

7th Annual Public Policy Summit

National Press Club * Virtual * November 20, 2024

The National Kidney Patient Consumer Agenda...Where are we now?

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

<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>10:10 a.m. – 10:30 a.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; 27-year kidney transplant patient</i></p>	<p>Discussion Topic #1: Opportunities and Barriers in the Advancement of Next Generation Transplant Drugs and other Innovations for Transplant Patient Care – How U.S. Food and Drug Administration (FDA) Decisions Impact Kidney Transplant Recipients</p> <p>Panelists:</p> <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 • Jonathan Haydak, AAKP Board of Director, Ambassador; <i>former dialysis patient, current kidney transplant recipient</i> • Dana Deighton, Director of Communications and Engagement, Melanoma Research Alliance (MRA); Member, Public Access to SunScreens (PASS) Coalition
<p>Read, Watch, and Learn!</p>	<ul style="list-style-type: none"> • 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 • 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!

	<ul style="list-style-type: none"> • Transplant Therapeutics and Innovation Must Evolve – Sign the Petition! • Become a KidneyVoter™! Register to vote today!
<p>10:35 a.m. – 10:55 a.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; 27-year kidney transplant patient</i></p>	<p>Discussion Topic #2: Opportunities and Barriers in the Advancement of the Next Generation of Organs – How U.S. Food and Drug Administration (FDA) Decisions Impact People Living with Kidney Failure</p> <p>Panelists:</p> <ul style="list-style-type: none"> • Winfred Williams, MD; Clinical Investigator, Associate Professor of Nephrology, Mass General Research Institute; Associate Professor of Medicine, Harvard Medical School; Physician, Nephrology, Massachusetts General Hospital; Deputy Editor, The New England Journal of Medicine • Kevin Fowler, Founder and CEO, The Voice of the Patient, Inc.; AAKP Ambassador; <i>pre-emptive kidney transplant recipient</i>
<p>Read, Watch, and Learn!</p>	<ul style="list-style-type: none"> • Xenotransplantation: Research and Ethics (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)
<p>Take Action!</p>	<ul style="list-style-type: none"> • Become a KidneyVoter™! Register to vote today!
<p>11:00 a.m. – 11:20 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 #3: Transformation Unfolds Across America’s Transplant System – Opportunities and Risks to Closely Watch</p> <p>Panelists:</p> <ul style="list-style-type: none"> • Matthew Cooper, MD; Chief of the Division of Transplantation in the Department of Surgery, Medical College of Wisconsin; Director of the Joint Solid Organ Transplantation Program, Froedtert Health and Children’s Wisconsin; Mark B. Adams Chair in Transplant Surgery; Past President of United Network for Organ Sharing (UNOS); 2020 AAKP Medal of Excellence Award Recipient • Steven Potter, MD, FACS; Professor, Surgery and Urology; Director, Pancreas Transplantation, MedStar Georgetown Transplant Institute; Georgetown University School of Medicine; Chair, ASTS Surgical Policy Assessment Committee; Vice Chair, OPTN Operations and Safety Committee; Immediate Past Chair, ASTS Legislative and Regulatory Committee; 2024 AAKP Medal of Excellence Award Recipient
<p>Read, Watch, and Learn!</p>	<ul style="list-style-type: none"> • Policy Roundtable: Transformation Unfolds Across American’s Transplant System (Watch OnDemand) • Read Now! Statement of Policy Principles and Solutions: Living Organ Donation – a joint statement by AST, ASTS, and AAKP • Read Now! Organ Donation Referral Improvement Act (H.R. 9939) • Under the Dome: Government Determinants of Health (GDoH) – The New Barrier on the Block (Watch OnDemand)

