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American
Kidney
Fund®

PATIENT ACCESS INITIATIVE 2025

SUMMIT



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Overview

The third annual American Kidney Fund (AKF) Patient Access Initiative Summit brought together patients, caregivers, advocates, physicians, healthcare professionals, researchers, policy experts and industry partners in Washington, D.C. on Nov. 21, 2025. Throughout the day, speakers and attendees examined how policy solutions, prevention and innovation can work together to improve early detection, strengthen access to treatment, increase clinical trials and innovation and support better outcomes for people living with or at risk for kidney disease. These discussions underscore the need for decisive policy action in 2026 to accelerate early diagnosis, ensure access to quality care and translate innovation into better treatment options.

THE 2025 SUMMIT HIGHLIGHTED:

- The impact of federal policy decisions on screening, diagnosis and treatment.
- How innovation and research are reshaping kidney care.
- The systemic challenges that delay early diagnosis and limit access to effective treatments.
- Opportunities to advance upstream care and strengthen patient-centered policies.



Holly Bode, Vice President of Government Affairs at the American Kidney Fund, opened the Summit by welcoming participants and reaffirming the goals of the Patient Access Initiative—to

identify barriers and solutions—across the kidney care continuum. She emphasized the importance of shared expertise and active discussion throughout the day, particularly from patients and caregivers. “Collaboration is what will drive real progress for people living with kidney disease,” she said.



LaVarne Burton, President and Chief Executive Officer of the American Kidney Fund, followed with remarks underscoring the urgency of early diagnosis and accessible treatment. She

noted the growing burden of kidney disease in the United States and worldwide, calling attention to a recent study identifying kidney disease as a top global cause of death. “The urgency is clear. One in seven American adults is living with kidney disease, and millions more remain at risk,” Burton said.

She also highlighted findings and policy solutions from AKF’s new report, “[Stemming the Tide of Kidney Disease](#),” and reinforced the need for improved screening guidelines, stronger care collaboration between cardiovascular and kidney care, expanded education and broader coverage that support prevention.



Congressional Remarks

U.S. Representative Terri Sewell (D-AL)

U.S. Representative Terri Sewell (D-AL) delivered a virtual address to open the Summit, underscoring the urgency of the nation's kidney disease crisis.

She noted that more than 35 million Americans are affected by kidney disease, yet most remain undiagnosed. Rep. Sewell emphasized that expanding access to quality, innovative and affordable care is one of her top priorities. As a member of the House Ways & Means Committee, she highlighted her work on legislation designed to strengthen Medicare's kidney care programs.

Rep. Sewell discussed the Kidney Care Access Protection Act (H.R. 6214), which aims to modernize dialysis payment systems and improve access to new treatment options for end-stage renal disease. She also called attention to significant gaps in rare kidney disease treatment. With about 150 rare kidney conditions and no FDA-approved treatments for most of them, she said the status quo is unacceptable. She stated that she is also proud to champion the New Era of Preventing End-Stage Kidney Disease Act (H.R. 1518), which seeks to improve diagnosis and understanding of rare kidney disease.

Rep. Sewell praised AKF's leadership in promoting innovation, early detection and screening. As policymakers consider the next generation of kidney policy, she encouraged continued advocacy, noting the potential to meaningfully improve patients' lives through policy-focused solutions.

**“
I know there is
significant potential
for us to improve the
lives of those living with
kidney disease if we
work together.
”**

**U.S. Representative
Terri Sewell**

Navigating the Federal Policy Environment

This panel examined how recent federal policy proposals could shape access, research and coverage for people with kidney disease, while identifying where advocacy can shape implementation and ensure that the voices of kidney patients are heard.



Leo Cuello, JD

*Research Professor,
Georgetown University
McCourt School of Public
Policy*

Leo Cuello outlined how proposals in H.R. 1 (also known as the “One Big Beautiful Bill Act,” which was signed into law in July 2025) will significantly reshape Medicaid, noting that “we have a really problematic context ahead of us” as policymakers consider major funding cuts, new work requirements and higher cost sharing.

He explained that these changes could cause millions to lose coverage, including many people with chronic kidney disease (CKD) who rely on Medicaid coverage for routine medical treatment. Cuello emphasized that the ripple effects on state budgets, providers and families underscore the need for strong, coordinated advocacy to help patients stay insured.



