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KidneyCARE Study

Community Access to Research Equity™

Research Update | November 2025

Exciting Updates in Kidney Research: Highlights from the American Society of Nephrology (ASN) Conference

Dear KidneyCARE Study Community,

This year's American Society of Nephrology (ASN) Kidney Week conference brought together thousands of healthcare professionals, scientists, and patient advocates from around the world in Houston, Texas. They were all united by a single goal: finding better ways to prevent and treat kidney disease.

Because of your participation in the KidneyCARE Study, you are part of that progress. We wanted to share a few of the most exciting highlights from the meeting so that you can see how kidney disease research has been advancing.

Patient Voices Took Center Stage at the Conference

Patient advocates played a key role at ASN this year, serving as featured speakers, contributing to scientific poster sessions, and participating in private meetings with industry to review clinical trial plans and research priorities. Their involvement helped ensure that discussions reflected what matters most to patients.

We're especially proud that several members of the KidneyCARE Study Patient Advisory Working Group contributed to this important work: Curtis Warfield attended the meeting and engaged with attendees at the KidneyCARE Study poster (shown below). Curtis also gave a presentation on the topic of "Clinical Trial Outcomes and Treatment Decisions in Nephrology: A Patient's Perspective".

In this Issue:

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4) The KidneyCARE Study was Featured at ASN!

Patient Voices Took Center Stage at the Conference (cont.)

Curtis also spoke at the Dimerix ACTION 3 Study Update meeting, where he told his story and described his journey of living with Focal Segmental Glomerulosclerosis (FSGS). He also met with four pharmaceutical companies on whose Patient Advisory Boards he serves, to ensure that patient experiences are taken into consideration in ongoing kidney disease research and development.

Mary Baliker also represented the patient voice at ASN. As a member of several patient advisory boards, she also met with pharmaceutical companies to discuss clinical trial plans for medications currently in development.

Both Mary and Curtis are active members of the Kidney Health Initiative (KHI) and attended the release of KHI's new Three-Year Strategic Plan during the conference. They had the opportunity to review and provide input into this initiative prior to its release. This shows the growing role of patients as true partners in shaping the future of kidney research and innovation.

Together, their contributions underscored the importance of including patient perspectives in research and treatment decisions, and served as a reminder that progress in kidney disease management starts with listening to patients.

Patient Advocates

Curtis Warfield

Mary Baliker

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New Therapies are Advancing

Researchers at ASN 2025 presented encouraging updates about treatments for several different types of kidney disease. Here are a few key highlights:

Type 1 Diabetes with Chronic Kidney Disease (CKD)

- The FINE-ONE clinical trial tested the medication finerenone in people living with type 1 diabetes and CKD. Treatment with finerenone helped reduce the amount of protein in the urine – an important marker of kidney health - compared with placebo. While finerenone is not yet approved for use in type 1 diabetes and CKD, these findings offer hope for future treatment options.

IgA Nephropathy (IgAN) - Emerging Therapies

Several investigational therapies for IgAN were presented at the ASN meeting:

- Sibeprenlimab (VISIONARY Study) - This investigational antibody reduces the activity of APRIL, a protein that helps certain immune cells produce antibodies, including IgA. In IgA nephropathy, overactive APRIL can lead to too much of a harmful type of IgA that can build up in the kidneys and cause damage. After one year, participants treated with sibeprenlimab had lower protein levels in their urine and higher rates of proteinuric remission – meaning that their urine protein levels returned to near-normal. While sibeprenlimab is not yet approved for use in IgAN, these findings are encouraging and support further study of this medication.

New Therapies are Advancing (cont.)

IgA Nephropathy (IgAN) - Emerging Therapies (Cont.)

- Atacicept (ORIGIN 3 Phase 3 Trial) – This medication reduces the activity of BAFF and APRIL, two proteins that help certain immune cells produce antibodies, including IgA. In IgA nephropathy, these proteins are overactive, leading to too much of a harmful type of IgA that can build up in the kidneys and cause damage. Atacicept reduced protein in the urine (Urine Protein to Creatinine Ratio or UPCR) by 42% compared with placebo at 36 weeks, and hematuria (blood in the urine) resolved in 81% of patients. This medication is still experimental and not yet approved.

