



American Association of Kidney Patients
aakp.org

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

<p>10:00 a.m. – 10:15 a.m.</p>	<p>Welcome and Opening Remarks: Edward V. Hickey, III, USMC, President, AAKP; Chair, AAKP Veterans Health Initiative; former senior staff member, U.S. House of Representatives, United States Congress; <i>chronic kidney disease patient</i></p>
<p>10:15 a.m. – 10:55 a.m.</p>	<p>Discussion Topic: <i>The Great Flaw: How Quality Adjusted Life Years (QALYs) Promote Ethical Problems and Impede Access to Therapies and Drug Innovation</i></p> <p>Moderator: Paul T. Conway, Chair of Policy & Global Affairs, past president, AAKP; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 26-year kidney transplant recipient</i></p> <p>Panelists:</p> <ul style="list-style-type: none"> • 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; <i>former dialysis patient, 16-year transplant recipient</i>
<p>Take Action!</p>	<ul style="list-style-type: none"> • 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!)
<p>11:05 a.m. – 11:45 a.m.</p>	<p>Discussion Topic: <i>How Payment Policies Can Disrupt or Impact Patient Care Choice and Access</i></p> <p>Moderator: Paul T. Conway, Chair of Policy & Global Affairs, past president, AAKP; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient, 26-year kidney transplant recipient</i></p>

	<p>Panelists:</p> <ul style="list-style-type: none"> • 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; <i>9-year home dialysis patient</i> • Erin Mistry, Chief Commercial Officer; CorMedix, Inc. • Kevin Bernier, Executive Director; U.S. Advocacy Relations, Bayer Pharmaceuticals
<p>Take Action!</p>	<ul style="list-style-type: none"> • <i>Read the Home Dialysis Risk Prevention Act (H.R. 3118)</i> • <i>Learn about AAKP's Patient Voice Patient Choice™</i> • <i>Raise Your Voice...Ensure Access to All FDA Approved Drug Treatments – Sign Petition!</i> • <i>Visit the AAKP Action Center to TAKE ACTION!</i>
<p>11:55 a.m. – 12:25 p.m.</p>	<p><i>Discussion Topic: Issues Impacting Living Organ Donation and Living Donor Protections</i></p> <p>Moderator: Edward V. Hickey, III, USMC, President, AAKP; Chair, AAKP Veterans Health Initiative; former senior staff member, U.S. House of Representatives; <i>chronic kidney disease patient</i></p> <p>Special Guest:</p> <ul style="list-style-type: none"> • 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) <p>Panelists:</p> <ul style="list-style-type: none"> • 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, <i>The Reluctant Donor, living kidney donor</i>
<p>Take Action!</p>	<ul style="list-style-type: none"> • <i>Read...Living Donor Protection Act (H.R. 2923 / S. 1384)</i> • <i>Send a letter to YOUR Congressional Leaders (TAKE ACTION!)</i> • <i>Read the Press Release...Congress Targets Bias Against Living Organ Donors</i>
<p>12:35 p.m. – 12:55 p.m.</p>	<p><i>Discussion Topic: Issues Impacting Living Organ Donation and Living Donor Protections and Assistance – Supportive Services</i></p> <p>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; <i>chronic kidney disease patient</i></p>

	<p>Panelists:</p> <ul style="list-style-type: none"> • Marie-Claire Walters; Senior Coordinator, National Living Donor Assistance Center (NLDAC), American Society of Transplant Surgeons (ASTS) • David Rodriguez, AAKP Board of Directors, AAKP Ambassador; <i>kidney and liver transplant recipient</i> • Jennifer Jones, USMC, AAKP Vice President, AAKP Ambassador; <i>two-time kidney transplant recipient</i>
<p>Take Action!</p>	<ul style="list-style-type: none"> • <u>Learn more...National Living Donor Assistance Center</u> • <u>Watch OnDemand...Understanding the National Living Donor Assistance Center</u>
<p>1:05 p.m. – 1:45 p.m.</p>	<p>Discussion Topic: <i>The Future of Transplant Drug Innovation</i></p> <p>Moderator: Paul T. Conway, Chair of Policy & Global Affairs, past president, AAKP; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient; 26-year kidney transplant recipient</i></p> <p>Panelists:</p> <ul style="list-style-type: none"> • Ericka Downey, AAKP Ambassador, <i>living kidney donor</i> • 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, <i>two-time kidney transplant recipient</i> • Jonathan Haydak, AAKP Ambassador, <i>3-year kidney transplant recipient</i>
<p>Take Action!</p>	<ul style="list-style-type: none"> • <i>Raise Your Voice...Take the AAKP <u>Flash Survey on Transplant Medication!</u></i> • <i>Raise Your Voice...Transplant Therapeutics and Innovation Must Evolve – <u>Sign Petition!</u></i>
<p>1:45 p.m. – 2:00 p.m.</p>	<p>Closing Observations: Paul T. Conway, Chair of Policy & Global Affairs, past president, AAKP; former Chief of Staff, U.S. Department of Labor; <i>former dialysis patient, 26-year kidney transplant recipient</i></p>