



8th Annual Public Policy Summit

Midpoint of the Decade of the Kidney™:

Re-Prioritizing Patients Across Policy, Regulatory, and Payment Decisions

About the Public Policy Summit: The AAKP Public Policy Summit is hosted annually by the American Association of Kidney Patients (AAKP), the nation's oldest and largest independent kidney patient organization. The event informs policymakers and influencers of specific barriers confronting kidney patients and their care choices as well as challenges faced by innovation leaders working to advance new medical diagnostics, drugs, and devices. Speakers include kidney patient consumers along with elected and appointed leaders, kidney health and organ transplant experts, industry leaders, researchers and other stakeholders. The Summit emphasizes core AAKP initiatives, such as KidneyVoter™ and Patient Voice Patient Choice™, as channels for the organized voices of patients to impact future kidney policies.

Since its launch in 2018, the Summit has served as a forum to organize support for major policy changes including the inclusion of living organ donors under the Family Medical Leave Act (2018), the Trump Administration's *Executive Order on Advancing American Kidney Health* (2019), and the extension of federal immunosuppressive drug coverage to ensure long-term transplant survival (2020). In recent years, the Policy Summit has been a vital platform to spotlight Government Determinants of Health (GDOH) – federal regulatory and payment decisions that impede the lives and livelihoods of kidney patients and further burden American taxpayers.

About the 2025 Public Policy Summit: 2025 is the midpoint of the AAKP-led Decade of the Kidney™, a ten-year drive to transcend high-cost, high mortality status quo kidney care through greater innovation and increased opportunities for transplantation. This year's Public Policy Summit will highlight common sense solutions that: re-prioritize patients within federal kidney policy decisions, help slow disease progression, improve patient health and transplant readiness, better protect living organ donors, and increase attention on long-term transplant patient survival.

Date: Friday, June 27, 2025

Time: 10:00 a.m. – 2:00 p.m.ET (doors open at 9:30 a.m.)

Location: The National Press Club, 529 14th St. NW, Washington, DC 20045

Livestream Option Available

<p>10:00 a.m. – 10:30 a.m.</p> <p>Moderator: Paul T. Conway, Vice President & Chair of Policy and Global Affairs, American Association of Kidney Patients; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 28-year kidney transplant patient</i></p>	<p>Welcome and Opening Remarks Diana Clynes, AAKP Executive Director</p> <p>Edward V. Hickey, III, USMC, President, American Association of Kidney Patients (AAKP); Chair, AAKP Veterans Health Initiative; former U.S. Congressional senior staff member; <i>chronic kidney disease patient</i></p> <p>Honoring the Recipient of the AAKP President’s Award Murray Sheldon, MD; Former Associate Director for Technology & Innovation, Center for Devices and Radiological Health (CDRH), U.S. Food & Drug Administration (FDA)</p> <p>Special Presentation: Micro Constituencies in Action: KidneyVoters™ and Policy Lessons from 2024</p> <ul style="list-style-type: none"> Kristian Hemphill, Vice President, Grassroots Targeting
<p>Read, Watch, and Learn!</p>	<ul style="list-style-type: none"> Statement: AAKP Commemorates Juneteenth (Read Now) AAKP Press Release (2019): AAKP Previews Decade of the Kidney™ (Read Now) Executive Order (2019): Advancing American Kidney Health (Read Now) AAKP Statement (2019) on Executive Order Advancing American Kidney Health (Read Now) <p>Federal Embrace of Patient Insights</p> <ul style="list-style-type: none"> AAKP Global Summit on Kidney Disease Innovations: Pathways to Artificial Implantable Organs, presented by Murray Sheldon, MD CJASN article: Overview of Various Components of the Science of Patient Input, authored by Murray Sheldon, MD CJASN Patient Voice article: Legitimization and Incorporation of Patient Preferences, authored by Paul T. Conway and Richard Knight CJASN article: Integrating Patient Perspectives into Medical Device Regulatory Decision Making to Advance Innovation in Kidney Disease, authored by Michelle E. Tarver, MD and Carolyn Neuland, PhD CJASN article: Using Patient Preference Information to Inform Regulatory Decision Making: An Opportunity to Spur Patient-Centered Innovation in Kidney Replacement Therapy Devices, authored by Jennifer E. Flythe, PhD and Melissa West CJASN article: Incorporating Patient Preferences via Bayesian Decision Analysis, authored by Shomesh E. Chandhuri, MD and Andrew W. Lo <p>AAKP KidneyVoter™</p> <ul style="list-style-type: none"> Kidney Patients Expand Voter Registration in 50 States in 50 Days (Press Release)