- Povetacicept (RUBY-3 Phase 1/2 Trial) – This medication also targets BAFF and APRIL, as described above. Patients with IgAN who took povetacicept saw a 64% reduction in proteinuria (UPCR) at week 48, with hematuria resolving in 90% of participants. This medication is also experimental and not yet approved.

- Telitacicept (Phase 3 Trial) – This medication is an investigational therapy that also targets BAFF and APRIL, as described above. In a Phase 3 study, patients treated for 39 weeks experienced a 55% reduction in urine protein levels (24-hour UPCR) compared to placebo. They also experienced higher rates of remission of proteinuria, along with reduced risk of eGFR decline. This therapy is experimental and not yet approved.

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New Therapies are Advancing (cont.)

Alport Syndrome

- Researchers presented the first safety data from a clinical trial of setanaxib in people with Alport Syndrome. Setanaxib works by targeting inflammation and fibrosis in the kidneys, processes that contribute to disease progression. The Phase 2a study included 20 patients ages 12-40 with genetically confirmed Alport Syndrome. The trial focused on tracking serious side effects and safety concerns over 24 weeks of treatment. Setanaxib was well tolerated, with side effects similar to those taking placebo. There were no adverse events of concern that were related to the drug. These results indicate that setanaxib appears to be safe for people with Alport Syndrome. Researchers will continue to study it in additional trials to better understand its potential benefits.

SGLT2 Inhibitors

- Many people with chronic kidney disease (CKD) – especially those with diabetes – are now taking medications called SGLT2 inhibitors (brand names include Jardiance®, Farxiga®, and Steglatro®). These medicines help protect the kidneys and slow the progression of kidney disease.
- Studies showed that SGLT2 inhibitors can significantly reduce kidney disease progression, even for people at early or later stages of CKD. One analysis of over 70,000 patients showed a 38% lower risk of kidney function decline in patients taking these medications. These findings reinforce the effectiveness of SGLT2 inhibitors in protecting kidney function.

New Therapies are Advancing (cont.)

Membranous Nephropathy (MN)

- Provetacicept is an investigational medication that blocks BAFF and APRIL, two immune system signals that drive the autoantibodies involved in MN. In the RUBY-3 clinical trial, patients with MN taking povetacicept saw an 82% reduction in proteinuria (UPCR) at week 48 and an 83% drop in anti-PLA2R antibodies. All participants achieved partial or complete immunologic remission. Povetacicept is experimental and is not yet approved for the treatment of MN.

Lupus Nephritis (LN)

- A recently approved therapy called obinutuzumab (GAZYVA®) continues to show promise for people living with lupus nephritis. The treatment helps patients achieve a “complete kidney response”, meaning that their kidney function and urine protein levels have returned to near-normal.
- New kidney biopsy data showed that even patients who didn’t meet the criteria for a full clinical response still showed significant improvement of their kidney tissue, known as “histological remission”. Histological remission is important because it may reduce the risk of future lupus kidney flares and help protect kidney health over the long term.

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New Therapies are Advancing (cont.)

Antibody-Mediated Rejection (AMR) After Kidney Transplant

- An investigational therapy called felzartamab is showing early promise for people who develop antibody-mediated rejection (AMR) after a kidney transplant. Antibody-mediated rejection occurs when the body's immune system mistakenly attacks the transplanted kidney, which can lead to a loss of kidney function.
- Felzartamab is a monoclonal antibody that targets the immune cells which produce these harmful antibodies. In a recent Phase 2 clinical trial, treatment with felzartamab led to a substantial reduction in kidney inflammation and healthier kidney tissue compared to the placebo group.
- Building on these encouraging findings, a Phase 3 clinical trial called TRANSCEND is now underway to assess the benefits of felzartamab in a larger group of kidney transplant recipients. Felzartamab is not yet approved for the treatment of AMR, but these findings are encouraging and add to ongoing research aimed at protecting transplanted kidneys from antibody-mediated rejection.

