

KidneyCARE Study

Community Access to Research Equity™

Community Update | August 2025

Welcome to the KidneyCARE Study Community Update

This edition of the KidneyCARE Study Community Update highlights recent scientific and clinical developments. Our goal is to keep you informed about advances that could benefit the kidney community.

Over 1,700 participants from across the country have enrolled in the KidneyCARE Study to date, helping to create a powerful dataset to advance kidney disease research. In this third edition, we're sharing timely updates – from newly approved treatments that offer fresh hope to podcasts featuring the KidneyCARE Study team and some of our patient ambassadors. We hope that this information helps you to stay informed and to feel empowered every step of the way.

Staying Connected: How Your Updates Help Drive Kidney Research

We check in with KidneyCARE Study participants every 6 months, and many of you have stayed engaged – thank you!

Kidney disease can change slowly or quickly, and it affects each person differently. By hearing from you regularly, researchers can see how symptoms, treatments, and quality of life evolve. This may help uncover important trends that may improve care and lead to the development of new treatments.

Every 6 months, we send you email reminders with a secure link for you to log in and update your surveys. This usually takes just a few minutes. Even if nothing has changed, updating your information helps us build a clearer and more accurate picture of kidney disease over time.

If you miss a follow-up, don't worry – you'll remain an important part of the study and will receive another invitation to update your surveys 6 months later. It's never too late to check back in.



In this Issue:

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

- [Staying Connected: How Your Updates Help Drive Kidney Research](#)
- [Spotlight on Newly Approved Treatments](#)
- [KidneyCARE Study in the Media](#)
- [Upcoming Awareness Days in the Kidney Community](#)
- [Frequently Asked Questions](#)

KidneyCARE Study

Community Access to Research Equity™



Staying Connected: How Your Updates Help Drive Kidney Research (cont.)

By the Numbers (as of August 2025):

- 954 participants have completed the first (baseline) survey
- 38% of participants updated their information at the 6-month follow-up
- 36% of participants updated their information at the 1-year follow-up

Quick Reminder:

- The Core Survey (My Kidney Journey) is pre-filled at follow-up and only needs to be updated if anything has changed for you.
- The EQ-5D-5L (Health Survey) and KDQOL-36 (Kidney Health Survey) are refreshed each time to capture how you are feeling at that moment.

Your participation is making a real difference. Thank you for sharing your journey with the KidneyCARE Study.

Spotlight on Newly Approved Treatments

The FDA has recently approved several new medications for different types of kidney disease. These treatments are the result of years of research, and provide new options that may help to slow disease progression and support long-term kidney health:

For Adults with Type 2 Diabetes and Chronic Kidney Disease:

Ozempic® (semaglutide) was already approved to help manage type 2 diabetes. It has now also been approved to reduce the risk of kidney disease progression, kidney failure, and cardiovascular-related death in adults with both type 2 diabetes and chronic kidney disease. Ozempic belongs to a class of medications called GLP-1 receptor agonists (GLP-1 RAs), which not only lower blood sugar levels but also offer additional benefits for kidney and heart health.

[For further information, click here to read the official press release.](#)

KidneyCARE Study in the Media

The KidneyCARE Study has been featured in several recent podcasts. Tune in to hear more from our team and learn about the Study's impact and goals:

1. NKF's Hot Topics in Kidney Health - KidneyCARE Study: One Year Update.
2. Kent's Kidney Stories - The Heart of Kidney Research - Why Your Story Matters. Hosted by Kent Bressler, FSGS patient advocate.
3. Kidney Stories 2 with Uncle Jim Myers. Hosted by Jim Myers, an ADPKD patient advocate.

KidneyCARE Study

Community Access to Research Equity



Spotlight on Newly Approved Treatments (cont.)

For Adults with Complement 3 Glomerulopathy (C3G):

Fabhalta® (iptacopan) was the first FDA-approved treatment for C3G, a rare form of kidney disease. This new treatment has been shown to reduce proteinuria (excess protein in the urine) for those affected by C3G. It belongs to a class of medications known as complement inhibitors, which work by targeting the complement system to reduce inflammation and damage.

For further information, click here to read the official press release.

For Adults and Adolescents with C3G or IC-MPGN:

Empaveli® (pegcetacoplan) has been approved by the FDA as the first treatment for both C3 Glomerulopathy (C3G) and Primary Immune Complex Membranoproliferative Glomerulonephritis (IC-MPGN), two rare kidney diseases that can lead to kidney failure. In clinical trials, Empaveli helped reduce proteinuria, stabilize kidney function, and decrease signs of abnormal immune activity. Benefits were seen in people with both native and transplanted kidneys. Empaveli is approved for patients 12 years and older.

For further information, click here to read the official press release.

For Adults with Immunoglobulin A Nephropathy (IgAN):

Vanrafia® (atrasentan) has been approved as a treatment option for adults with IgAN who are at risk of rapid disease progression. This newly approved treatment has been shown to significantly reduce proteinuria (excess protein in the urine) in people affected by IgAN. Vanrafia belongs to a class of medications called endothelin receptor antagonists, which help to reduce inflammation and scarring (fibrosis) in the kidneys.

For further information, click here to read the official press release.

Upcoming Awareness Days in the Kidney Community

These dates highlight kidney conditions that affect many individuals and their families. They offer opportunities to raise awareness, support research, and honor those living with these diseases.

