



American Association of Kidney Patients
aakp.org

Kidney Patient Consumer Policy Roundtable

The Critical Need to Overcome Government Determinants of Health (GDoH)

National Press Club * Virtual * February 20, 2024

<p>10:00 a.m. – 10:10 a.m.</p>	<p>Welcome and Opening Remarks 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>Read and Learn!</p>	<ul style="list-style-type: none"> • Read Now! 12 Tips to Nephrology Teams Supporting Patients with Advanced Kidney Disease (<i>Patient Voice editorial, CJASN</i>)
<p>10:10 a.m. – 10:30 a.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>Discussion Topic #1: Kidney Disease Screening – How the Federal Government Could Uphold its Commitment to Patients and Taxpayers for Earlier Kidney Disease Detection and Timely Intervention</p> <p>Panelist:</p> <ul style="list-style-type: none"> • Susan E. Quaggin, MD, FASN; Past President, American Society of Nephrologist (ASN); Charles Horace Mayo Professor of Medicine; Chief of Nephrology/Hypertension and Director, Feinberg Cardiovascular and Renal Research Institute, Northwestern University
<p>Read and Learn!</p>	<ul style="list-style-type: none"> • Read Now! Kidney Patients Put Innovation and Access on National Agenda • About the United States Preventative Services Taskforce • ICYMI! AAKP CKD Awareness Roundtable available OnDemand • Learn about AAKP’s Patient Voice Patient Choice™
<p>Take Action!</p>	<ul style="list-style-type: none"> • Kidney Patients Need Access to NEW, FDA-Approved, SAFE Treatments – Sign the Petition! • Become a KidneyVoter™! Register to vote today!

<p>10:35 a.m. – 11:15 a.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>Discussion Topic #2: Opportunities and Challenges for Stakeholders - Federal Policy Implementation/Interpretations Impacting Kidney Patients and Medical Innovation</p> <p>Part 1: Transformation Unfolds Across America’s Transplant System Panelists:</p> <ul style="list-style-type: none"> • Alicia Hennie, Vice President, External Affairs; United Network of Organ Sharing (UNOS) • Peggy Tighe, Principal, Powers, Pyles, Sutter & Verville PC; Legal Counsel, American Society of Transplant Surgeons (ASTS) • Paul T. Conway, Chair of Policy and Global Affairs, American Association of Kidney Patients; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 26-year kidney transplant patient</i> <p>Part 2: Misalignments in Federal Regulatory and Payment Decisions Determine Patient Access to Vital Innovations Panelists:</p> <ul style="list-style-type: none"> • Chris Bowlin, Executive Director, Head of Public Policy and Government Affairs, CorMedix, Inc. • Laura A. Williams, MD, MPH, Chief Medical Officer, Ardelyx, Inc. • Paul T. Conway, Chair of Policy and Global Affairs, American Association of Kidney Patients; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 26-year kidney transplant patient</i>
<p>Read and Learn!</p>	<ul style="list-style-type: none"> • Read Now! Statement of Policy Principles and Solutions: Living Organ Donation – a joint statement by AST, ASTS, and AAKP • Read Now! Government Determinants of Health Must Not Impede Long-Term Access to Infection Prevention Innovations • Issue of Serious Concern: Infection Prevention Innovation and Patient Access • Read Now! Members of Congress urge CMS to properly classify the first and only FDA-approved antimicrobial catheter lock solution to ensure all patients have access • Read the Home Dialysis Risk Prevention Act (H.R. 3118) • Learn about AAKP’s Patient Voice Patient Choice™
<p>Take Action!</p>	<ul style="list-style-type: none"> • Postpone adding oral-only phosphate lowering therapies into CMS bundle – Visit AAKP’s Action Center • Ensure Detection of Venous Needle Dislodgement for Home Hemodialysis Patients – Visit AAKP’s Action Center • Become a KidneyVoter™! Register to vote today!
<p>11:20 a.m. – 11:40 a.m.</p> <p>Moderator:</p>	<p>Discussion Topic #3: The Long and Winding Road...FDA’s Decades-Long Effort to Jumpstart the Next Generation of Transplant Drugs</p> <p>Panelists:</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>	<ul style="list-style-type: none"> • Kenneth Newell, MD; 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 • Kevin Fowler, Founder and CEO, The Voice of the Patient, Inc.; AAKP Ambassador; <i>pre-emptive kidney transplant recipient</i>
<p>Read and Learn!</p>	<ul style="list-style-type: none"> • 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 • Learn about AAKP’s Patient Voice Patient Choice™
<p>Take Action!</p>	<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! • Become a KidneyVoter™! Register to vote today!
<p>11:40 a.m. – 11:55 p.m.</p> <p>Moderator: Paul T. Conway, Chair of Policy and Global Affairs, American Association of Kidney Patients; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 26-year kidney transplant patient</i></p>	<p>Fireside Chat: <i>The Body’s Keeper: A Social History of Kidney Failure and Its Treatments</i></p> <ul style="list-style-type: none"> • Paul L. Kimmel, MD, MACP, FRCP, FASN; Clinical Professor of Medicine, Emeritus, George Washington University
<p>Take Action!</p>	<ul style="list-style-type: none"> • Order Your Copy Today! <i>The Body’s Keeper: A Social History of Kidney Failure and Its Treatments</i>
<p>12:00 p.m. – 12:20 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>Discussion Topic #4: Transplant Diagnostic Testing - The 2023 HHS/CMS Policy Change that Disrupted Transplant Professionals and Medicare Transplant Patients and Contradicted Stated Presidential Commitments</p> <p>Panelists:</p> <ul style="list-style-type: none"> • Steven Potter, MD, FACS, Transplant Surgeon, MedStar Georgetown Transplant Institute; Professor of Surgery and Urology, Georgetown University School of Medicine; Chair, Legislative and Regulatory Committee, American Society of Transplant Surgeons (ASTS); Chair, CMMI Living Donor Demonstration Project, ASTS; 2024 AAKP Medal of Excellence Award Recipient

