



# AAKP 4<sup>th</sup> ANNUAL POLICY SUMMIT

## *Patient Voice & Patient Choice:*

*Patient voices at the policy table today...  
determine tomorrow's innovations & patient care choices.*

**June 17, 2021**

<b>Time</b>	<b>Session</b>	<b>Speaker(s)</b>
10:00 a.m.	<b>4<sup>th</sup> Annual Policy Summit - Welcome</b>	<b>Richard Knight, AAKP President, former dialysis patient, current transplant recipient</b>
	<b>AAKP Remembers Brian Hess, former Board of Director, Ambassador (July 21, 1981 – December 3, 2020)</b>	<b>Laura Hess, sister of Brian Hess</b>
	<b>AAKP Policy Summit Purpose</b>	<b>Paul T. Conway, AAKP Chair of Policy &amp; Global Affairs, former dialysis patient, current transplant recipient</b>
	<p><b>Opportunities: Current and Emerging Policy and Legislative Issues (Part 1)</b></p> <ul style="list-style-type: none"> <li>• The Kidney Project: Updates to an Artificial Implantable Organ</li> <li>• Current Hill Environment and Relevant Legislative Priorities</li> <li>• Advancing Home Dialysis Care: Aligning Policies Across Agencies</li> <li>• Rare Kidney Disease Revolution</li> </ul>	<p><b>Moderator:</b> Paul T. Conway, AAKP Chair of Policy &amp; Global Affairs, <i>former dialysis patient, current transplant recipient</i></p> <p><b>Session Presenters:</b></p> <ul style="list-style-type: none"> <li>• Shuvo Roy, PhD; Technical Director, The Kidney Project; Professor, Departments of Bioengineering and Therapeutics Sciences and Surgery</li> <li>• Rob Blaser, Director of Public Policy, Renal Physicians Association (RPA)</li> <li>• Chris Leibundguth, Director, Federal Government Affairs and Alliance Development, Baxter Healthcare Corporation</li> <li>• Chris Porter, Vice President of Government Affairs and Policy, Traverre Therapeutics</li> </ul>

5 MIN	<b>Wellness Break</b>	<b>Thank You to Our Sponsors!</b>
	<p><b>Opportunities: Research and Policy on the Horizon</b></p> <ul style="list-style-type: none"> <li>• Use of Race in eGFR – Is it a relevant measure?</li> <li>• The Scientific Registry of Transplant Recipients: Information to Support Transplant System Evaluation and Improvement</li> <li>• Strategies to Reduce Kidney Discard</li> <li>• Advancing Your Kidney Health Through Optimal Medication Management</li> <li>• Community Policy: A United Effort to Create and Enhance the National Living Donor Assistance Center to Increase Kidney Transplantation</li> </ul>	<p><b>Moderator: Richard Knight, AAKP President, former dialysis patient, current transplant recipient</b></p> <p><b>Session Presenters:</b></p> <ul style="list-style-type: none"> <li>• Crystal A. Gadegbeku, MD, FASN, Founding Member, Diversity, and Inclusion Committee; Member, Public Policy Board, American Society of Nephrology (ASN)</li> <li>• Jon Snyder, PhD, Director, Scientific Registry of Transplant Recipients (SRTR); Director, Transplant Epidemiology, Hennepin Healthcare Research Institute</li> <li>• Lloyd E. Ratner, MD, MPH, FACS, FICS (Hon), Director, Renal and Pancreatic Transplantation, Department of Surgery Columbia University Medical Center; Immediate Past President, American Society of Transplant Surgeons (ASTS) – transplant professional perspective</li> <li>• Wendy L. St. Peter, PharmD, FCCP, FASN, FNKF, Professor, College of Pharmacy, University of Minnesota</li> <li>• Kim A. Gifford, MBA, Program Manager, National Living Donor Assistance Center, American Society of Transplant Surgeons</li> </ul>
5 MIN	<b>Wellness Break</b>	<b>Thank You to Our Sponsors!</b>
	<p><b>AAKP National President’s Award</b></p> <p><i>Presented to Griffin P. Rodgers, MD, MACP, Director, National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH)</i></p>	<p><b>Award Presentation by Richard Knight, AAKP President, former dialysis patient, current transplant recipient</b></p>
5 MIN	<b>Wellness Break</b>	<b>Thank You to Our Sponsors!</b>