Focal Segmental Glomerulosclerosis (FSGS)

- A recent clinical trial called the DUPLEX Study found that people with FSGS who were treated with sparsentan were more likely to achieve lower protein levels in their urine – a sign of improved kidney health – compared with those who received the standard therapy, irbesartan. Although these results are promising, sparsentan is not yet approved for the treatment of FSGS.

A Focus on Remission

A major theme at this year's ASN conference was remission – not just slowing kidney disease, but actually helping people's kidney health improve. Researchers shared encouraging evidence showing that remission is becoming an achievable goal in more types of kidney disease than ever before. This represents an important shift in kidney disease care – from simply managing disease to actively working towards remission and long-term recovery.

The KidneyCARE Study was Featured in the ASN!

We were also proud to showcase the KidneyCARE Study at ASN Kidney Week in our first-ever scientific presentation! Our poster, shown below, highlights how patient-reported outcomes (from your survey responses) and electronic health record data can drive new insights in kidney disease research. This milestone was made possible by your participation, and reflects the growing recognition of how patient voices are transforming kidney disease care.

Poster Image on page 6 and included as an attachment to this email.

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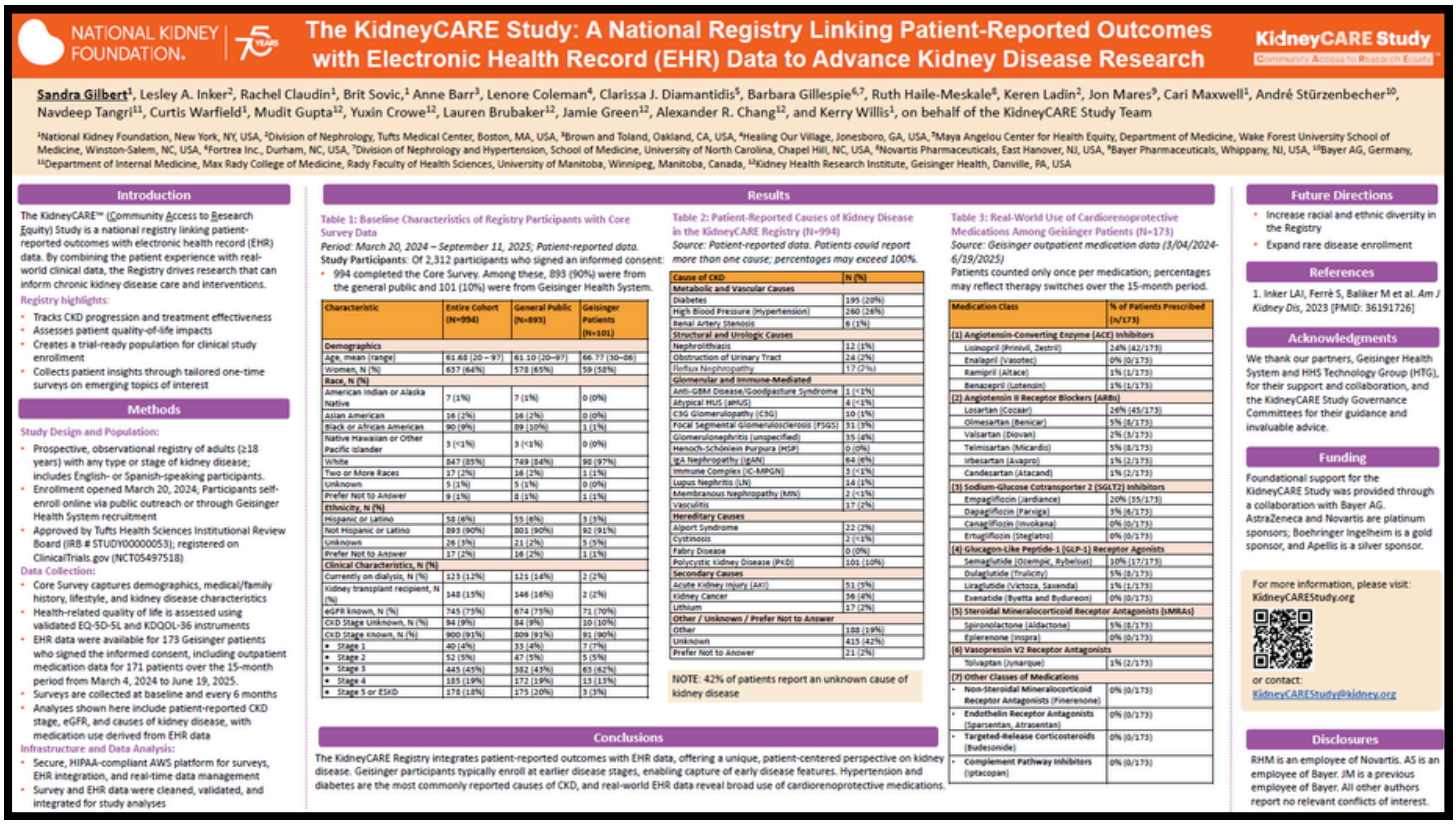
KidneyCARE Study Poster