	<ul style="list-style-type: none"> • AAKP Editorial: Of Presidents, Policies, and Patients, authored by Edward V. Hickey, III and Paul T. Conway • Kidney Patients Expand Impact as KidneyVoters™ in 2020 (Press Release) • AAKP Article by Paul T. Conway: 2020 and Kidney Voters – AAKP Members Flex Growing Muscle • AAKP Article by Dale Rogers: I am a KidneyVoter™. Are You?
Take Action!	<ul style="list-style-type: none"> • Become a KidneyVoter™! Register to vote today! • AAKP Action Center! Sign up for Alerts!
<p>10:35 a.m. – 11:30 a.m.</p> <p>Moderator: Paul T. Conway, Vice President & Chair of Policy and Global Affairs, American Association of Kidney Patients; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 28-year kidney transplant patient</i></p> <p>Moderator: Edward V. Hickey, III, USMC, President, American Association of Kidney Patients (AAKP); Chair, AAKP Veterans Health Initiative; former U.S. Congressional senior staff member; <i>chronic kidney disease patient</i></p>	<p>Discussion Topic #1: Protecting Kidney Patients & Organ Donor Health: Policy Opportunities for 2025</p> <p>Panelists:</p> <ul style="list-style-type: none"> • Quality Adjusted Life Years (QALYs) <ul style="list-style-type: none"> ○ Rai Downs, Co-Founder and Partner, Tarplin, Downs, and Young, LLC; Representative, Partnership to Improve Patient Care (PIPC) • Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 1520 / S. 1782) <ul style="list-style-type: none"> ○ Anna Fedewa, Senior Manager, Government Relations, National Down Syndrome Society (NDSS) ○ Charlotte Woodward, Programs Associate, National Down Syndrome Society (NDSS) • SAFE Sunscreen Standards Act (H.R. 3686) <ul style="list-style-type: none"> ○ Parker Reynolds, Associate, Holland and Knight; Representative, Public Access to Sunscreen (PASS) Coalition <p>Special Guest:</p> <ul style="list-style-type: none"> • Living Donor Protection Act (S. 1552) <ul style="list-style-type: none"> ○ The Honorable Jerrold Nadler (D-NY), Member, U.S. House of Representatives, United States Congress; Co-Sponsor, Living Donor Protection Act
Read, Watch, and Learn!	<ul style="list-style-type: none"> • Living Donor Protection Act (S. 1552) • Gillibrand, Cotton, Nadler, Bacon Introduce Bipartisan, Bicameral Legislation to Protect Organ Donors (Read Now) • Statement of Policy Principles and Solutions: Living Organ Donation (Read Now) • House Votes to Ban Metric Used to Deny Care for People with Disabilities and Chronic Illnesses (Read Now) • Support Federal Legislation to Ban Quality Adjusted Life Years (QALYs) in federal programs (Read Now) • Charlotte Woodward Organ Transplant Discrimination Act (H.R. 1520 / S. 1782) • Click here to see list of organizations in support of the Charlotte Woodward Organ Transplant Discrimination Prevention Act • SAFE Sunscreen Standards Act (H.R. 3686)

