

KidneyCARE Study

Community Access to Research Equity™

Community Update | January 2026



KidneyCARE Study Newsletter: Your Latest Kidney Health News

Dear KidneyCARE Study Community,

Happy New Year and welcome to the first KidneyCARE Study newsletter of 2026! As we begin this new year, we're excited to share the latest updates, research opportunities, and advancements in kidney health. Our goal is to keep you informed about ways to participate in research, learn about emerging treatments, and to stay engaged within the kidney disease community.

In this issue, you'll find highlights from the KidneyCARE Study and opportunities to participate in a new Genetics of Kidney Disease Study and an IgAN clinical trial (if appropriate). We also take a closer look at xenotransplantation – an emerging area of kidney disease research exploring the transplantation of kidneys from animals into humans as a potential future treatment for kidney failure. We also share upcoming awareness days and answers to frequently asked questions from study participants.

Thank you for being part of the KidneyCARE Study community. Together, your participation helps advance research and improve care for people living with kidney disease.

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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Questions? Comments?

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What We're Learning from the KidneyCARE Study Data: How Kidney Disease is Treated in Everyday Care

One of the strengths of the KidneyCARE Study is that it combines information you share about your medical history and health status with clinical data from electronic health records (EHRs). This helps researchers better understand how kidney disease is treated in everyday medical practice, not just in clinical trials.

For a recent analysis, we looked at EHR data from Geisinger Medical Center in Danville, PA, one of the health systems partnering with the KidneyCARE Study and contributing EHR data on enrolled patients. We examined medication use among 173 Geisinger patients over a 15-month period. These findings were recently presented at the American Society of Nephrology (ASN), a national medical conference for kidney specialists.

The analysis focused on medications commonly used to protect kidney and heart health, including ACE inhibitors and ARBs (which help to control blood pressure and reduce stress on the kidneys), SGLT2 inhibitors (which slow kidney disease progression and protect the heart), and GLP-1 receptor agonists (which may help with blood sugar control, weight management, and cardiovascular health).

Many patients were prescribed medications recommended in the clinical guidelines. Some of the newer kidney-protective therapies were prescribed less often, which is common in real-world care. Medication choices depend on many factors, including side effects, other health conditions, cost, insurance coverage, and individual patient preferences.

This type of real-world data helps researchers understand how kidney disease care is delivered in different settings and highlights opportunities to improve access to treatments and support shared decision-making, where patients and healthcare providers work together to choose treatments for patient's health needs, values, and goals.

By participating in the KidneyCARE Study, you are helping generate evidence that impacts research and ultimately supports better kidney disease care for patients everywhere.

Medication Use Among KidneyCARE Study Participants at Geisinger Medical Center

The following table (Table 1) summarizes how often different types of kidney- and heart-protective medications appeared in electronic health records for 173 KidneyCARE Study participants over a 15-month study period.

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Table 1

Medication Class	% of Patients Prescribed (n/173)
(1) Angiotensin-Converting Enzyme (ACE) Inhibitors	
Lisinopril (Prinivil, Zestril)	24% (42/173)
Enalapril (Vasotec)	0% (0/173)
Ramipril (Altace)	1% (1/173)
Benazepril (Lotensin)	1% (1/173)
(2) Angiotensin II Receptor Blockers (ARBs)	
Losartan (Cozaar)	26% (45/173)
Olmесartan (Benicar)	5% (8/173)
Valsartan (Diovan)	2% (3/173)
Telmisartan (Micardis)	5% (8/173)
Irbesartan (Avapro)	1% (2/173)
Candesartan (Atacand)	1% (2/173)
(3) Sodium-Glucose Cotransporter 2 (SGLT2) Inhibitors	
Empagliflozin (Jardiance)	20% (35/173)
Dapagliflozin (Farxiga)	3% (6/173)
Canagliflozin (Invokana)	0% (0/173)
Ertugliflozin (Steglatro)	0% (0/173)

