You will be asked to share your experiences by answering survey questions about your health and day-to-day life. The KidneyCARE Study will also link health information from other data sources to your account. All your survey answers and health information will be securely held within your KidneyCARE Study account.

What materials do I need before registering?

Materials that will be beneficial to gather before registering include your recent lab results, medical records, and genetic test results related to your kidney disease (if any). If you do not have these materials, you can input information from these items periodically.