

KidneyCARE Study

Community Access to Research Equity™

Community Update | October 2025



Welcome to the KidneyCARE Study Community Update

Welcome to the October 2025 issue of the KidneyCARE Study newsletter! Each quarter, we share resources, updates, and opportunities to help you stay informed and engaged in your kidney health journey. In this issue, you'll find new educational tools in the Patient Portal, information about home dialysis, a mental health survey you may want to take part in, and details about clinical trial opportunities for people living with Lupus Nephritis (LN) and Immune Complex-Membranoproliferative Glomerulonephritis (IC-MPGN).

You'll also see findings from your self-reported experiences with kidney and heart health. These insights are based on what all of you have shared about your own health, which helps researchers understand how different types of kidney disease can affect overall health.

We hope you find these resources helpful, and as always, we thank you for being part of this community.

Heart Health and Kidney Health: What We're Learning Together

The KidneyCARE Study includes people living with many different underlying causes of kidney disease. Some forms of kidney disease develop from common conditions like diabetes or high blood pressure. Others are glomerular diseases, which affect the kidney's filtering units, such as IgA nephropathy (IgAN) or Focal Segmental Glomerulonephritis (FSGS). Some are inherited, like Alport Syndrome or Polycystic Kidney Disease. Still other types of kidney disease result from kidney stones, obstructions, cancer, or kidney injury.

In this Issue:

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

1) Heart Health and Kidney Health: What We're Learning Together

2) Did You Know? Home Dialysis is an Option

3) New and Updated Resources in the Patient Portal

4) Share your Experience and Help Improve Mental Health Support for People Living with Kidney Disease

5) Clinical Trial Opportunities for People with Rare Kidney Conditions

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Heart Health and Kidney Health: What We're Learning Together (cont.)

All of these conditions lead to loss of kidney function, which is known as Chronic Kidney Disease (CKD). CKD is not a single disease – it's the result of many different causes. One goal of the KidneyCARE Study is to help participants better understand the underlying reason for their CKD and how it affects their overall health.

One area we're examining is the connection between kidney disease and cardiovascular (heart and blood vessel) disease, since the two are closely linked. Our study participants have shared their own health experiences, and the rates of cardiovascular disease they report vary depending on their underlying cause of kidney disease, as follows:

- **Alport Syndrome: 6%**
- **IgA nephropathy (IgAN): 9%**
- **Polycystic Kidney Disease (PKD): 14%**
- **Focal Segmental Glomerulonephritis (FSGS): 18%**
- **Kidney cancer-related kidney disease: 18%**
- **Diabetes-related kidney disease: 25%**
- **Acute Kidney Injury (AKI): 34%**

These findings help researchers better understand how heart and kidney health interact across the many different types of kidney disease.

Your participation in this study makes insights like this possible. Each survey you complete helps researchers learn more about the connection between kidney and heart health, and may help them find new ways to protect both kidney and heart health for everyone living with kidney disease.

Did You Know? Home Dialysis is an Option

If your kidney function declines to the point where dialysis is needed, there may be more than one option available to you – including the possibility of performing dialysis at home.

Home dialysis options include:

- **Peritoneal Dialysis (PD):** This is a needle-free dialysis option that uses the lining of your abdomen (called the peritoneum) to filter waste and extra fluid from your blood. A soft tube called a catheter is placed in your abdomen during a minor procedure, and dialysis is performed by filling and draining fluid through this tube. Peritoneal dialysis can be done during the day, or overnight while you sleep, offering greater flexibility.
- **Home Hemodialysis (HHD):** This is a form of hemodialysis that is performed at home using a dialysis machine. It can be performed more often than in-center dialysis, which may help some people feel better and have more energy.

Some people prefer home dialysis because it gives them more independence and control over their schedules. It may not be right for everyone, but it can be helpful to learn more and to discuss this option with your doctor.

[Click here for more information on home dialysis.](#)

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New and Updated Resources in the Patient Portal

We've recently refreshed the KidneyCARE Study Patient Portal with new educational tools and support options to help you stay informed and connected. Highlights include:

- A list of chronic kidney disease (CKD) causes, each with links for more information
- The new NKF Patient Journey, guiding you through what to expect after diagnosis, from understanding lab results to exploring treatment options and living well with kidney disease
- The NKF Nutrition Hub, featuring kidney-friendly recipes, expert tips from dietitians, and tools to support your nutrition goals
- An updated listing of common prescription medications used to help manage kidney disease.
- A new online support community for the LGBTQIA+ members of the kidney community. This is a safe and inclusive space to share experiences and find support. NKF now hosts six online communities.
 - NKF Kidney Disease Community
 - NKF Dialysis Community
 - NKF Transplant Community
 - NKF Kidney Donor Community
 - NKF Parents of Children with Kidney Disease Community
 - NKF LGBTQIA+ Kidney Community (NEW!)

Log in to the [KidneyCARE Study Patient Portal](#) to explore these resources and discover even more tools to support your kidney health.

Share Your Experience and Help Improve Mental Health Support for People Living with Kidney Disease

Living with kidney disease can affect not just your body, but your emotional and mental well-being as well. The National Kidney Foundation (NKF) wants to hear directly from patients like you to better understand these challenges.

We've created a short Mental Health and Kidney Disease Survey to learn about your experiences with stress, anxiety, depression, "brain fog", and other mental and emotional challenges related to kidney disease. Your responses will help NKF identify areas where care can be improved, and will help guide a national Working Group developing recommendations to strengthen mental health support for people living with kidney disease.