The KidneyCARE Study: A National Registry Linking Patient-Reported Outcomes with Electronic Health Record (EHR) Data to Advance Kidney Disease Research

KidneyCARE Study

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Introduction

The KidneyCARE™ (Community Access to Research Equity) Study is a national registry linking patient-reported outcomes with electronic health record (EHR) data. By combining the patient experience with real-world clinical data, the Registry drives research that can inform chronic kidney disease care and interventions.

Registry highlights:

- Tracks CKD progression and treatment effectiveness
- Assesses patient quality-of-life impacts
- Creates a trial-ready population for clinical study enrollment
- Collects patient insights through tailored one-time surveys on emerging topics of interest

Methods

Study Design and Population:

- Prospective, observational registry of adults (≥18 years) with any type or stage of kidney disease; includes English- or Spanish-speaking participants.
- Enrollment opened March 20, 2024; Participants self-enroll online via public outreach or through Geisinger Health System recruitment
- Approved by Tufts Health Sciences Institutional Review Board (IRB # STUDY00000053); registered on ClinicalTrials.gov (NCT05497518)

Data Collection:

- Core Survey captures demographics, medical/family history, lifestyle, and kidney disease characteristics
- Health-related quality of life is assessed using validated EQ-5D-5L and KDQOL-36 instruments
- EHR data were available for 173 Geisinger patients who signed the informed consent, including outpatient medication data for 171 patients over the 15-month period from March 4, 2024 to June 19, 2025.
- Surveys are collected at baseline and every 6 months
- Analyses shown here include patient-reported CKD stage, eGFR, and causes of kidney disease, with medication use derived from EHR data

Infrastructure and Data Analysis:

- Secure, HIPAA-compliant AWS platform for surveys, EHR integration, and real-time data management
- Survey and EHR data were cleaned, validated, and integrated for study analyses

Results

Table 1: Baseline Characteristics of Registry Participants with Core Survey Data

Period: March 20, 2024 – September 11, 2025; Patient-reported data.

Study Participants: Of 2,312 participants who signed an informed consent:

- 994 completed the Core Survey. Among these, 893 (90%) were from the general public and 101 (10%) were from Geisinger Health System.

Characteristic	Entire Cohort (N=994)	General Public (N=893)	Geisinger Patients (N=101)
Demographics			
Age, mean (range)	61.68 (20 – 97)	61.10 (20–97)	66.77 (30–86)
Women, N (%)	637 (64%)	578 (65%)	59 (58%)
Race, N (%)			
American Indian or Alaska Native	7 (1%)	7 (1%)	0 (0%)
Asian American	16 (2%)	16 (2%)	0 (0%)
Black or African American	90 (9%)	89 (10%)	1 (1%)
Native Hawaiian or Other Pacific Islander	3 (<1%)	3 (<1%)	0 (0%)
White	847 (85%)	749 (84%)	98 (97%)
Two or More Races	17 (2%)	16 (2%)	1 (1%)
Unknown	5 (1%)	5 (1%)	0 (0%)
Prefer Not to Answer	9 (1%)	8 (1%)	1 (1%)
Ethnicity, N (%)			
Hispanic or Latino	58 (6%)	55 (6%)	3 (3%)
Not Hispanic or Latino	893 (90%)	801 (90%)	92 (91%)
Unknown	26 (3%)	21 (2%)	5 (5%)
Prefer Not to Answer	17 (2%)	16 (2%)	1 (1%)
Clinical Characteristics, N (%)			
Currently on dialysis, N (%)	123 (12%)	121 (14%)	2 (2%)
Kidney transplant recipient, N (%)	148 (15%)	146 (16%)	2 (2%)
eGFR known, N (%)	745 (75%)	674 (75%)	71 (70%)
CKD Stage Unknown, N (%)	94 (9%)	84 (9%)	10 (10%)
CKD Stage known, N (%)	900 (91%)	809 (91%)	91 (90%)
• Stage 1	40 (4%)	33 (4%)	7 (7%)
• Stage 2	52 (5%)	47 (5%)	5 (5%)
• Stage 3	445 (45%)	382 (43%)	63 (62%)
• Stage 4	185 (19%)	172 (19%)	13 (13%)
• Stage 5 or ESKD	178 (18%)	175 (20%)	3 (3%)