	<ul style="list-style-type: none"> • Paul T. Conway, Chair of Policy and Global Affairs, American Association of Kidney Patients; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 26-year kidney transplant patient</i>
<p>Read and Learn!</p>	<ul style="list-style-type: none"> • Read Now! Kidney Patients Target Medicare Transplant Double Standard • Read Now! A Closer Look – Molecular Blood Testing and Kidney Transplant Surveillance – A New Double Standard For Medicare Patients • Read Now! Congressional Black Caucus expresses concern with recent actions taken by MoIDX to restrict access to post-transplant testing • Read Now! Bipartisan Letters Members of Congress expresses concern with recent actions taken by MoIDX to restrict access to post-transplant testing (August 2023 Letter) (October 2023 Letter) • Read Now! UNOS statement regarding Medicare billing guidance for organ transplant monitoring tests • Read Now! Health Equity in Transplant (HEITC), New Report Published by AAKP Exposes Alarming Medicare Paradox • Issue of Serious Concern: Access to Diagnostic Testing for Transplant Recipients • Watch OnDemand! Remarks by AAKP Paul Conway, Chair of Policy & Global Affairs: MoIDX Open Hearing on Transplant Test (partial) • Watch OnDemand! Remarks by AAKP Paul Conway, Chair of Policy & Global Affairs: MoIDX Open Hearing on Transplant Test (full) • Read Now! Real Clear Politics - Medicare’s Private Contractors are Gaslighting Transplant Patients • Read Now! The Hill – New Health Equity Coalition • Read Now! The Wall Street Journal Editorials (Sept. 10th Editorial) (Sept. 22nd Editorial) (Sept. 26th Editorial) (Feb. 22nd Editorial) • Learn about AAKP’s <u>Patient Voice Patient Choice™</u>
<p>Take Action!</p>	<ul style="list-style-type: none"> • Become a KidneyVoter™! Register to vote today!
<p>12:20 p.m. – 12:30 p.m.</p>	<p><i>Closing Observations</i> 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>

*This event is hosted by the American Association of Kidney Patients
Center for Patient Engagement and Advocacy and supported by donations from the
following partners:*

CSL Vifor

