



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><b>10:00 a.m. – 10:10 a.m.</b></p>	<p><b><i>Welcome and Opening Remarks</i></b> 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><b>10:10 a.m. – 10:30 a.m.</b></p> <p><b>Moderator:</b> 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><b><i>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</i></b></p> <p><b>Panelist:</b></p> <ul style="list-style-type: none"> <li>• 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</li> </ul>
<p><b>Read and Learn!</b></p>	<ul style="list-style-type: none"> <li>• <a href="#">Read Now! Kidney Patients Put Innovation and Access on National Agenda</a></li> <li>• <a href="#">About the United States Preventative Services Taskforce</a></li> <li>• <a href="#">ICYMI! AAKP CKD Awareness Roundtable</a> available OnDemand</li> <li>• Learn about AAKP’s <a href="#">Patient Voice Patient Choice™</a></li> </ul>
<p><b>Take Action!</b></p>	<ul style="list-style-type: none"> <li>• <b>Kidney Patients Need Access to NEW, FDA-Approved, SAFE Treatments – <a href="#">Sign the Petition!</a></b></li> <li>• <b>Become a KidneyVoter™! <a href="#">Register to vote today!</a></b></li> </ul>
<p><b>10:35 a.m. – 11:15 a.m.</b></p> <p><b>Moderator:</b> 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><b><i>Discussion Topic #2: Opportunities and Challenges for Stakeholders - Federal Policy Implementation/Interpretations Impacting Kidney Patients and Medical Innovation</i></b></p> <p><b>Part 1: Transformation Unfolds Across America’s Transplant System</b></p> <p><b>Panelists:</b></p> <ul style="list-style-type: none"> <li>• Alicia Hennie, Vice President, External Affairs; United Network of Organ Sharing (UNOS)</li> <li>• Peggy Tighe, Principal, Powers, Pyles, Sutter &amp; Verville PC; Legal Counsel, American Society of Transplant Surgeons (ASTS)</li> </ul>

	<ul style="list-style-type: none"> <li>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></li> </ul> <p><b>Part 2: Misalignments in Federal Regulatory and Payment Decisions Determine Patient Access to Vital Innovations</b></p> <p><b>Panelists:</b></p> <ul style="list-style-type: none"> <li>Chris Bowlin, Executive Director, Head of Public Policy and Government Affairs, CorMedix, Inc.</li> <li>Laura A. Williams, MD, MPH, Chief Medical Officer, Ardelyx, Inc.</li> <li>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></li> </ul>
<p><b>Read and Learn!</b></p>	<ul style="list-style-type: none"> <li><a href="#">Read Now!</a> <b>Statement of Policy Principles and Solutions: Living Organ Donation – a joint statement by AST, ASTS, and AAKP</b></li> <li><a href="#">Read Now!</a> <b>Government Determinants of Health Must Not Impede Long-Term Access to Infection Prevention Innovations</b></li> <li><a href="#">Issue of Serious Concern:</a> <b>Infection Prevention Innovation and Patient Access</b></li> <li><a href="#">Read Now!</a> <b>Members of Congress urge CMS to properly classify the first and only FDA-approved antimicrobial catheter lock solution to ensure all patients have access</b></li> <li><b>Read the Home Dialysis Risk Prevention Act (<a href="#">H.R. 3118</a>)</b></li> <li><b>Learn about AAKP’s <a href="#">Patient Voice Patient Choice™</a></b></li> </ul>
<p><b>Take Action!</b></p>	<ul style="list-style-type: none"> <li><a href="#">Ensure Detection of Venous Needle Dislodgement for Home Hemodialysis Patients – Visit AAKP’s Action Center</a></li> <li><b>Become a KidneyVoter™! <a href="#">Register to vote today!</a></b></li> </ul>
<p><b>11:20 a.m. – 11:40 a.m.</b></p> <p><b>Moderator:</b> 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><b>Discussion Topic #3: The Long and Winding Road...FDA’s Decades-Long Effort to Jumpstart the Next Generation of Transplant Drugs</b></p> <p><b>Panelists:</b></p> <ul style="list-style-type: none"> <li>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</li> <li>Kevin Fowler, Founder and CEO, The Voice of the Patient, Inc.; AAKP Ambassador; <i>pre-emptive kidney transplant recipient</i></li> </ul>
<p><b>Read and Learn!</b></p>	<ul style="list-style-type: none"> <li><a href="#">Read Now!</a> <b>One Kidney for Life</b></li> <li><a href="#">Read Now!</a> <b>Innovation in Transplantation: Accountability, Collaboration, and the Value of the Patient Voice</b></li> <li><a href="#">Read Now!</a> <b>The Value of the Patient Voice in Kidney Transplantation</b></li> </ul>