Take Action!	<ul style="list-style-type: none"> • Become a KidneyVoter™! Register to vote today! • AAKP Action Center! Sign up for Alerts!
<p>11:35 a.m.- 12:25 p.m.</p> <p>Moderator: Edward V. Hickey, III, USMC, President, American Association of Kidney Patients (AAKP); Chair, AAKP Veterans Health Initiative; former U.S. Congressional senior staff member; <i>chronic kidney disease patient</i></p> <p>Moderator: Paul T. Conway, Vice President & Chair of Policy and Global Affairs, American Association of Kidney Patients; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 28-year kidney transplant patient</i></p> <p>Moderator: Paul T. Conway, Vice President & Chair of Policy and Global Affairs, American Association of Kidney Patients; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 28-year kidney transplant patient</i></p>	<p>Discussion Topic #2: Overcoming Government Determinants of Health (GDoH) in Kidney Care Through Payment and Policy Innovation</p> <ul style="list-style-type: none"> • Panel 1: Improving Outcomes and Reducing Costs with Timely Detection, Diagnosis, and Intervention of Kidney Disease (Diagnostics) <ul style="list-style-type: none"> ○ Suzanne Watnick, MD, FASN; American Society of Nephrology (ASN) Health Policy Scholar in Residence; Professor of Medicine, University of Washington (UW) • Panel 2: Unbundling with Purpose: Designing a More Patient-Centered Payment System that Reflects Patient Priorities (Drugs) <ul style="list-style-type: none"> ○ Ankur Shah, MD; Assistant Professor of Medicine, Associate Program Director for Research, and Medical Director for Peritoneal Dialysis, Division for Kidney Disease and Hypertension, Warren Alpert Medical School, Brown University ○ Laura Williams, MD, MPH, Chief Patient Officer, Ardelyx, Inc. ○ Elizabeth Hurlburt, Chief Clinical Strategy and Operations Officer, CorMedix Inc. • Panel 3: From Innovation to Access: Creating a Clear Path for Kidney Device Choice (Devices) <ul style="list-style-type: none"> ○ Tammy Gilon, B.Sc, CEO and Co-Founder, Laminate Medical Technologies ○ James A. Sloand, MD, FACP, FASN; Chief Medical Officer, Simergent; Adjunct Professor of Medicine, Division of Kidney Diseases and Hypertension, George Washington University School of Medicine and Health Sciences; Founder and Managing Director, JAS Renaissance LLC
<p>Read, Watch, and Learn!</p>	<ul style="list-style-type: none"> • Overcoming Barriers to Therapeutic Innovation in Kidney Disease, presented during the American Society of Nephrology's (ASN) Nephro-Economics Symposium, featuring Dr. Ankur Shah (Watch OnDemand) • Patients, Quality, and Payment System: Why the Patient Voice Matters (Watch OnDemand) • Misalignments in Federal Regulatory and Payment Decisions and the Consequences for Kidney Patients: How Decisions Made by CMS Impact Unmet Patient Needs and the Future of Innovation, featuring Tammy Gilon (Laminate Medical) (Watch OnDemand) • Government Determinants of Health: Misalignments in Regulatory & Payment Determine Patient Access, featuring Dr. Laura Williams (Ardelyx, Inc.) (Watch OnDemand) • The Hidden 'P' in Kidney Disease (Watch OnDemand) • We are Listening: The Role of Patient Consumers in Innovation, featuring Elizabeth Hurlburt (CorMedix) (Watch OnDemand)

	<ul style="list-style-type: none"> • Infection Prevention Strategies for Patients with Central Venous Catheters, featuring Elizabeth Hurlburt (CorMedix) (Watch OnDemand) • Kidney Group Unveils Risk Campaign During National Safety Month (Press Release)
Take Action!	<ul style="list-style-type: none"> • Raise Your Voice...Take the AAKP Flash Survey on Access to Phosphate Lowering Therapies! • Raise Your Voice...Take the AAKP Flash Survey on Dialysis Patient Safety & Infection Prevention! • Become a KidneyVoter™! Register to vote today! • AAKP Action Center! Sign up for Alerts!
12:30 p.m. – 1:10 p.m. Moderator: Edward V. Hickey, III, USMC, President, American Association of Kidney Patients (AAKP); Chair, AAKP Veterans Health Initiative; former U.S. Congressional senior staff member; <i>chronic kidney disease patient</i>	Discussion Topic #3: Innovations the FDA Must Support to Advance Kidney Transplantation Panelists: <ul style="list-style-type: none"> • Kenneth Newell, MD, PhD; Professor of Surgery, Division of Transplantation and Program Director, Abdominal Transplant Surgery Fellowship, Emory University School of Medicine; Committee Member, Transplant Therapeutics Consortium (TTC); 2024 AAKP Medal of Excellence Award Recipient • Jennifer Leonard, Director, U.S. Medical Affairs and Clinical Field Operations, Hansa Biopharma • Jennifer Bergheiser, Chief Business Officer, eGenesis, Inc.
Read, Watch, and Learn!	<ul style="list-style-type: none"> • ProPublica article: His Kidney Failed. He'll Never Know if a Transplant Drug From a Banned Factory Was to Blame • The Next Generation of Transplant Drugs and Other Innovations for Transplant Patient Care, featuring Dr. Kenneth Newell (Watch OnDemand) • Policy Roundtable: Decades Long Effort to Jumpstart the Next Generation of Transplant Drugs (Watch OnDemand) • Read Now! FDA November 9, 2023, Meeting Transcript – Endpoints and Trial Designs to Advance Drug Development in Kidney Transplantation • Read Now! One Kidney for Life • Read Now! Innovation in Transplantation: Accountability, Collaboration, and the Value of the Patient Voice • Read Now! The Value of the Patient Voice in Kidney Transplantation • Issue of Serious Concern: America's Next Generation of Transplant Drugs • The Next Generation of Organs: How U.S. FDA Decisions Impact People Living with Kidney Failure (Watch OnDemand) • Xenotransplantation: Research and Ethics (Watch OnDemand) • Highly Sensitized Kidney Patients Lead to New Insights (Watch OnDemand) • Alternatives to Human Organs: Xenotransplantation, featuring Dr. Robert Montgomery and Dr. Michael Curtis (eGenesis) (Watch OnDemand) • Alternatives to Human Organs: Xenotransplantation, Adam D. Griesemer, MD, NYU Langone Health (Watch OnDemand) • Alternatives to Human Organs: Xenotransplantation, Leonardo V. Riella, MD, Harvard Medical School (Watch OnDemand)