Erika Miller, JD

Partner, CRD Associates

Erika Miller described how proposed changes at the U.S. Department of Health and Human Services (HHS) and the National Institutes of Health (NIH) could weaken kidney-focused research and slow advances in prevention, diagnosis and treatment, especially for children and patients with rare kidney

diseases. Looking ahead in 2026, she stressed that kidney disease cannot be deprioritized as agencies face restructuring and potential funding cuts. Miller cautioned that political scrutiny of grants has already influenced what projects researchers are able to pursue, including studies supporting pediatric innovation and clinical trials.

“We have to make sure this administration understands what kidney disease looks like on the ground,” she said, explaining that strong engagement is needed to protect research pathways and maintain progress for rare and pediatric conditions.



Pesh Patel

Founder, A Kidney Life

Pesh Patel highlighted how policy changes can affect patients' daily lives long before they appear in budget

documents or agency rules. Coverage losses, he explained, can delay diagnosis, disrupt dialysis and limit access to transplant evaluation.

Patel spoke to the emotional burden these gaps create, noting that “it is scary, frustrating and in some cases it all seems hopeless” for patients trying to maintain stability. He urged policymakers to include patients at every stage of decision-making looking ahead, so the system reflects their needs and realities.

This panel was moderated by **Rob Blaser**, director of public policy for the Renal Physicians Association.

Advancing Innovative Practices in Prevention, Screening and Diagnosis

This panel pointed to a future in which kidney risk is identified earlier, across settings and before irreversible damage occurs by integrating clinical innovation, AI-enabled risk assessment and patient and care partner perspectives.



Charles German, MD

Director of Preventive Cardiology, Medstar Georgetown University Hospital; Assistant Professor of Medicine, Georgetown University

Dr. Charles German explained that cardiovascular-kidney-metabolic (CKM) syndrome reflects how kidney, cardiovascular and metabolic health are deeply interconnected, requiring earlier and more coordinated screening. He said upstream identification of risk is essential because “the way you really help people is by preventing them from developing the disease in the first place.”

Dr. German highlighted how new risk-assessment tools now include kidney-centered metrics for the first time and emphasized empowering primary care to act earlier. Multidisciplinary care, he noted, is key to improving long-term outcomes for patients at risk.



Severence MacLaughlin, PhD

Founder and CEO, DeLorean AI

Dr. Severence MacLaughlin outlined the role that Artificial Intelligence (AI) may play in increasing access to screening and diagnosis, with DeLorean AI as an example. He explained that AI-driven models can analyze clinical data in real time, allowing clinicians to identify risks earlier and make more informed decisions about follow-up care. Rather than replacing providers, he said these tools are designed

to support them by predicting which patients may become unstable and can recommend action to prevent disease progression.

As science continues to move faster than policy, Dr. MacLaughlin emphasized that AI has already shown promise in reducing avoidable hospitalizations and could help improve early detection across the kidney community.



Yojana Rodriguez-Humbert, EdD(c)

Founder and Executive Director, Kaya Girl Legacy, Inc.

Yojana Rodriguez-Humbert described how her daughter Kaya's rare disease diagnosis set her on a path to advocacy. She shared the challenges of navigating newborn screening, genetic uncertainty and the emotional weight of being told her child had a rare disease.

Through her nonprofit, Kaya Girl Legacy, dedicated to the memory of her daughter, Kaya, she works to expand awareness and early testing so families can make informed decisions. “Most of us believe serious illness happens to other people, until it happens to us,” she said, underscoring the need for primary care providers to lead conversations about screening, risk and early diagnosis. Rodriguez-Humbert highlighted the critical role of patient and care partner voices in advocacy.

This panel was moderated by **Lauren Lee**, vice president of patient advocacy for Travers Therapeutics.



Keynote Discussion



Katalin Susztak, MD, PhD

Professor of Medicine and Genetics and Director of the Penn/CHOP Kidney Innovation Center, Nephrologist

Dr. Katalin Susztak described how a patient with a rare genetic disease she met in medical school sparked her interest in nephrology and shaped her scientific path. “That experience set the stage for how I think about kidney medicine,” she said, showing how research and clinical care can—and should—inform each other.

By developing comparative mouse and human models, Dr. Susztak and her team built one of the largest kidney biobanks in the world. Her group has gathered genetic data from millions of patients to examine every gene active in the kidney, enabling researchers to identify biomarkers and better understand why kidney disease develops. “Kidney disease has a strong hereditary component, and many people carry different pieces of the puzzle,” she said.

As Dr. Susztak noted, these biological insights can point to new therapeutic targets and enable a shift toward precision medicine. She emphasized that kidney biology begins to decline long before traditional diagnostics detect problems. “We can now study every cell type in the kidney, and that lets us design therapies that address specific mechanisms,” she said. With new molecular tools, clinicians will be able to diagnose diseases earlier and match treatments more precisely.