	<p><b>Challenges: Innovations Hitting the National Radar - Barriers to Innovation, Patient Choice, and Access to Care (Part 1)</b></p> <ul style="list-style-type: none"> <li>• Advancements in Anemia and the Call for Complete Patient Access</li> <li>• Improving Access to Transplant Care, Telehealth, and Technology to Enable Patients Along the Transplant Journey</li> <li>• Early Identification and Intervention Advancements in Diabetic Kidney Disease</li> <li>• Managing Hyperparathyroidism in Hemodialysis</li> </ul>	<p><b>Moderator:</b> Edward V. Hickey, III, USMC veteran; Vice President, AAKP; Chair of Veterans Health Initiative; <i>current chronic kidney disease patient</i></p> <p><b>Session Presenters:</b></p> <ul style="list-style-type: none"> <li>• John Butler, President and CEO, Akebia Therapeutics, Inc.</li> <li>• Reginald Seeto, President and CEO, CareDx, Inc.</li> <li>• Amit Sharma, MD, U.S. Vice President of Medical Affairs, Cardiovascular &amp; Renal, Bayer Pharmaceuticals</li> <li>• Kevin Martin, MD, Professor of Internal Medicine, Director of the Division of Nephrology, St. Louis University</li> </ul>
5 MIN	<b>Wellness Break</b>	<b>Thank You to Our Sponsors!</b>
	<p><b>Challenges: Innovations Hitting the National Radar - Barriers to Innovation, Patient Choice, and Access to Care (Part 2)</b></p> <ul style="list-style-type: none"> <li>• Barriers to Patient Choice and Access to Care</li> <li>• Paradigm shift: Equitable access to genetic testing</li> <li>• New Entry to an Existing Market: Do policies support innovation?</li> <li>• An Innovative Solution for Hemodialysis Patients: Challenges in Delivering a New Technology to Patients that Need Innovation the Most</li> </ul>	<p><b>Moderator:</b> Diana Clynes, Executive Director, AAKP</p> <p><b>Session Presenters:</b></p> <ul style="list-style-type: none"> <li>• Eric Turowski, Vice President of Market Access, Aurinia Pharmaceuticals</li> <li>• Andrew E. Lazar, MD, Chief, Department of Nephrology, Ahuja Medical Center</li> <li>• Tricia Brooks, Vice President, Government Affairs and Policy, Ardelyx, Inc.</li> <li>• Shawn Gage, PA-C, Founder and Director, Clinical Operations, InnAVasc Medical, Inc.</li> </ul>
	<p><b>End of day observations</b></p> <p><b>Look Ahead to 2022</b></p>	<p><b>Richard Knight, AAKP President, former dialysis patient, current transplant recipient</b></p> <p><b>Paul T. Conway, AAKP Chair of Policy &amp; Global Affairs, dialysis patient, current transplant recipient</b></p>

\*Session start times are approximate.

## **AAKP After Hours – Featured OnDemand Content**

<p><b>AAKP Addresses Clinical Trials, Diversity, &amp; Inclusion</b></p>	<ul style="list-style-type: none"> <li>• <b>Clinical Trials: Expanding Opportunities for All Kidney Patients in the Midst of COVID-19 and Beyond</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Richard Knight, AAKP President, presents Patient Perspective on Diversity in COVID-19 Clinical Trials</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Paul T. Conway, AAKP Chair of Policy and Global Affairs’ public comment to National Academies of Sciences’ draft COVID-19 Vaccine Allocation framework</b> (<a href="#">Click to Watch</a>)</li> </ul>
<p><b>AAKP Allies &amp; Medical Expert Filmed Segments on Clinical Trials</b></p>	<ul style="list-style-type: none"> <li>• <b>Clinical Trials: Best Practices for Inclusivity in Rare/Genetic Conditions</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Who Is at Risk? Understanding the Connection Between APOL 1 Gene and Kidney Diseases</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Kidney Research and Clinical Trials: Patients Guiding Advancements (Session 1)</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Kidney Research and Clinical Trials: Patients Guiding Advancements (Session 2)</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>How Innovation and Community Engagement Furthers Kidney Research at NIDDK</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Clinical Trials in Kidney Disease: International Perspective on Patient Engagement</b> (<a href="#">Click to Watch</a>)</li> </ul>
<p><b>AAKP Allies &amp; Medical Expert Filmed Segments on Diabetic Kidney Disease</b></p>	<ul style="list-style-type: none"> <li>• <b>Kidney Disease Management and Preemptive Treatments for Diabetic Kidney Disease</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Emerging Research in Kidney Disease: Preemptive Treatments for Diabetic Kidney Disease</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Treatment for CKD in Diabetes</b> (<a href="#">Click to Watch</a>)</li> </ul>
<p><b>AAKP Allies &amp; Medical Expert Filmed Segments on Home Dialysis Therapies</b></p>	<ul style="list-style-type: none"> <li>• <b>A Global Need to Support an Ever-Growing Home Dialysis Community</b> (<a href="#">Click to Watch</a>)</li> </ul>
<p><b>AAKP Allies &amp; Medical Expert Filmed Segments on Emerging Research</b></p>	<ul style="list-style-type: none"> <li>• <b>Identification and Diagnosis of Kidney Diseases: Kidney Precision Medicine Project</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Emerging Research with Global Implications: Advancements Toward Artificial Organs</b> (<a href="#">Click to Watch</a>) <ul style="list-style-type: none"> <li>○ <b>KidneyX Artificial Kidney Prize</b> (<a href="#">Click to Watch</a>)</li> <li>○ <b>The Kidney Project</b> (<a href="#">Click to Watch</a>)</li> <li>○ <b>WAK 3.0</b> (<a href="#">Click to Watch</a>)</li> </ul> </li> </ul>
<p><b>AAKP-hosted COVID-19 Educational Webinar Series</b></p>	<ul style="list-style-type: none"> <li>• <b>Coronavirus and Kidney Patients USA Centers for Disease Control Expert Webinar: Update on Vaccinations &amp; Variant Strains</b> hosted by AAKP (<a href="#">Click to Watch</a>)</li> <li>• <b>Kidney Patients and the COVID-19 Vaccine</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Coronavirus and Kidney Patients: Planning for a Safe Holiday Season</b> (<a href="#">Click to Watch</a>)</li> <li>• <b>Coronavirus and Kidney Patients USA Centers for Disease Control Expert Webinar</b> hosted by AAKP (<a href="#">Click to Watch</a>)</li> <li>• <b>Coronavirus and Transplant Patients: Get the Facts, Save a Life</b> hosted by AAKP in partnership with American Society of Transplantation and American Society of Transplant Surgeons (<a href="#">Click to Watch</a>)</li> </ul>