Table 2: Patient-Reported Causes of Kidney Disease in the KidneyCARE Registry (N=994)

Source: Patient-reported data. Patients could report more than one cause; percentages may exceed 100%.

Cause of CKD	N (%)
Metabolic and Vascular Causes	
Diabetes	195 (20%)
High Blood Pressure (Hypertension)	260 (26%)
Renal Artery Stenosis	6 (1%)
Structural and Urologic Causes	
Nephrolithiasis	12 (1%)
Obstruction of Urinary Tract	24 (2%)
Reflux Nephropathy	17 (2%)
Glomerular and Immune-Mediated	
Anti-GBM Disease/Goodpasture Syndrome	1 (<1%)
Atypical HUS (aHUS)	6 (<1%)
C3G Glomerulopathy (C3G)	10 (1%)
Focal Segmental Glomerulosclerosis (FSGS)	31 (3%)
Glomerulonephritis (unspecified)	35 (4%)
Henoch-Schönlein Purpura (HSP)	0 (0%)
IgA Nephropathy (IgAN)	64 (6%)
Immune Complex (IC-MPGN)	5 (<1%)
Lupus Nephritis (LN)	14 (1%)
Membranous Nephropathy (MN)	2 (<1%)
Vasculitis	17 (2%)
Hereditary Causes	
Alport Syndrome	22 (2%)
Cystinosis	2 (<1%)
Fabry Disease	0 (0%)
Polycystic Kidney Disease (PKD)	101 (10%)
Secondary Causes	
Acute Kidney Injury (AKI)	51 (5%)
Kidney Cancer	36 (4%)
Lithium	17 (2%)
Other / Unknown / Prefer Not to Answer	
Other	188 (19%)
Unknown	415 (42%)
Prefer Not to Answer	21 (2%)

NOTE: 42% of patients report an unknown cause of kidney disease

Table 3: Real-World Use of Cardiorenoprotective Medications Among Geisinger Patients (N=173)

Source: Geisinger outpatient medication data (3/04/2024-6/19/2025)

Patients counted only once per medication; percentages may reflect therapy switches over the 15-month period.

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)
Olmesartan (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)
(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)

Conclusions

The KidneyCARE Registry integrates patient-reported outcomes with EHR data, offering a unique, patient-centered perspective on kidney disease. Geisinger participants typically enroll at earlier disease stages, enabling capture of early disease features. Hypertension and diabetes are the most commonly reported causes of CKD, and real-world EHR data reveal broad use of cardiorenoprotective medications.

Future Directions

- Increase racial and ethnic diversity in the Registry
- Expand rare disease enrollment

References

1. Inker LAI, Ferrè S, Balliker M et al. *Am J Kidney Dis*, 2023 [PMID: 36191726]

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For more information, please visit: KidneyCAREStudy.org

or contact: KidneyCAREStudy@kidney.org

Disclosures

RHM is an employee of Novartis. AS is an employee of Bayer. JM is a previous employee of Bayer. All other authors report no relevant conflicts of interest.

Thank You

Thank you for being part of the KidneyCARE Study and for helping to move kidney disease research forward. Every survey completed brings us closer to better treatments and hopefully, someday, a cure.

With gratitude,
The KidneyCARE Study Team
National Kidney Foundation