

KidneyCARE Study

Community Access to Research Equity™

Participant Newsletter | May 2025

Welcome to the KidneyCARE Study

Welcome to the second edition of the KidneyCARE Study newsletter! We're excited to share that over 1,400 people from across the country are now enrolled in the study. This includes participants with a wide range of kidney diseases – including those caused by diabetes, high blood pressure, and a number of rare conditions.

In this issue, you'll find updates on kidney learning opportunities and helpful tips to support your journey. Thank you for being a valued member of the KidneyCARE community!

Share Your Thoughts on Xenotransplantation

The National Kidney Foundation (NKF) is conducting an independent survey to understand how people living with kidney disease and their care partners feel about kidney xenotransplantation, an experimental procedure that involves transplanting a genetically modified pig kidney into a human who needs a new kidney.

Note: This survey is not a part of the KidneyCARE Study, but is a separate NKF initiative designed to gather patient and care partner perspectives.

While kidney xenotransplantation is still in the experimental stages and is not yet available as a transplant option, the U. S. Food and Drug Administration (FDA) recently gave approval for clinical trials to begin. To learn more about kidney xenotransplantation, click [here](#).

The NKF has created a survey to understand your perspective - including your hopes, fears, and concerns - about kidney xenotransplantation and the upcoming clinical trials - including whether you would consider (or support) having such a transplant. This information will help NKF to better understand the community perspective on kidney xenotransplantation.

To start the survey, click [here](#).



In this Issue:

Here's what we are covering inside this newsletter. Click on any of the topics listed below for more information

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Learning More About Your Kidney Health

You Can Find Your Kidney Diagnosis in Your Electronic Health Record (EHR)!

When you participate in the KidneyCARE Study, we ask you to share the cause of your kidney disease (your diagnosis). This information is critical, as it helps researchers better understand the different types of kidney conditions and how they affect patients like you. Interestingly, about 40% of study participants have told us that they don't know the cause of their kidney disease.

Knowing your diagnosis can help you to: (1) Learn about treatment options specific to your condition; (2) Ask better questions of your healthcare team; (3) Find resources and support tailored to your disease type.

You may be able to find your kidney diagnosis in your Electronic Health Record (EHR), which is a digital record of your health history. EHRs are often accessible through online patient portals that you can access yourself. To find your kidney diagnosis, log in to your account and navigate to the section that lists your medical history or diagnoses. Depending on which EHR system you use, it may be under a category like "Medical Records", "Health History", or "Diagnoses". Look for terms related to kidney disease or Chronic Kidney Disease (CKD).

If you are still not sure of the underlying cause of your kidney disease, we encourage you to talk to your healthcare team. You can ask them: "What is the cause of my kidney disease?" and "Is there anything more I can do to manage my condition?"

If you previously selected "unknown" as your cause of disease in our survey, you can update your answer the next time you receive our 6 month check-in emails.

Healthy Living Tip

What you eat plays a critical role in protecting your kidneys and supporting your overall health. NKF's Nutrition Coach is your one-stop shop for making kidney-friendly dietary choices.

The site features delicious recipes, expert cooking videos, blog posts on meal preparation, and practical tips for meal preparation and staying hydrated. It also includes information on different dietary approaches - like the DASH Diet, which helps to manage high blood pressure; the Kidney Stones Diet, which helps to reduce the risk of kidney stones; and low-sodium and low-potassium plans tailored for people with reduced kidney function. You can also find a kidney dietitian near you to help create a personalized nutrition plan.

You can explore these resources at [kidney.org/nutrition](https://www.kidney.org/nutrition).

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Kidney Health Learning Opportunity

Upcoming Webinar: Your Kidney Health (with a Spotlight on IgA Nephropathy)

Wednesday, May 14, 2025

1:00 – 2:15 PM (PT)

2:00 – 3:15 PM (MT)

3:00 – 4:15 PM (CT)

4:00 – 5:15 PM (ET)

We invite you to join an upcoming webinar hosted by NKF's West Region team focused on understanding kidney health, with a spotlight on IgA Nephropathy (IgAN) – a kidney disease that is more common in Asian populations. This free, virtual event is open to everyone and will provide valuable information for anyone living with any type of kidney disease.

The webinar will begin with Dr. Brian Brady of Stanford providing an overview of kidney health, including the stages and causes of CKD, along with tips for kidney care. Dr. Ray Hsu of the University of California, San Francisco (UCSF) will then deliver a 10-minute talk on IgAN. The webinar will also feature a patient panel moderated by Kelly Chen, a nephrology nurse practitioner who personally lives with IgAN. The session will conclude with a Question and Answer session where medical experts will be available to answer your questions about IgAN and other kidney conditions.

We hope you'll join us for this informative and engaging session!

[Register here](#)

This Month in Kidney Awareness

May 10 – World Lupus Day

Lupus is a chronic autoimmune disease that can affect many organs, including the kidneys. When lupus affects the kidneys, it's called Lupus Nephritis – a serious condition that can result in kidney damage if untreated. World Lupus Day is a time to raise visibility for this condition, highlight the importance of early detection, and provide support for people living with lupus.

To learn more about Lupus Nephritis, click [here](#).

May 14 – IgA Nephropathy (IgAN) Awareness Day

IgAN is a chronic kidney disease that occurs when the IgA antibody builds up in the kidneys, leading to inflammation and potential kidney damage. IgAN Awareness Day calls attention to this condition and the importance of early detection and support for people living with IgAN.

To learn more about IgAN, click [here](#).

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Frequently Asked Questions

Why am I getting reminders to complete surveys again?

- One of the goals of the study is to understand how kidney disease affects daily life over time. That's why we send you a check-in email every 6 months to ask if anything has changed.
- The check-in includes three surveys:
 - "My Kidney Journey" - review and update your previous answers as needed.
 - "Health Survey" - complete a new version.
 - "Kidney Health Survey" - complete a new version.
- When you receive your reminder emails, please log into kidneycarestudy.org, and click on the "Surveys" tab, and follow the prompts. Thank you for continuing to advance kidney research!

I forgot my username or password. How do I retrieve them?

- Your username is the email address you used to sign up. If you forgot your password, click "Did You Forget Your Password?" from the login page to reset it.

Will my personal information be made public in this or any other research projects?

- Your personal information—such as your name, phone number and address—will NEVER be disclosed without your written permission. Any data you provide will be combined with data from other study participants and used in aggregate form. This means that your responses will be grouped with those of many others to identify general trends and insights. Your individual information will always remain private and unidentifiable.

Contact Information:

Questions? Comments?

Contact the KidneyCARE Study Team:
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