She also highlighted how AI is driving progress. Tools developed at the University of Pennsylvania, including CellSpectra and SISKKA, can model how a treatment may work for an individual patient. “Genetics is not your destiny,” she said. “AI lets us run investigations to guide the right combination of treatments for a patient.”

Dr. Susztak called for stronger pathways to translate scientific advances into patient care, noting that diagnostics already exist to identify risks before disease begins. She emphasized that the central challenge for 2026 is not scientific discovery, but bringing those advances into routine clinical care. “In the next 10 years, I believe we can move toward eliminating end-stage renal disease,” she said, “The science is ready. Now we must deliver it.”

This discussion was moderated by **Holly Bode**, vice president of government affairs at the American Kidney Fund.

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**Katalin Susztak,
MD, PhD**

”

Driving Innovation Across the Kidney Care Continuum

This panel examined how innovation across the kidney care continuum must address patient, caregiver and family realities, align payment policy with scientific progress and elevate patient voices to ensure new treatments reach those who need them.



Kaushal Amatya, PhD
*Attending Psychologist,
Children's National Hospital;
Associate Professor, GWU
School of Medicine and
Health Sciences*

Dr. Kaushal Amatya explained that innovation must address the social, emotional and cognitive factors that shape adherence in pediatric transplant care. He said families often face competing stresses that affect treatment consistency and that mental health reflects overall well-being, in addition to formal diagnoses. Dr. Amatya highlighted the challenges of transitioning to adult care and noted that providers must “understand the entire patient’s story” to support long term success and improve quality of life for young transplant recipients.



Jennifer Friedman
*Senior Vice President, Federal
Health Policy Strategies*

Jennifer Friedman described how Medicare’s End-Stage Renal Disease bundle, originally designed to control rapidly increasing costs, now limits access to innovation. Using a real-world example, she explained that the Centers for Medicare and Medicaid Services (CMS) reimbursed dialysis providers for a breakthrough treatment for pruritus, severe itching experienced by dialysis patients, as if it were comparable to a low-cost antihistamine. This inadequate payment made providers less likely to prescribe it and therefore more difficult for patients to access. She said the current system “is not rewarding or encouraging innovation” and called for clearer incentives, greater transparency and stronger inclusion of patient perspectives to ensure dialysis patients benefit from new treatments and emerging technologies.



Mark Lim, PhD
*Vice President of Research,
Discovery, and Innovation,
American Society of
Nephrology’s Alliance for
Kidney Health*

Dr. Mark Lim outlined how the American Society of Nephrology (ASN) is advancing innovation through research support and multi-stakeholder collaboration. He noted that funding gaps have threatened scientific progress and that ASN has invested in bridge grants to help researchers continue their work. Dr. Lim highlighted ASN’s Kidney Health Initiative as an essential platform for aligning science with patient priorities. “The science is there—we just need to guide it toward patients,” Lim said, emphasizing the importance of patient-informed drug and device development in the coming year.



Sejal Patel, MD
*Research Collaborator,
Mayo Clinic*

Dr. Sejal Patel described how her two kidney transplants and pancreas transplant motivated her work in research and advocacy. Diagnosed with type 1 diabetes at age 10 and later facing kidney failure after medical school, she said the uncertainty of repeated procedures showed her how urgently the field needs progress. Dr. Patel emphasized that “patients cannot wait for innovation” and noted that sharing her story helped her understand the power of patient voices in advancing transplant research and improving long-term outcomes.

This panel was moderated by **Anne Rohall, JD**, director of public policy for the American Kidney Fund.

Prioritizing Upstream Care in Kidney Disease

This panel emphasized that upstream kidney care is no longer optional, but essential to sustainability, equity and outcomes in the future. This can be accomplished in 2026 by expanding early detection, employer engagement and accessible education.



Ge Bai, PhD, CPA

*Professor of Accounting,
Johns Hopkins Carey
Business School;
Professor of Health Policy
and Management, Johns
Hopkins Bloomberg School of Public Health*

Dr. Ge Bai discussed the major stake employers have in improving upstream kidney care. She explained that earlier detection often involves commercially insured patients, making employers critical partners in promoting screening and prevention.

Dr. Bai noted that value-based models can create positive incentives and highlighted research showing that billions in savings to our healthcare system are possible if employers invest in kidney health. She emphasized that “if we want to help patients, we must address accessibility and affordability.”