September 4 – PKD Awareness Day

Polycystic Kidney Disease (PKD) causes fluid-filled cysts to grow in the kidneys, often leading to kidney failure. This day brings visibility to one of the most common inherited kidney diseases. [Click here to learn more about Polycystic Kidney Disease.](#)

September 13 – World aHUS Day

Atypical Hemolytic Uremic Syndrome (aHUS) is a rare condition that can cause blood clots in small vessels, damaging the kidneys and other organs. Increased awareness of this condition may help to drive earlier diagnosis and treatment. [Click here to learn more about aHUS.](#)

September 25 – C3G Awareness Day

C3 Glomerulopathy (C3G) is a rare disease caused by abnormal immune system activity that damages the kidneys. Increased awareness of C3G may lead to earlier detection and better outcomes for people who are affected. [Click here to learn more about C3G.](#)

October 1 – Fabry Disease Awareness Day

Fabry Disease is a rare, inherited condition caused by an enzyme deficiency that leads to the buildup of a fatty substance in tissues. Over time, this can damage organs, including the kidney. Greater awareness supports earlier diagnosis, family testing, and access to treatment. [Click here to learn more about Fabry Disease.](#)

KidneyCARE Study

Community Access to Research Equity™

Frequently Asked Questions

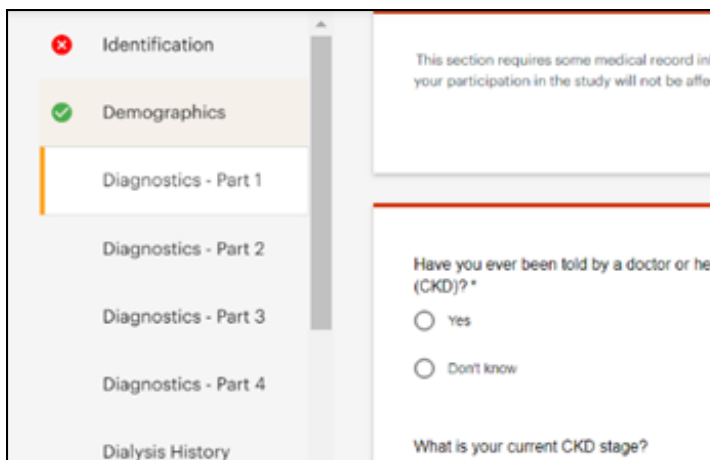
Q: Why do I receive a verification code sent to my email when I login?

A: The KidneyCARE Study uses the most up-to-date security measures to keep all Study data safe. Although it is an extra step before you can access your account, this is an important method to keep your data and account secure.

Q: Why can't I click the "Submit" button at the end of my survey?

A: If the "Submit" button is gray and not working, it usually means that a required question has not been answered. Look for any questions marked with a red asterisk (*) – those are required questions. Try scrolling back through the survey or checking each section to see if all the required questions are filled out before submitting. *See the below and side screenshots to see where questions are missing.

***Desktop screenshot. Red error flags show where there is a question missing in that section**



Identification

Demographics

Diagnostics - Part 1

Diagnostics - Part 2

Diagnostics - Part 3

Diagnostics - Part 4

Dialysis History

This section requires some medical record info
your participation in the study will not be affected

Have you ever been told by a doctor or he
(CKD)? *

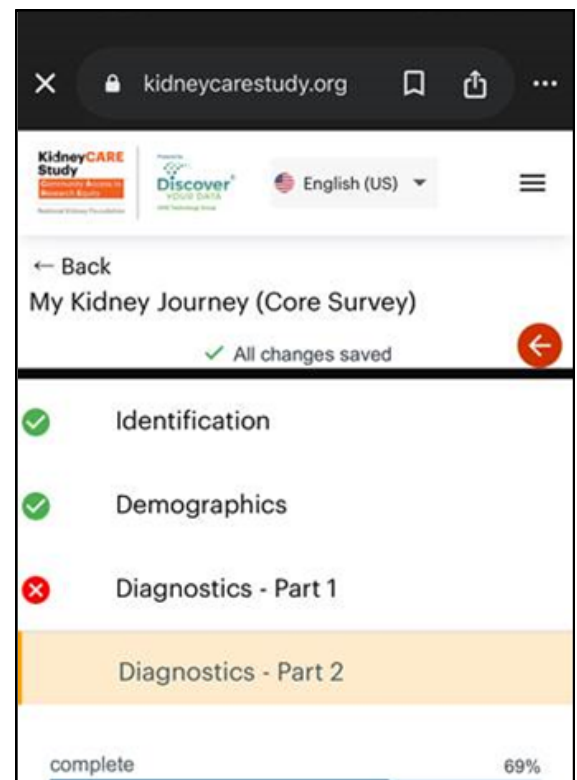
☐ Yes

☐ Don't know

What is your current CKD stage?



***Mobile screenshot. Red error flags show where is a question missing in that section.**



kidneycarestudy.org

KidneyCARE Study
Community Access to Research Equity™
National Kidney Foundation

Discover
YOUR DATA
2020 Technology Award

English (US)

← Back

My Kidney Journey (Core Survey)

✓ All changes saved

Identification

Demographics

Diagnostics - Part 1

Diagnostics - Part 2

complete 69%

Contact Information:
Questions? Comments?

Contact the KidneyCARE Study Team:
Email: kidneycarestudy@kidney.org
Phone: 212.889.2210 x134