

KidneyCARE Study

Community Access to Research Equity™

Newsletter | February 2025

Welcome to the KidneyCARE Study

From all of us at the National Kidney Foundation (NKF), thank you for participating in the KidneyCARE Study! Your willingness to share your experiences living with kidney disease is vital to the advancement of kidney research. The information that you share will provide researchers with key insights into how kidney disease impacts people's daily lives.

The KidneyCARE Study launched almost 11 months ago. We are excited to share our very first newsletter with you now. We plan to share future editions regularly to keep you informed about new developments, and to make you aware of how your participation in the study helps to advance kidney health research and improved health outcomes for people with kidney disease.

As a reminder, after registering, you will receive emails every 6 months prompting you to update your surveys with any changes in your kidney health. This ongoing information will help researchers understand trends in how kidney disease influences people's mental and physical health over time. These insights will guide the development of improved treatments, policies, and care strategies.

Thank you for your participation in this study. Together, we can help to shape a better future for those living with kidney disease!

Insights from the KidneyCARE Study: First Look at Early Findings

As of mid-February 2025, the KidneyCARE Study has enrolled 837 participants from across the United States, including all 50 states and the Commonwealth of Puerto Rico. This nationwide representation ensures that the study captures a diverse range of patient experiences, helping us better understand the kidney disease journey.

Here's what we've learned so far from the 501 participants who have completed their Core Surveys (continued on page 2)



What's Inside This Issue

Here's what we're covering in this issue of the newsletter. Click on any of the topics listed below to go to the page:

- (1) [Insights from the KidneyCARE Study: First Look at Early Findings](#)
- (2) [Kidney Research News: Highlights from the American Society of Nephrology Annual Meeting](#)
- (3) [Healthy Living Tip](#)
- (4) [Clinical Trial Spotlight](#)
- (5) [Frequently Asked Questions](#)



kidneycaresstudy.org

Questions? Contact us:

If you have questions, please call the KidneyCARE Study team at 212.889.2210 ext.134 M-F 10am-4pm CT or email kidneycaresstudy@kidney.org

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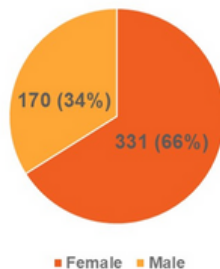


Insights from the KidneyCARE Study: First Look at Early Findings

Gender Distribution:

- Two-thirds of study participants are female, while one-third are male. In addition, 2 individuals identify as transgender (Figure 1)

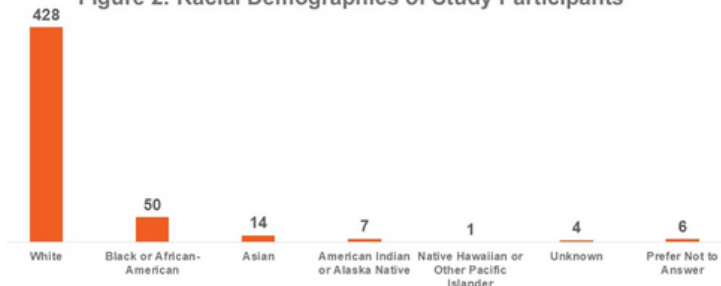
Figure 1: Sex Assigned at Birth



Racial and Ethnic Diversity

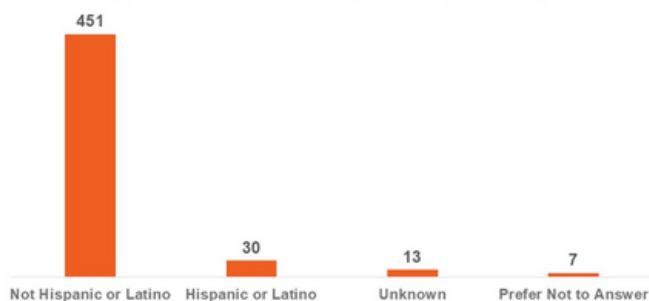
- 82% of study participants are White/Caucasian, 10% are Black/African American, 3% are Asian, 2% are American Indian or Alaska Native, and 1 individual is Native Hawaiian or Other Pacific Islander (Figure 2)

Figure 2: Racial Demographics of Study Participants



- 6% of Study participants identify as Hispanic/Latino (Figure 3)

Figure 3: Ethnic Diversity of Study Participants



Know Your Cause of CKD

It's extremely important to know the underlying cause of your CKD because this can help you to take effective action in controlling your disease. Understanding your diagnosis will allow you and your healthcare team to develop a treatment plan tailored to your specific needs.