Vanessa Evans,

*Director of Patient Advocacy
and Communities, Fresenius
Medical Care*

Vanessa Evans, a long-time dialysis patient, drew on both professional and personal experience to explain how early detection changes the entire patient journey by giving people time to understand their condition, make lifestyle modifications and connect with peers

who can guide them through difficult decisions. She said transparency empowers patients and that early conversations help them navigate a complex system with more confidence.

Evans emphasized the need for accessible education and outreach, noting that “we want to do a better job of educating and elevating the advocates who work alongside industry” so patients receive support long before reaching a crisis stage.



Waleed Zafar, MD

*Assistant Professor of
Medicine and Investigator at
the Center for Kidney Health
Research, Geisinger*

Dr. Waleed Zafar described why diagnosing and treating kidney disease early is essential for patients and the health system. He noted that earlier detection reduces complications, slows progression and lowers the chance that someone will “crash” into dialysis.

He emphasized that cardiovascular risk is central to an early CKD diagnosis and can help reduce disparities and improve cost effectiveness. Dr. Zafar highlighted value-based tools at Geisinger, saying “there is a vast number of high-risk patients who are not being screened,” which is why innovative approaches are needed to close gaps.

This panel was moderated by **Mike Ly**, director of public policy at the American Kidney Fund.

2026 Policy Priorities for Kidney Care

The 2025 Patient Access Initiative Summit reinforced a clear message: the science is ready, patients are waiting and policy must catch up. As the kidney community looks to 2026, these priorities, which reflect the lived patient experiences shared throughout the Summit, will guide advocacy to expand early detection, protect access and ensure that innovation reaches patients.



1. PROTECT AND STRENGTHEN COVERAGE

- a. Prevent administrative barriers that delay diagnosis and treatment and disrupt continuity of care.
- b. Ensure healthcare coverage keeps pace with innovation so patients can access new diagnostics and treatments.



2. MAKE EARLY DETECTION THE STANDARD

- a. Advance routine CKD screening guidelines to support earlier identification of the disease.
- b. Integrate kidney risk into primary care and chronic disease management across care settings.
- c. Expand access to genetic testing and counseling to inform risk and guide early intervention.
- d. Recognize the link between CKD and cardiovascular disease and increase knowledge about CKM syndrome.



3. ALIGN PAYMENT WITH INNOVATION

- a. Reform payment systems that discourage the adoption of new treatments and innovative care models.
- b. Support value-based models that prioritize quality by rewarding prevention, early intervention and improved outcomes.
- c. Ensure pediatric and rare kidney disease innovation is not sidelined by outdated payment structures.



4. INVEST IN RESEARCH AND ADVANCEMENT

- a. Protect and expand NIH and kidney-focused research funding to sustain scientific progress.
- b. Reduce delays between scientific advances and real-world use to improve patient outcomes faster.



5. PATIENT-CENTERED CARE

- a. Ensure patient voices are part of policy design and implementation at every stage.
- b. Promote early patient participation to inform clinical trial design and research priorities
- c. Support navigation, education and caregiver engagement as core components of kidney care.

These priorities reflect a shared vision across patients, advocates, clinicians, researchers and industry. In 2026, the opportunity is not only to understand kidney disease better, but to also act decisively to prevent it earlier and treat it more effectively.

What Success Looks Like in 2026

- ▶ More patients are screened and diagnosed with kidney disease earlier, before irreversible disease progression.
- ▶ Patients experience stable, affordable coverage with fewer delays caused by prior authorization or administrative barriers.
- ▶ Clinicians are supported with modern tools, data and payment models that reward prevention, innovation, quality and early intervention.
- ▶ New diagnostics and treatments reach patients more quickly through clearer pathways from research to care.
- ▶ Patient and care partner perspectives are meaningfully included in kidney policy development and implementation.
- ▶ Patients are empowered to manage their own care through education, resources and community support.
- ▶ Patients are equipped and encouraged to advocate for improvements in kidney policy and legislation and to share their personal experiences with policymakers.



Thank you to all the patients, clinicians, caregivers, researchers, stakeholders, advocates, and industry representatives who contributed to the 2025 Patient Access Initiative Summit. The conversations throughout the day reinforced a shared commitment to earlier diagnosis, stronger patient support and continued innovation in kidney care. Using the insights gathered here, the Patient Access Initiative will focus next on policies that improve access, support the healthcare workforce and strengthen prevention. The American Kidney Fund looks forward to continuing this momentum together.

To learn more about topics discussed at the Summit and the American Kidney Fund's policy priorities and advocacy initiatives, visit KidneyFund.org.



ABOUT THE AMERICAN KIDNEY FUND

The American Kidney Fund's mission is to fight kidney disease and help people live healthier lives.

KidneyFund.org