	<ul style="list-style-type: none"> <li>• Taking Care of Your Dialysis Access During the COVID-19 Pandemic (<a href="#">Click here to Watch</a>)</li> <li>• Fighting Coronavirus Upstream - What Early Stage Kidney Disease Patients Need to Know (<a href="#">Click to Watch</a>)</li> <li>• New American Telemedicine Policies &amp; Utilization in the COVID-19 Era: What Patients Should Know (<a href="#">Click to Watch</a>)</li> <li>• The USA Department of Veterans Affairs Kidney Program's Response to COVID-19 (<a href="#">Click to Watch</a>)</li> <li>• Kidney Patient Mental Health Management During COVID-19: Staying Connected while Staying at Home (<a href="#">Click to Watch</a>)</li> <li>• Kidney Patient Nutrition &amp; COVID-19: The Importance of Keeping it Kidney Friendly (<a href="#">Click Here to Watch</a>)</li> <li>• Clinical Trials: Expanding Opportunities for All Kidney Patients in the Midst of COVID-19 and Beyond (<a href="#">Click to Watch</a>)</li> <li>• Diversity and Inclusion in COVID-19 Trials: Insights and Tactics (<a href="#">Click to Watch</a>)</li> </ul>
<p><b>AAKP Allies &amp; Medical Expert Filmed Segments on COVID-19</b></p>	<ul style="list-style-type: none"> <li>• Top Health Concerns: COVID-19 Current Efforts on Variants and Need for Vaccinations (<a href="#">Click to Watch</a>)</li> <li>• Top Health Concerns: COVID-19 Implications on Transplant Patients (<a href="#">Click to Watch</a>)</li> <li>• America's Veterans: Kidney Health During COVID-19 (<a href="#">Click to Watch</a>)</li> <li>• How Innovation and Community Engagement Furthers Kidney Research at NIDDK (<a href="#">Click to Watch</a>)</li> <li>• Coronavirus: Treatment Immunosuppressed Populations during a Global Pandemic (<a href="#">Click to Watch</a>)</li> <li>• Coronavirus: Kidney Community Stakeholder Response to Global Pandemic (<a href="#">Click to Watch</a>)</li> <li>• Coronavirus: America's Largest Kidney Innovation Collaborative Responds (<a href="#">Click to Watch</a>)</li> <li>• Coronavirus: Observations of Healthcare Systems Responses to Pandemic (Nonprofit, Private, and VA) (<a href="#">Click to Watch</a>)</li> <li>• Coronavirus: Accelerating the Adoption of Telehealth &amp; Telemedicine (<a href="#">Click to Watch</a>)</li> <li>• Coronavirus: Transitioning Patients from Telehealth &amp; Telemedicine Back to In-person Care (<a href="#">Click to Watch</a>)</li> </ul>

**Watch all AAKP OnDemand Educational Content at**  
<http://bit.ly/AAKPOnDemand>