For example:

- If your CKD is due to diabetes or high blood pressure, then aggressive management of blood sugar or blood pressure may prevent further kidney damage.
- If your CKD is instead caused by a rare disease like IgAN or FSGS, then targeted therapies or clinical trials may be available to help slow disease progression.
- Early awareness of genetic conditions such as Alport Syndrome can enable an assessment of risks for other family members.
- Knowing your cause of CKD can also help you to make informed lifestyle changes.

Ask your doctor about tests – such as urine tests, blood tests, and genetic tests – that may help to determine the underlying cause of your CKD. The more you understand your condition, the more empowered you are to protect your kidney health. Talk to your doctor to uncover the cause of your CKD and to make sure that you are receiving the best possible treatment.

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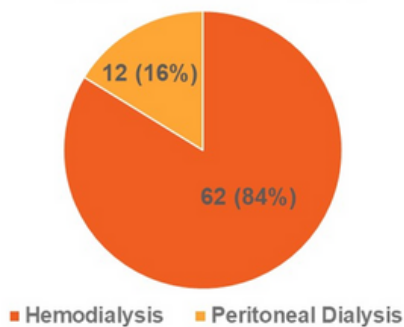


Insights from the KidneyCARE Study: First Look at Early Findings

End-Stage Kidney Disease

- 67 Study participants are currently undergoing dialysis. The majority of them (85%) are on hemodialysis, while 15% are on peritoneal dialysis (Figure 4)

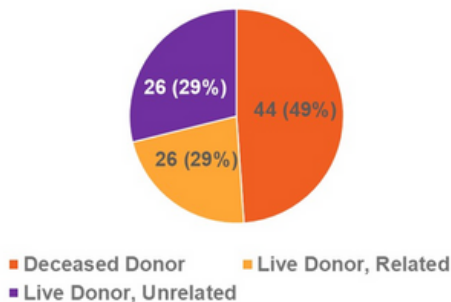
Figure 4: Dialysis Types - Hemodialysis Versus Peritoneal Dialysis



Kidney Transplant

- 85 participants have received a kidney transplant to date, with nearly equal representation of live and deceased donation (Figure 5)

Figure 5: Sources of Kidney Donations – Living Versus Deceased Donors



Causes of Chronic Kidney Disease (CKD)

- High blood pressure and diabetes were the most common causes of CKD reported by the Study participants. In addition, rare forms of kidney disease such as IgA Nephropathy, C3 Glomerulopathy (C3G), Focal Segmental Glomerulosclerosis (FSGS), and Alport Syndrome are represented in the Study. Strikingly, 40% of participants reported not knowing the cause of their CKD.

Healthy Living Tip

Weather emergencies can impact your ability to manage your kidney disease. It is essential for people living with kidney disease to create an emergency plan to ensure access to medications, dialysis care, and communications with healthcare professionals.

To help you prepare an emergency plan, you are welcome to review NKF's [Emergency Resource guide](#). This guide is also available within the KidneyCARE Study portal, on the educational resources page. Taking these protective steps can help you stay safe and maintain your health during unexpected situations.

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Kidney Research News: Highlights from the American Society of Nephrology Annual Meeting

The National Kidney Foundation (NKF) attended the American Society of Nephrology (ASN) Annual Meeting in October 2024, where new breakthroughs in kidney disease research were showcased. Among the meeting highlights were promising results for new therapies targeting rare kidney diseases such as IgA nephropathy (IgAN), C3 Glomerulopathy (C3G), Immune-Complex Membranoproliferative Glomerulonephritis (IC-MPGN) and Focal Segmental Glomerulosclerosis (FSGS). Promising results for diabetic kidney disease were also reported. Some of the key findings are listed below, organized by disease type:

IgA Nephropathy (IgAN):

- Sparsentan (FILSPARI) – Sparsentan is already FDA-approved to slow the decline of kidney function in adults with primary IgAN who are at risk for disease progression. New data shared at the meeting reinforced its benefits in treating IgAN. [Learn more.](#)
- Atrasentan – A Phase III study demonstrated that atrasentan was associated with significant and meaningful reductions in proteinuria in patients with IgAN. [Learn more.](#)
- Sibeprenlimab – In a Phase III trial, sibeprenlimab was associated with a significant and meaningful reduction in urine protein-to-creatinine ratio (uPCR) in adults with IgAN. [Learn more.](#)

C3 Glomerulopathy (C3G):

