## AAKP 4th ANNUAL POLICY SUMMIT

**Patient Voice & Patient Choice:**

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

### June 17, 2021

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:00 a.m.</td>
<td><strong>4th Annual Policy Summit - Welcome</strong></td>
<td>Richard Knight, AAKP President, former dialysis patient, current transplant recipient</td>
</tr>
<tr>
<td></td>
<td><strong>AAKP Remembers Brian Hess, former Board of Director, Ambassador</strong></td>
<td>Laura Hess, sister of Brian Hess</td>
</tr>
<tr>
<td></td>
<td>(July 21, 1981 – December 3, 2020)</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>AAKP Policy Summit Purpose</strong></td>
<td>Paul T. Conway, AAKP Chair of Policy &amp; Global Affairs, former dialysis patient, current transplant recipient</td>
</tr>
<tr>
<td></td>
<td><strong>Opportunities: Current and Emerging Policy and Legislative Issues (Part 1)</strong></td>
<td>Moderator: Paul T. Conway, AAKP Chair of Policy &amp; Global Affairs, former dialysis patient, current transplant recipient</td>
</tr>
<tr>
<td></td>
<td>• The Kidney Project: Updates to an Artificial Implantable Organ</td>
<td>Session Presenters:</td>
</tr>
<tr>
<td></td>
<td>• Current Hill Environment and Relevant Legislative Priorities</td>
<td>- Shuvo Roy, PhD; Technical Director, The Kidney Project; Professor, Departments of Bioengineering and Therapeutics Sciences and Surgery</td>
</tr>
<tr>
<td></td>
<td>• Advancing Home Dialysis Care: Aligning Policies Across Agencies</td>
<td>- Rob Blaser, Director of Public Policy, Renal Physicians Association (RPA)</td>
</tr>
<tr>
<td></td>
<td>• Rare Kidney Disease Revolution</td>
<td>- Chris Leibundguth, Director, Federal Government Affairs and Alliance Development, Baxter Healthcare Corporation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Chris Porter, Vice President of Government Affairs and Policy, Travere Therapeutics</td>
</tr>
</tbody>
</table>
### Opportunities: Research and Policy on the Horizon
- Use of Race in eGFR – Is it a relevant measure?
- The Scientific Registry of Transplant Recipients: Information to Support Transplant System Evaluation and Improvement
- Strategies to Reduce Kidney Discard
- Advancing Your Kidney Health Through Optimal Medication Management
- Community Policy: A United Effort to Create and Enhance the National Living Donor Assistance Center to Increase Kidney Transplantation

**Moderator:** Richard Knight, AAKP President, *former dialysis patient, current transplant recipient*

**Session Presenters:**
- Crystal A. Gadegbeku, MD, FASN, Founding Member, Diversity, and Inclusion Committee; Member, Public Policy Board, American Society of Nephrology (ASN)
- Jon Snyder, PhD, Director, Scientific Registry of Transplant Recipients (SRTR); Director, Transplant Epidemiology, Hennepin Healthcare Research Institute
- 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
- Wendy L. St. Peter, PharmD, FCCP, FASN, FNKF, Professor, College of Pharmacy, University of Minnesota
- Kim A. Gifford, MBA, Program Manager, National Living Donor Assistance Center, American Society of Transplant Surgeons
<table>
<thead>
<tr>
<th>Challenges: Innovations Hitting the National Radar - Barriers to Innovation, Patient Choice, and Access to Care (Part 1)</th>
<th>Moderator: Edward V. Hickey, III, USMC veteran; Vice President, AAKP; Chair of Veterans Health Initiative; current chronic kidney disease patient</th>
</tr>
</thead>
</table>
| • Advancements in Anemia and the Call for Complete Patient Access  
• Improving Access to Transplant Care, Telehealth, and Technology to Enable Patients Along the Transplant Journey  
• Early Identification and Intervention Advancements in Diabetic Kidney Disease  
• Managing Hyperparathyroidism in Hemodialysis | Session Presenters:  
• John Butler, President and CEO, Akebia Therapeutics, Inc.  
• Reginald Seeto, President and CEO, CareDx, Inc.  
• Amit Sharma, MD, U.S. Vice President of Medical Affairs, Cardiovascular & Renal, Bayer Pharmaceuticals  
• Kevin Martin, MD, Professor of Internal Medicine, Director of the Division of Nephrology, St. Louis University |
| 5 MIN Wellness Break | Thank You to Our Sponsors! |
| Challenges: Innovations Hitting the National Radar - Barriers to Innovation, Patient Choice, and Access to Care (Part 2) | Moderator: Diana Clynes, Executive Director, AAKP |
| • Barriers to Patient Choice and Access to Care  
• Paradigm shift: Equitable access to genetic testing  
• New Entry to an Existing Market: Do policies support innovation?  
• An Innovative Solution for Hemodialysis Patients: Challenges in Delivering a New Technology to Patients that Need Innovation the Most | Session Presenters:  
• Eric Turowski, Vice President of Market Access, Aurinia Pharmaceuticals  
• Andrew E. Lazar, MD, Chief, Department of Nephrology, Ahuja Medical Center  
• Tricia Brooks, Vice President, Government Affairs and Policy, Ardelyx, Inc.  
• Shawn Gage, PA-C, Founder and Director, Clinical Operations, InnAVasc Medical, Inc. |
| End of day observations | Richard Knight, AAKP President, former dialysis patient, current transplant recipient |
| Look Ahead to 2022 | Paul T. Conway, AAKP Chair of Policy & Global Affairs, dialysis patient, current transplant recipient |