Medication Class	% of Patients Prescribed (n/173)
(4) Glucagon-Like Peptide-1 (GLP-1) Receptor Agonists	
Semaglutide (Ozempic, Rybelsus)	10% (17/173)
Dulaglutide (Trulicity)	5% (8/173)
Liraglutide (Victoza, Saxenda)	1% (1/173)
Exenatide (Byetta and Bydureon)	0% (0/173)
(5) Steroidal Mineralocorticoid Receptor Antagonists (sMRAs)	
Spironolactone (Aldactone)	5% (8/173)
Eplerenone (Inspra)	0% (0/173)
(6) Vasopressin V2 Receptor Antagonists	
Tolvaptan (Jynarque)	1% (2/173)
(7) Other Classes of Medications	
• Non-Steroidal Mineralocorticoid Receptor Antagonists (Finerenone)	0% (0/173)
• Endothelin Receptor Antagonists (Sparsentan, Atrasentan)	0% (0/173)
• Targeted-Release Corticosteroids (Budesonide)	0% (0/173)
• Complement Pathway Inhibitors (Iptacopan)	0% (0/173)

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Research Opportunity: Genetics of Kidney Disease Study

Participants in the KidneyCARE Study may be eligible to join a new research study led by the Rutgers University Genetics Coordinating Center, in collaboration with the Regeneron Genetics Center and the National Kidney Foundation (NKF). NKF is proud to be a partner in this effort to better understand the role that genes play in kidney disease, both in how it develops and how it progresses over time. The study is called the Genetics of Kidney Disease Study.

If you choose to participate, you'll begin by completing a brief survey about your kidney disease history. Then you'll receive a saliva collection kit in the mail. This will allow researchers to analyze your DNA. While you will not receive individual genetic results related to kidney disease, you will receive a FREE ancestry report based on your DNA results.

By sharing your DNA and your medical history in the Genetics of Kidney Disease Study, you'll help researchers uncover genetic factors that may contribute to kidney disease. Some genes may increase a person's risk for kidney disease, while others may protect against it. This research may eventually help doctors detect kidney disease earlier in people who have a high genetic risk. It could also lead to treatments that are better matched to a person's specific genetic profile – making them more effective, with fewer side effects. This may help advance the field of “personalized medicine” – where care is tailored to each person's unique genetic makeup, rather than relying on a one-size-fits-all approach.

Any information you provide, including your genetic data, will be stored and analyzed in a secure system that protects your privacy. Your participation in the Genetics of Kidney Disease Study is completely optional and will not affect your involvement in the KidneyCARE Study. To learn more or to enroll, please visit the Genetics of Kidney Disease webpage by clicking [here](#).



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Clinical Trial Opportunity for People Living with IgA Nephropathy

The KidneyCARE Study is committed to keeping you informed about opportunities to participate in clinical research. Below is an ongoing clinical trial for people living with IgA Nephropathy (IgAN), also known as Berger’s disease. If you have IgAN, you are welcome to review the study details below to see whether you might be able to participate.

I CAN Study

The I CAN Study is a clinical trial evaluating an investigational treatment called ravulizumab for people with IgAN. The goal of the study is to determine whether ravulizumab can help reduce protein in the urine and slow the decline of kidney function (eGFR) in people with IgAN.

Ravulizumab is an investigational treatment being studied for IgAN. Its effectiveness for IgAN and safety have not yet been established. To be eligible for the study, participants must meet the following criteria:

- Have a diagnosis of IgAN (based on kidney biopsy)
- Be at least 18 years of age
- Not have had a kidney transplant
- Must have protein in their urine
- Have been treated with appropriate doses of blood pressure medications for more than three months before screening
- Meet additional criteria assessed during screening

Full eligibility will be determined by the clinical trial’s study team. If you would like to learn more about this study and see whether you may qualify, please visit the I CAN clinical trial webpage [here: I CAN Study](#).

The website contains a “See If You May Qualify” section to help assess your eligibility. This provides an option for you to be contacted by a local research team if you pass the online screening and are interested in potentially taking part in the study.

Spotlight on New Drug Approvals

Exciting progress continues in kidney disease research. The U.S. Food and Drug Administration (FDA) has recently approved two new treatments for specific kidney conditions. These approvals offer new options for some patients, and demonstrate ongoing advances in care.

New Treatment Approved for Lupus Nephritis: GAZYVA® (obinutuzumab)

The FDA has approved GAZYVA for adults with active Lupus Nephritis (LN) who are receiving standard therapy. GAZYVA is a type of medicine called a monoclonal antibody, which works by targeting specific cells in the immune system that contribute to kidney inflammation. It is given through intravenous infusions.