<p>Take Action!</p>	<ul style="list-style-type: none"> • Become a KidneyVoter™! Register to vote today!
<p>11:25 a.m. – 11:45 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 #4: Transformation Unfolds Across America’s Transplant System – Key Issues Targeted by Current and Emerging Legislation</p> <p>Panelists:</p> <ul style="list-style-type: none"> • Peggy Tighe, Principal, Powers, Pyles, Sutter & Verville PC; Legal Counsel, American Society of Transplant Surgeons (ASTS) • Alicia Hennie, Vice President, External Affairs; United Network for Organ Sharing (UNOS)
<p>Read, Watch, and Learn!</p>	<ul style="list-style-type: none"> • Policy Roundtable: Transformation Unfolds Across American’s Transplant System (Watch OnDemand) • Read Now! Statement of Policy Principles and Solutions: Living Organ Donation – a joint statement by AST, ASTS, and AAKP • Read Now! Organ Donation Referral Improvement Act (H.R. 9939) • Under the Dome: Government Determinants of Health (GDoH) – The New Barrier on the Block (Watch OnDemand)
<p>Take Action!</p>	<ul style="list-style-type: none"> • Become a KidneyVoter™! Register to vote today!
<p>11:50 a.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 #5: Misalignments in Federal Regulatory and Payment Decisions and the Consequences for Kidney Patients – How Decisions Made by the Centers for Medicare and Medicaid Services (CMS) Impact Unmet Patient Needs and the Future of Innovation</p> <p>Panelists:</p> <ul style="list-style-type: none"> • John Butler, President and CEO, Akebia Therapeutics • Chris Leibundguth, Director, Federal Government Affairs and Alliance Development, Baxter Healthcare Corporation • Erin Mistry, Executive Vice President, Chief Commercial Officer, CorMedix, Inc. • Tammy Gilon, Chief Executive Officer, Co-Founder, Laminate Medical • Steven Potter, MD, FACS; Professor, Surgery and Urology; Director, Pancreas Transplantation, MedStar Georgetown Transplant Institute; Georgetown University School of Medicine; Chair, ASTS Surgical Policy Assessment Committee; Vice Chair, OPTN Operations and Safety Committee; Immediate Past Chair, ASTS Legislative and Regulatory Committee; 2024 AAKP Medal of Excellence Award Recipient
<p>Read, Watch, and Learn!</p>	<ul style="list-style-type: none"> • Policy Roundtable: Misalignments in Regulatory and Payment Determine Patient Access (Watch OnDemand) • Policy Roundtable: HHS/CMS Policy Change that Disrupted Transplant Diagnostic Testing Access (Watch OnDemand)

	<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) • Read Now! VasQ® Extravascular Support Granted Transitional Pass Through (TPT) Payment • From Concept to Consumer: Understanding the Product Development Lifecycle (Watch OnDemand) • Learn about AAKP’s Patient Voice Patient Choice™
<p>Take Action!</p>	<ul style="list-style-type: none"> • Become a KidneyVoter™! Register to vote today!
<p>12:25 p.m. – 12:40 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 #6: Building and Retaining the Expert Workforce Required for the Future of Patient-Centered Kidney Care</p> <p>Panelists:</p> <ul style="list-style-type: none"> • Robert Blaser, Director, Public Policy, Renal Physicians Association (RPA)
<p>Take Action!</p>	<ul style="list-style-type: none"> • Become a KidneyVoter™! Register to vote today!

<p>12:45 p.m. – 1:05 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 #7: Kidney Disease Screening – Implications and Costs to People, Taxpayers, Employers, and Disease Prevention Efforts if the Federal Government Fails to Embrace Kidney Disease Screening</p> <p>Panelists:</p> <ul style="list-style-type: none"> • Barry Smith, PhD, MD; President, Applied Medical Research, Dreyfus Health Policy and Research Center; Rise Up New York; AAKP National Board of Director • Tamara Windau-Melmer, MPH; Director, Advocacy Relations, Cardiovascular and Renal, Bayer U.S., LLC
<p>Read, Watch, and Learn!</p>	<ul style="list-style-type: none"> • Policy Roundtable: Early Kidney Disease Detection and Intervention (Watch OnDemand) • Impacting Community Health: Acting Locally, Thinking Globally (Watch OnDemand) • Early Prediction of Diabetic Kidney Disease and Heart Failure (Watch OnDemand) • Innovations in Kidney Disease: From “Bench to Bedside,” National Institute of Standards and Technology (Watch OnDemand) • Technology to Support Early Identification of Kidney Disease (Watch OnDemand) • 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>1:05 p.m. – 1:10 p.m.</p>	<p>Closing 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>

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:

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