*Session start times are approximate.*
### AAKP After Hours – Featured OnDemand Content

<table>
<thead>
<tr>
<th>Category</th>
<th>Content</th>
</tr>
</thead>
</table>
| AAKP Addresses Clinical Trials, Diversity, & Inclusion | - Clinical Trials: Expanding Opportunities for All Kidney Patients in the Midst of COVID-19 and Beyond ([Click to Watch](#))  
- Richard Knight, AAKP President, presents Patient Perspective on Diversity in COVID-19 Clinical Trials ([Click to Watch](#))  
- Paul T. Conway, AAKP Chair of Policy and Global Affairs’ public comment to National Academies of Sciences’ draft COVID-19 Vaccine Allocation framework ([Click to Watch](#)) |
| AAKP Allies & Medical Expert Filmed Segments on Clinical Trials | - Clinical Trials: Best Practices for Inclusivity in Rare/Genetic Conditions ([Click to Watch](#))  
- Who Is at Risk? Understanding the Connection Between APOL 1 Gene and Kidney Diseases ([Click to Watch](#))  
- Kidney Research and Clinical Trials: Patients Guiding Advancements (Session 1) ([Click to Watch](#))  
- Kidney Research and Clinical Trials: Patients Guiding Advancements (Session 2) ([Click to Watch](#))  
- How Innovation and Community Engagement Furthers Kidney Research at NIDDK ([Click to Watch](#))  
- Clinical Trials in Kidney Disease: International Perspective on Patient Engagement ([Click to Watch](#)) |
| AAKP Allies & Medical Expert Filmed Segments on Diabetic Kidney Disease | - Kidney Disease Management and Preemptive Treatments for Diabetic Kidney Disease ([Click to Watch](#))  
- Emerging Research in Kidney Disease: Preemptive Treatments for Diabetic Kidney Disease ([Click to Watch](#))  
- Treatment for CKD in Diabetes ([Click to Watch](#)) |
| AAKP Allies & Medical Expert Filmed Segments on Home Dialysis Therapies | - A Global Need to Support an Ever-Growing Home Dialysis Community ([Click to Watch](#)) |
| AAKP Allies & Medical Expert Filmed Segments on Emerging Research | - Identification and Diagnosis of Kidney Diseases: Kidney Precision Medicine Project ([Click to Watch](#))  
- Emerging Research with Global Implications: Advancements Toward Artificial Organs ([Click to Watch](#))  
  - KidneyX Artificial Kidney Prize ([Click to Watch](#))  
  - The Kidney Project ([Click to Watch](#))  
  - WAK 3.0 ([Click to Watch](#)) |
| AAKP-hosted COVID-19 Educational Webinar Series | - Coronavirus and Kidney Patients USA Centers for Disease Control Expert Webinar: Update on Vaccinations & Variant Strains hosted by AAKP ([Click to Watch](#))  
- Kidney Patients and the COVID-19 Vaccine ([Click to Watch](#))  
- Coronavirus and Kidney Patients: Planning for a Safe Holiday Season ([Click to Watch](#))  
- Coronavirus and Kidney Patients USA Centers for Disease Control Expert Webinar hosted by AAKP ([Click to Watch](#))  
- Coronavirus and Transplant Patients: Get the Facts, Save a Life hosted by AAKP in partnership with American Society of Transplantation and American Society of Transplant Surgeons ([Click to Watch](#)) |
| AAKP Allies & Medical Expert Filmed Segments on COVID-19 | • Taking Care of Your Dialysis Access During the COVID-19 Pandemic ([Click here to Watch](http://bit.ly/AAKPOnDemand))  
• Fighting Coronavirus Upstream - What Early Stage Kidney Disease Patients Need to Know ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• The USA Department of Veterans Affairs Kidney Program's Response to COVID-19 ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Kidney Patient Mental Health Management During COVID-19: Staying Connected while Staying at Home ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Kidney Patient Nutrition & COVID-19: The Importance of Keeping it Kidney Friendly ([Click Here to Watch](http://bit.ly/AAKPOnDemand))  
• Clinical Trials: Expanding Opportunities for All Kidney Patients in the Midst of COVID-19 and Beyond ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Diversity and Inclusion in COVID-19 Trials: Insights and Tactics ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Top Health Concerns: COVID-19 Current Efforts on Variants and Need for Vaccinations ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Top Health Concerns: COVID-19 Implications on Transplant Patients ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• America’s Veterans: Kidney Health During COVID-19 ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• How Innovation and Community Engagement Furthers Kidney Research at NIDDK ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Coronavirus: Treatment Immunosuppressed Populations during a Global Pandemic ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Coronavirus: Kidney Community Stakeholder Response to Global Pandemic ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Coronavirus: America’s Largest Kidney Innovation Collaborative Responds ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Coronavirus: Observations of Healthcare Systems Responses to Pandemic (Nonprofit, Private, and VA) ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Coronavirus: Accelerating the Adoption of Telehealth & Telemedicine ([Click to Watch](http://bit.ly/AAKPOnDemand))  
• Coronavirus: Transitioning Patients from Telehealth & Telemedicine Back to In-person Care ([Click to Watch](http://bit.ly/AAKPOnDemand)) |