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Spotlight on New Drug Approvals (cont.)

In clinical studies, patients treated with GAZYVA along with standard therapy were more likely to achieve a complete renal response compared with standard therapy alone. This means that their kidneys showed improved function and fewer signs of active disease. The treatment was also associated with lower levels of protein in the urine, an important marker of kidney health. Overall, these findings suggest GAZYVA may help protect kidney function and reduce the risk of progressing to kidney failure.

For more details, you can read the official press release here: [Genentech: Press Releases | Sunday, Oct 19, 2025](#)

If you are living with Lupus Nephritis, you may wish to talk to your doctor to see if this new treatment might be appropriate for you.

You can also learn more about Lupus Nephritis from the National Kidney Foundation's patient resources:

[Lupus Nephritis information](#)

New Treatment Approved for IgA Nephropathy: VOYXACT® (sibeprenlimab-szsi)

The FDA also approved VOYXACT for adults with Immunoglobulin A Nephropathy (IgAN). VOYXACT is a monoclonal antibody that targets a protein involved in kidney damage in IgAN. It is taken as a self-administered injection under the skin once every 4 weeks.

VOYXACT works by blocking a protein called APRIL (A-PRoliferation-Inducing Ligand). APRIL plays a key role in IgAN by helping to produce the abnormal IgA proteins that can damage the kidneys. By blocking APRIL, VOYXACT helps reduce inflammation and protects the kidneys. In clinical studies, patients treated with VOYXACT along with supportive therapy had about a 50% reduction in protein in the urine over 9 months, which is a sign of improved kidney health. These results suggest VOYXACT may help slow kidney damage, as significant reductions in protein in the urine have been correlated with reduced risk of disease progression.

For more details, you can read the official press release here: [Otsuka Press Release: FDA Accelerated Approval of VOYXACT® \(sibeprenlimab-szsi\)](#)

If you are living with IgA Nephropathy, you may wish to talk to your doctor about whether this new treatment might be appropriate for you.

You can also learn more about IgA Nephropathy from the National Kidney Foundation's patient resources:

- [IgA Nephropathy information](#)

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Xenotransplantation: An Emerging Area of Kidney Disease Research

One emerging area of current kidney disease research is xenotransplantation (pronounced “ZEE-no-trans-plan-TAY-shun”).

Xenotransplantation refers to the transplantation of organs from animals – most often pigs – into humans. Researchers are exploring this approach as a way to help address the ongoing shortage of human donor kidneys.

In recent years, scientific advances have brought xenotransplantation closer to reality. These advances include genetic modifications to donor animals to reduce the risk of organ rejection, as well as improvements in immune-suppressing therapies. Early research studies have shown promising short-term results, and clinical trials are now beginning at a small number of transplant centers.

It’s important to note that xenotransplantation is still experimental and is not yet available as a standard treatment. Researchers are carefully studying safety, long-term outcomes, and ethical considerations before this approach can be more widely used. However, many experts believe that with continued research, xenotransplantation could one day expand treatment options for people with kidney failure who are waiting for a life-saving organ.

The National Kidney Foundation (NKF) continues to follow developments in xenotransplantation closely and supports research efforts that prioritize patient safety, transparency, and equitable access.

To learn more about xenotransplantation, please visit [NKF’s xenotransplantation webpage](#).

Upcoming Awareness Days

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

February 28th - Rare Disease Day

Rare disease day raises awareness for the millions of people worldwide living with rare medical conditions. Some of these rare diseases impact the kidneys, such as Fabry disease, C3 Glomerulopathy (C3G), Atypical Hemolytic Uremic Syndrome (aHUS), Alport Syndrome, Focal Segmental Glomerulosclerosis (FSGS), IgA Nephropathy (IgAN), Membranous Nephropathy (MN), Polycystic Kidney Disease, and Nephrotic Syndrome, among others. Increased awareness of rare diseases supports earlier diagnosis and access to care.

March – National Kidney Month

National Kidney Month is dedicated to raising awareness about kidney health, kidney disease prevention, and the importance of early detection. It’s a time to encourage education, screening, and healthy habits that help protect kidney health.