	<ul style="list-style-type: none"> <li>• <a href="#">Issue of Serious Concern: America’s Next Generation of Transplant Drugs</a></li> <li>• Learn about AAKP’s <a href="#">Patient Voice Patient Choice™</a></li> </ul>
<p><b>Take Action!</b></p>	<ul style="list-style-type: none"> <li>• <b>Raise Your Voice...Take the AAKP <a href="#">Flash Survey on Transplant Medication!</a></b></li> <li>• <b>Transplant Therapeutics and Innovation Must Evolve – <a href="#">Sign the Petition!</a></b></li> <li>• <b>Become a KidneyVoter™! <a href="#">Register to vote today!</a></b></li> </ul>
<p><b>11:40 a.m. – 11:55 p.m.</b></p> <p><b>Moderator:</b> 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><b>Fireside Chat: <i>The Body’s Keeper: A Social History of Kidney Failure and Its Treatments</i></b></p> <ul style="list-style-type: none"> <li>• Paul L. Kimmel, MD, MACP, FRCP, FASN; Clinical Professor of Medicine, Emeritus, George Washington University</li> </ul>
<p><b>Take Action!</b></p>	<ul style="list-style-type: none"> <li>• <a href="#">Order Your Copy Today! <i>The Body’s Keeper: A Social History of Kidney Failure and Its Treatments</i></a></li> </ul>
<p><b>12:00 p.m. – 12:20 p.m.</b></p> <p><b>Moderator:</b> 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><b>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</b></p> <p><b>Panelists:</b></p> <ul style="list-style-type: none"> <li>• 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</li> <li>• 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></li> </ul>
<p><b>Read and Learn!</b></p>	<ul style="list-style-type: none"> <li>• <a href="#">Read Now! Kidney Patients Target Medicare Transplant Double Standard</a></li> <li>• <a href="#">Read Now! A Closer Look – Molecular Blood Testing and Kidney Transplant Surveillance – A New Double Standard For Medicare Patients</a></li> <li>• <a href="#">Read Now! Congressional Black Caucus expresses concern with recent actions taken by MoIDX to restrict access to post-transplant testing</a></li> <li>• <a href="#">Read Now! Bipartisan Letters Members of Congress expresses concern with recent actions taken by MoIDX to restrict access to post-transplant testing (<a href="#">August 2023 Letter</a>) (<a href="#">October 2023 Letter</a>)</a></li> </ul>

	<ul style="list-style-type: none"> <li>• <a href="#">Read Now!</a> Health Equity in Transplant (HEiTC), New Report Published by AAKP Exposes Alarming Medicare Paradox</li> <li>• <a href="#">Read Now!</a> FDA November 9, 2023 Meeting Transcript – Endpoints and Trial Designs to Advance Drug Development in Kidney Transplantation</li> <li>• <a href="#">Issue of Serious Concern:</a> Access to Diagnostic Testing for Transplant Recipients</li> <li>• <a href="#">Watch OnDemand!</a> Remarks by AAKP Paul Conway, Chair of Policy &amp; Global Affairs: MoIDX Open Hearing on Transplant Test (partial)</li> <li>• <a href="#">Watch OnDemand!</a> Remarks by AAKP Paul Conway, Chair of Policy &amp; Global Affairs: MoIDX Open Hearing on Transplant Test (full)</li> <li>• <a href="#">Read Now! Real Clear Politics</a> - Medicare’s Private Contractors are Gaslighting Transplant Patients</li> <li>• <a href="#">Read Now!</a> The Hill – New Health Equity Coalition</li> <li>• <a href="#">Read Now!</a> The Wall Street Journal Editorials (<a href="#">Sept. 10<sup>th</sup> Editorial</a>) (<a href="#">Sept. 22<sup>nd</sup> Editorial</a>) (<a href="#">Sept. 26<sup>th</sup> Editorial</a>)</li> <li>• Learn about AAKP’s <a href="#">Patient Voice Patient Choice™</a></li> </ul>
Take Action!	<ul style="list-style-type: none"> <li>• Become a KidneyVoter™! <a href="#">Register to vote today!</a></li> </ul>
12:20 p.m. – 12:30 p.m.	<p><b>Closing Observations</b>  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**

