### 6th Annual Public Policy Summit

*Issues and Implications: What Kidney Patients Need to Know*

**Virtual Event * July 28, 2023**

*All sessions are in Eastern time*

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<th>Time</th>
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<td>10:00 a.m. – 10:15 a.m.</td>
<td><strong>Welcome and Opening Remarks:</strong> Edward V. Hickey, III, USMC, President, AAKP; Chair, AAKP Veterans Health Initiative; former senior staff member, U.S. House of Representatives, United States Congress; <em>chronic kidney disease patient</em></td>
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| 10:15 a.m. – 10:55 a.m. | **Discussion Topic:** The Great Flaw: How Quality Adjusted Life Years (QALYs) Promote Ethical Problems and Impede Access to Therapies and Drug Innovation  
**Moderator:** Paul T. Conway, Chair of Policy & Global Affairs, past president, AAKP; former Chief of Staff, U.S. Department of Labor; *former dialysis patient; 26-year kidney transplant recipient*  
**Panelists:**  
• Josie Cooper, Executive Director; Alliance for Patient Access (AfPA)  
• Adina Lasser, Manager, Public Policy; Alliance for Aging Research  
• Alvin Lin, Vice President; Vera Therapeutics  
• Richard Knight, Immediate Past President, AAKP; former senior staff member, U.S. House of Representatives, United States Congress; *former dialysis patient, 16-year transplant recipient* |
| 11:05 a.m. – 11:45 a.m. | **Discussion Topic:** How Payment Policies Can Disrupt or Impact Patient Care Choice and Access  
**Moderator:** Paul T. Conway, Chair of Policy & Global Affairs, past president, AAKP; former Chief of Staff, U.S. Department of Labor; *former dialysis patient, 26-year kidney transplant recipient* |

**Take Action!**  
- Read...**Protecting Health Care for All Patients Act (H.R. 485)**  
- Read...**Community Stakeholder Letter!**  
- View **Report**...Partnership to Improve Patient Care Chairman, Tony Coelho – “A look at the Use of Patient-Centered Outcomes in Value Assessment”  
- Watch OnDemand...**How will Medicare Negotiate Drug Prices? What Patients Need to Know** (*Video*)  
- Send a letter to YOUR Congressional Leaders (**TAKE ACTION!**)
Panelists:
- Joel Keralis, Legislative Assistant, The Honorable Adrian Smith (R-NE), Member, U.S. House of Representatives, United States Congress; Sponsor, Home Dialysis Risk Prevention Act (H.R. 3118)
- Nieltje Gedney, Executive Director; Home Dialyzors United (HDU); AAKP Ambassador; 9-year home dialysis patient
- Erin Mistry, Chief Commercial Officer; CorMedix, Inc.
- Kevin Bernier, Executive Director; U.S. Advocacy Relations, Bayer Pharmaceuticals

Take Action!
- Read the Home Dialysis Risk Prevention Act (H.R. 3118)
- Learn about AAKP’s Patient Voice Patient Choice™
- Raise Your Voice...Ensure Access to All FDA Approved Drug Treatments – Sign Petition!
- Visit the AAKP Action Center to TAKE ACTION!

11:55 a.m. – 12:25 p.m. Discussion Topic: Issues Impacting Living Organ Donation and Living Donor Protections

Moderator: Edward V. Hickey, III, USMC, President, AAKP; Chair, AAKP Veterans Health Initiative; former senior staff member, U.S. House of Representatives; chronic kidney disease patient

Special Guest:
- The Honorable Jerrold Nadler (D-NY), Member, U.S. House of Representatives, United States Congress; Co-Sponsor, Living Donor Protection Act (H.R. 2923 / S. 1384)

Panelists:
- Anita Sites, MSN, RN, AG-ACNP-BC, CCTC, Advanced Practice Provider-Transplant Surgery, Lead Living Donor Transplant Coordinator, University of Virginia Transplant Department; Board of Directors, Councilor-at-Large, NATCO, The Organization for Donation and Transplant Professionals
- Suzanne Ruff, AAKP Treasurer, AAKP Ambassador; author, The Reluctant Donor; living kidney donor

Take Action!
- Read...Living Donor Protection Act (H.R. 2923 / S. 1384)
- Send a letter to YOUR Congressional Leaders (TAKE ACTION!)
- Read the Press Release...Congress Targets Bias Against Living Organ Donors

12:35 p.m. – 12:55 p.m. Discussion Topic: Issues Impacting Living Organ Donation and Living Donor Protections and Assistance – Supportive Services

Moderator: Edward V. Hickey, III, USMC, President, AAKP; Chair, AAKP Veterans Health Initiative; former senior staff member, U.S. House of Representatives, United States Congress; chronic kidney disease patient
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<th><strong>Panelists:</strong></th>
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<td>Marie-Claire Walters; Senior Coordinator, National Living Donor Assistance Center (NLDAC), American Society of Transplant Surgeons (ASTS)</td>
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<td>David Rodriguez, AAKP Board of Directors, AAKP Ambassador; <em>kidney and liver transplant recipient</em></td>
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<td>Jennifer Jones, USMC, AAKP Vice President, AAKP Ambassador; <em>two-time kidney transplant recipient</em></td>
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**Take Action!**
- Learn more...National Living Donor Assistance Center
- Watch OnDemand...Understanding the National Living Donor Assistance Center

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<th><strong>1:05 p.m. – 1:45 p.m.</strong></th>
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<td><strong>Discussion Topic:</strong> <em>The Future of Transplant Drug Innovation</em></td>
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<td><strong>Moderator:</strong> Paul T. Conway, Chair of Policy &amp; Global Affairs, past president, AAKP; former Chief of Staff, U.S. Department of Labor; <em>former dialysis patient; 26-year kidney transplant recipient</em></td>
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**Panelists:**
- Ericka Downey, AAKP Ambassador, _living kidney donor_
- 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); Past President, American Society of Transplantation (AST)
- Karin Hehenberger, MD, PhD, Founder and CEO, Lyfebulb, _two-time kidney transplant recipient_
- Jonathan Haydak, AAKP Ambassador, _3-year kidney transplant recipient_

**Take Action!**
- Raise Your Voice...Take the AAKP Flash Survey on Transplant Medication!
- Raise Your Voice...Transplant Therapeutics and Innovation Must Evolve – Sign Petition!

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<td><strong>Closing Observations:</strong> Paul T. Conway, Chair of Policy &amp; Global Affairs, past president, AAKP; former Chief of Staff, U.S. Department of Labor; <em>former dialysis patient, 26-year kidney transplant recipient</em></td>
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