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Upcoming Awareness Days (cont.)

March – Alport Awareness Month

Alport Awareness Month coincides with National Kidney Month, in order to highlight this rare genetic kidney disorder that can lead to kidney failure. Awareness encourages early diagnosis and supports affected individuals and their families.

March 12th – World Kidney Day

World Kidney Day is a global campaign focused on highlighting the importance of kidneys to overall health. This special day for our community highlights prevention, early detection, and management of kidney disease worldwide.

April 28th – APOL1-Mediated Kidney Disease (AMKD) Awareness Day

APOL1-Mediated Kidney Disease Awareness Day raises recognition of kidney disease caused by high-risk variants of the APOL1 gene. This condition disproportionately affects individuals of African ancestry and can lead to chronic kidney disease and kidney failure. Awareness helps promote early detection, genetic counseling, and access to care.

April – Fabry Disease Awareness Month

Fabry Disease is a rare, inherited condition caused by an enzyme deficiency that leads to the buildup of certain fats in the body. This buildup of fats can occur in the kidneys, heart, and other organs, potentially causing kidney failure, heart attacks and strokes. Increased awareness supports earlier diagnosis and family screening.

To learn more about Fabry Disease, please visit [NKF's "Fabry Disease" webpage](#).

April – National Donate Life Month

National Donate Life Month honors organ donors and raises awareness about the life-saving impact of organ, eye, and tissue donations. For people living with kidney failure, kidney transplantation can be a life-changing option.

To learn more about kidney donation and transplantation, please visit [NKF's "Transplants for All" webpage](#).

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Frequently Asked Questions

Q: Where can I find the three surveys I need to complete?

A: After logging into the KidneyCARE Study portal, you will see three columns displaying the survey titles: “My Kidney Journey (Core Survey)”, “Health Survey (EQ-5D-5L)”, and “Kidney Health Survey (KDQOL-36)” (Image 1). You’ll also see a countdown showing how many days you have to complete each survey. Click the “Start” button to begin. Alternatively, you can access all surveys by clicking the “All Surveys” tab at the top of the page (Image 2).

Image 1

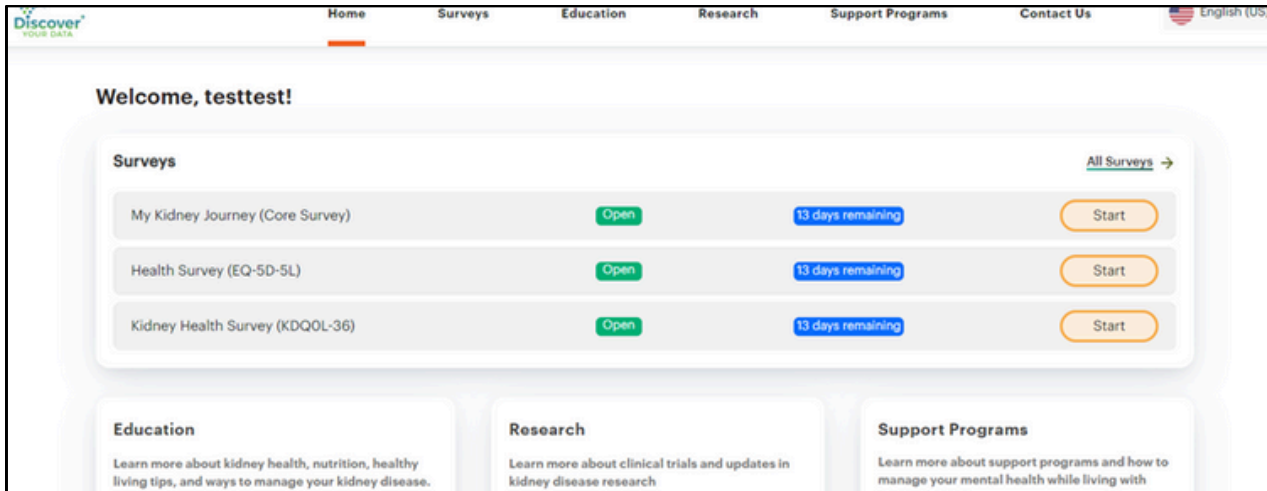


Image 2