	<ul style="list-style-type: none"> Kidney Patients Target Medicare Transplant Double Standard (Press Release)
Take Action!	<ul style="list-style-type: none"> Raise Your Voice...Take the AAKP Flash Survey on Transplant Medication! Transplant Therapeutics and Innovation Must Evolve – Sign the Petition! Raise Your Voice...Take the AAKP Flash Survey on Patient Insights on Xenotransplantation! Become a KidneyVoter™! Register to vote today! AAKP Action Center! Sign up for Alerts!
<p>1:15 p.m. – 2:00 p.m.</p> <p>Moderator: Paul T. Conway, Vice President & Chair of Policy and Global Affairs, American Association of Kidney Patients; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 28-year kidney transplant patient</i></p>	<p>Discussion Topic #4: Why Advancing Kidney Health Requires Challenging Status Quo Practices</p> <p>Panelists:</p> <ul style="list-style-type: none"> <i>The Rise of Medicare Advantage (MA): Challenges and Opportunities for the Kidney Community</i> <ul style="list-style-type: none"> Kevin H. Nguyen, PhD; Assistant Professor, Department of Health Law, Policy, and Management; Faculty Affiliate, Boston University Policy Lab; Senior Associate Editor, Journal of Ambulatory Care Management; Boston University School of Public Health <i>Optimizing Outcomes: Delivering the Right Treatment at the Right Time</i> <ul style="list-style-type: none"> Akhtar Ashfaq, MD; Senior Vice President, Clinical Research and Development, Medical Affairs and Pharmacovigilance, OPKO Pharmaceuticals <i>Avoiding Transplant Loss and Lowering Demand for Re-Transplantation: Opportunities to Improve Long-Term Transplant Graft Survival</i> <ul style="list-style-type: none"> Muralidharan Jagadeesan, MD, FACP, FASN; Professor of Medicine, Division of Renal Diseases and Hypertension, George Washington School of Medicine and Health Sciences (GW SMHS); Chairman of Transplant Medicine and the Medical Director of Kidney-Pancreas Transplant Program <p>Closing Remarks and Observations Edward V. Hickey, III, USMC, President, American Association of Kidney Patients (AAKP); Chair, AAKP Veterans Health Initiative; former U.S. Congressional senior staff member; <i>chronic kidney disease patient</i></p>
Read, Watch, and Learn!	<ul style="list-style-type: none"> AAKP HealthLine: Open Enrollment – Medicare vs Medicare Advantage ...Determining a Program Right for You! (Watch OnDemand) McKnights article: Medicare Advantage Marketing Practices Raise Concerns for Kidney Disease Patients Important Early Intervention Studies in Kidney Disease, featuring Dr. Akhtar Ashfaq (OPKO Renal) (Watch OnDemand) AJN article: Sustained Reduction of Elevated Intact Parathyroid Hormone Concentrations with Extended Release Calcifediol Slows CKD Progression in SPHT Patients, co-authored by Dr. Akhtar Ashfaq AJN article: Extended Release Calcifediol Normalized 1,25-Dihydroxyvitamin D and Prevention Progression of SHPT in Hemodialysis Patients in Randomized Clinical Trial, co-authored by Dr. Akhtar Ashfaq

	<ul style="list-style-type: none"> AJN article: Adjunctive Active Vitamin D Decreases Kidney Function during Treatment of SHPT with Extended Release Calcifediol in Non-Dialysis CKD in Randomized Trial, co-authored by Dr. Akhtar Ashfaq
Take Action!	<ul style="list-style-type: none"> Become a KidneyVoter™! Register to vote today! AAKP Action Center! Sign up for Alerts!

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