Whether or not you've ever talked about mental health with your care team, your perspective is very valuable. The survey only takes about 10 minutes and is open to people with any stage of CKD, including dialysis or transplant.

If you've already had a chance to complete this survey through another NKF channel, thank you! You don't need to take this survey again.

[Click here to take the survey.](#)

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Clinical Trial Opportunities for People with Rare Conditions

The KidneyCARE Study is committed to keeping you informed about opportunities to participate in clinical trials. Below are two ongoing studies for people living with Lupus Nephritis (LN) or Immune Complex Mediated Membranoproliferative Glomerulonephritis (IC-MPGN). If you have one of these conditions, you can check to see if you might be eligible to participate and learn more about the study details.

AUTOGRAPH-LN (SLE) Study – Lupus Nephritis (LN)

This study is looking at an investigational treatment (a treatment that has not yet been approved by the FDA) for people with systemic lupus erythematosus (SLE) or active, refractory lupus nephritis (LN). The goal of the study is to evaluate the effectiveness of this investigational treatment at a targeted dose as a single infusion. Researchers will look at how the treatment affects disease activity and remission in lupus, frequency of lupus flares, the need for steroid medications (glucocorticoids), and certain lab results, such as antinuclear antibodies.

Eligibility Highlights:

- Diagnosed with Lupus Nephritis within the past 7 years (or have had a flare within the last 6 months if your diagnosis was more than 7 years ago).
- Ages 18 to 75
- Additional health and lab criteria will be assessed during screening

Full eligibility will be assessed by the clinical trial's study team.

You can review additional details – including the study inclusion criteria and exclusion criteria – on the study's official website on [ClinicalTrials.gov](https://clinicaltrials.gov):

[Study Details | NCT06581198 | A Study of Rapcabtagene Autoleucel in Systemic Lupus Erythematosus \(SLE\) Patients With Active, Refractory Lupus Nephritis \(LN\) | ClinicalTrials.gov](https://clinicaltrials.gov/study/NCT06581198)

If you think you may be eligible and are interested in participating, please contact a nearby study site directly using the phone number or email address listed on the [ClinicalTrials.gov](https://clinicaltrials.gov) website.

Although Novartis is sponsoring the study, patients should contact a local study site, rather than Novartis, for information.

Please note: This study involves in-person visits to a study site. You must be able to travel to one of the study sites listed below for study visits and procedures. Travel to the site may be reimbursed for patient /caregiver.

Current U.S. study sites include:

San Francisco, CA; San Pablo, CA; Chicago, IL; Iowa City, IA; Lexington, KY; Boston, MA; Portland, OR; Houston, TX; Salt Lake City, UT
Additional site locations are planned.

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Clinical Trial Opportunities for People with Rare Conditions (cont.)

APPARENT Study – IC-MPGN

The APPARENT Study is a clinical trial for people with the rare kidney Immune Complex-Mediated Membranoproliferative Glomerulonephritis (IC-MPGN). Researchers are testing whether an investigational treatment called iptacopan can reduce protein in the urine, improve kidney function, and reduce fatigue.

Iptacopan is being studied for new uses for which effectiveness and safety have not been established. There is no guarantee it will become commercially available for the uses under investigation.

Eligibility Highlights:

- Diagnosis of IC-MPGN confirmed by kidney biopsy
- Ages 12 to 60
- Additional health and lab criteria will be assessed during screening

Full eligibility will be assessed by the clinical trial's study team.

You can review additional details – including the study inclusion criteria and exclusion criteria – on the study's official website on ClinicalTrials.gov:

[Study Details | Study of Efficacy and Safety of Iptacopan in Participants With IC-MPGN | ClinicalTrials.gov](https://ClinicalTrials.gov)

If you think you may be eligible and are interested in participating, please contact a nearby study site directly using the phone number or email address listed on the ClinicalTrials.gov website.

Although Novartis is sponsoring the study, patients should contact a local study site, rather than Novartis, for information.

Please note: This study involves in-person visits to a study site. You must be able to travel to one of the study sites listed below for study visits and procedures. Travel to the site may be reimbursed for patient and parent/caregiver.

Current U.S. study sites include:

Los Angeles, CA; Orange County, CA; San Francisco, CA; Sylmar, CA; Aurora, CO; Miami, FL; Boston, MA; Minneapolis, MN; New York, NY; Philadelphia, PA; Temple, TX; Salt Lake City, UT; Madison, WI

Additional site locations are planned.

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Frequently Asked Questions

Q: I received an email about updating my surveys. What are the next steps?

A: To update your surveys, login to www.kidneycarestudy.org, and go to your surveys tab. Click on the orange “Start Survey” button to begin. For the “My Kidney Journey” survey, your previous answers will already be pre-populated. You can review your answers, make any updates as needed to reflect your current health status, and then click the “Submit” button at the end to save your responses. For the “Health Survey” and the “Kidney Health Survey”, you will need to provide new answers about your current health status each time. Once completed, click the “Submit” button to record your answers. These two surveys typically take under 10 minutes to complete.

Q: What is a Patient Pulse survey?

A: A Patient Pulse survey is a short, one-time survey designed to gather insights on specific kidney health topics. These surveys are sent only to participants who have opted in to take part in opinion-gathering activities. They are hosted on SurveyMonkey and typically take less than 15 minutes to complete. Your responses help to support research projects beyond the KidneyCARE Study. These surveys are generally anonymous, meaning that we do not collect names or other identifying information, so your privacy is protected while your input helps advance kidney health research.

Contact Information:

Questions? Comments?

Contact the KidneyCARE Study Team:
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