- Iptacopan (FABHALTA) – Iptacopan is already FDA-approved for IgAN. New data showed that it may also provide sustained clinical benefits for people living with C3G. [Learn more.](#)
- Pegcetacoplan – In a Phase III study, pegcetacoplan was associated with a reduction in proteinuria, stabilization of eGFR, and a reduction in C3G staining in patients with C3G. [Learn more.](#)

Idiopathic Collapsing Membranoproliferative Glomerulonephritis (IC-MPGN):

- Pegcetacoplan – In a Phase III study, pegcetacoplan was associated with a reduction in proteinuria, stabilization of eGFR in patients with IC-MPGN. [Learn more.](#)

Focal Segmental Glomerulosclerosis (FSGS):

- Sparsentan (FILSPARI) – Sparsentan (FILSPARI) is already FDA-approved for IgAN. New data shared at the meeting showed that it might help patients with FSGS, as well. [Learn more.](#)

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Kidney Research News: Highlights from the American Society of Nephrology Annual Meeting (continued)

Chronic Kidney Disease (CKD):

- Empagliflozin (JARDIANCE) – Empagliflozin (JARDIANCE) is already FDA-approved for patients with CKD to reduce the risk of progression to kidney failure, cardiovascular death, and hospitalization. New data shared at the conference further confirmed its long-term benefits, demonstrating that it not only protects kidney health but also reduces cardiovascular risks. [Learn more.](#)
- Dapagliflozin (FARXIGA) – Dapagliflozin (FARXIGA) is FDA-approved to treat CKD, type 2 diabetes, and heart failure. The latest findings showed that dapagliflozin benefits patients even in advanced stages of CKD with low eGFR: Dapagliflozin slows kidney function decline, and improves cardiovascular outcomes in patients with stages 4 or 5 CKD. [Learn more.](#)

Type 2 Diabetes and Chronic Kidney Disease (CKD):

- Semaglutide (marketed as OZEMPIC, RYBELSUS and WEGOVY) – Semaglutide is FDA-approved for managing type 2 diabetes and for weight management. New findings showed that semaglutide therapy significantly reduces the risk of major kidney and cardiovascular events, as well as mortality, in patients with Type 2 Diabetes and CKD. These promising results suggest that semaglutide has the potential to improve kidney health in CKD patients with diabetes. [Learn more.](#)

These developments offer hope for better treatments and outcomes for people living with rare kidney diseases such as IgAN, FSGS, C3G and IC-MPGN, and with chronic kidney disease, or diabetic kidney disease. If you have questions about any of these available treatments, or the experimental therapies still in clinical trial development, consider discussing them with your healthcare provider.

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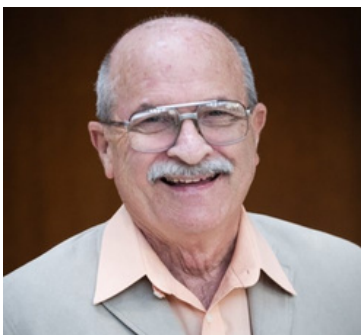


Clinical Trial Spotlight

Interested in clinical trials? NKF provides information on clinical trials in kidney disease and has spotlighted clinical trial opportunities for people living with IgAN (immunoglobulin A nephropathy), APOL-1 mediated kidney disease (AMKD), and Membranous Nephropathy. If you would like to explore clinical trial opportunities in your area – for a wide range of kidney-related diagnoses – the clinical trial finder tool can help match you to a clinical trial specific to your diagnosis.

Kent Bressler, MA, RN, is an NKF Kidney Patient Advocate living with FSGS (pictured below). He had this to say about the critical importance of clinical trial research for kidney disease:

“Unfortunately, I have seen little change in treatment for FSGS. It’s pretty much still steroid bombardment and blood pressure control... Seeing that the research is continuing, and the new drugs are surfacing in the pipeline, brings joy to my heart, as with all other kidney patients.”



To hear more from Kent, as well as NKF’s Chief Medical Officer Dr. Joseph Vassalotti and NKF’s Senior Vice President of Strategic Partnerships Anthony Gucciardo about CKD clinical trial research, check out NKF’s Hot Topics in Kidney Research podcast entitled “What do clinical end points and research mean for CKD research”

Frequently Asked Questions

How do I see the surveys that I need to complete?

- You will receive an email alert if there is a survey for you to complete. Login at kidneycarestudy.org. Once you are in the Study portal, you can click on the “surveys” button to find your surveys that need to be completed.

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.

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