Kidney Patient Consumer Policy Roundtable

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

National Press Club * Virtual * February 20, 2024

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<th>Time</th>
<th>Session</th>
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<td>10:00 a.m. – 10:10 a.m.</td>
<td><strong>Welcome and Opening Remarks</strong>&lt;br&gt;Edward V. Hickey, III, USMC, President, American Association of Kidney Patients (AAKP); Chair, AAKP Veterans Health Initiative; former U.S. Congressional senior staff member; <em>chronic kidney disease patient</em></td>
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| 10:10 a.m. – 10:30 a.m. | **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**  
**Panelist:**<br>• 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 |
| Read and Learn!          | • Read Now! 12 Tips to Nephrology Teams Supporting Patients with Advanced Kidney Disease (*Patient Voice editorial, CJASN*)  
**Read and Learn!**  
• 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™*  
**Take Action!**  
• Kidney Patients Need Access to NEW, FDA-Approved, SAFE Treatments – Sign the Petition!  
• Become a KidneyVoter™! Register to vote today! |
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<tr>
<th>Time</th>
<th>Discussion Topic #2: Opportunities and Challenges for Stakeholders - Federal Policy Implementation/Interpretations Impacting Kidney Patients and Medical Innovation</th>
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<td>10:35 a.m. – 11:15 a.m.</td>
<td>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; chronic kidney disease patient</td>
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| Part 1: Transformation Unfolds Across America’s Transplant System Panelists: |   - 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; former dialysis patient; 26-year kidney transplant patient |
   - 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; former dialysis patient; 26-year kidney transplant patient |

**Read and Learn!**
- **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
- Learn about AAKP’s **Patient Voice Patient Choice™**

**Take Action!**
- **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!](https://www.vote.org/register)

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<th>Time</th>
<th>Discussion Topic #3: The Long and Winding Road...FDA’s Decades-Long Effort to Jumpstart the Next Generation of Transplant Drugs</th>
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<td>11:20 a.m. – 11:40 a.m.</td>
<td>Moderator:</td>
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<td>Panelists:</td>
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| Edward V. Hickey, III, USMC, President, American Association of Kidney Patients (AAKP); Chair, AAKP Veterans Health Initiative; former U.S. Congressional senior staff member; chronic kidney disease patient | 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; pre-emptive kidney transplant recipient |
|---|---|
| **Read and Learn!** | **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™** |
| **Take Action!** | **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!** |
| 11:40 a.m. – 11:55 p.m. | **Fireside Chat:** *The Body’s Keeper: A Social History of Kidney Failure and Its Treatments*  
- Paul L. Kimmel, MD, MACP, FRCP, FASN; Clinical Professor of Medicine, Emeritus, George Washington University |
| **Take Action!** | **Order Your Copy Today!** *The Body’s Keeper: A Social History of Kidney Failure and Its Treatments* |
| 12:00 p.m. – 12:20 p.m. | **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  
**Panelists:**  
- 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 |
Paul T. Conway, Chair of Policy and Global Affairs, American Association of Kidney Patients; former Chief of Staff, U.S. Department of Labor; former dialysis patient; 26-year kidney transplant patient

Read and Learn!

- **Read Now!** Kidney Patients Target Medicare Transplant Double Standard
- **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
- **Learn about AAKP’s** Patient Voice Patient Choice™

Take Action!

- **Become a KidneyVoter™!** [Register to vote today!](#)

12:20 p.m. – 12:30 p.m.

**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; chronic kidney disease patient
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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Decade of the Kidney: American Association of Kidney Patients