

AAKP AFTER HOURS

All content listed below are supplemental resources, supporting the topics of this year’s Global Summit. All videos/presentations and articles are available OnDemand by clicking on the links.

Reading list featuring articles by AAKP-affiliated patient authors

Author	Article	Category
<p>Edward V. Hickey, III, USMC, <i>AAKP President, Chair, AAKP Veterans Health Initiative, current chronic kidney disease patient</i></p> <p>Paul T. Conway, <i>AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient</i></p>	<p>COVID-19 and Palliative Care: Observations, Extrapolations, and Cautions</p>	<p>COVID-19</p>
<p>Paul T. Conway, <i>AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient</i></p>	<p>An Honorable and Ongoing Fight: Protecting Organ Transplant Recipients against COVID-19 in the Age of Disinformation</p>	<p>COVID-19</p>
<p>Glenda V. Roberts, <i>AAKP Ambassador, kidney transplant recipient</i></p> <p>Patrick Gee, PhD, <i>AAKP Ambassador, former home dialysis patient, current transplant recipient</i></p>	<p>The Early Days: The Post Kidney Transplant Recipients’ COVID-19 Journey</p>	<p>COVID-19</p>
<p>Co-Authored by Janice Lea, MD, MSC, FASN, <i>AAKP National Board Member</i></p>	<p>Age, Comorbid Conditions, and Racial Disparities in COVID-19 Outcomes</p>	<p>COVID-19</p>
<p>Edward V. Hickey, III, USMC, <i>AAKP President; Chair, AAKP Veterans Health Initiative, current chronic kidney disease patient</i></p>	<p>12 Tips to Nephrology Teams Supporting Patients with Advanced Kidney Disease: An Advocate’s Dozen</p>	<p>Care Management, Nomenclature, and Technology</p>
<p>Paul T. Conway, <i>AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient</i></p>	<p>Nephrology Nomenclature: How to Accelerate Patient Anxiety, Suppress Engagement, and Mire the Advance of Medical Innovation</p>	<p>Care Management, Nomenclature, and Technology</p>

<p>Dale Rogers, AAKP Secretary, Ambassador, former dialysis patient, current transplant recipient</p>	<p>Patient Perspective of Smartphone-Based Apps for CKD Self-Care</p>	<p>Care Management, Nomenclature, and Technology</p>
<p>Paul T. Conway, AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient</p>	<p>Media Analysis of the Canadian Deemed Consent Policy</p>	<p>Care Management, Nomenclature, and Technology</p>
<p>Co-authored by Paul T. Conway, AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient</p>	<p>Breaking the Barriers to Innovation in Kidney Care: The Time is Now</p>	<p>Care Management, Nomenclature, and Technology</p>
<p>Paul T. Conway, AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient</p> <p>Richard A. Knight, AAKP Immediate Past President, former dialysis patient, current transplant recipient</p>	<p>Legitimization and Incorporate of Patient Preferences</p>	<p>Kidney Policy, Patient Insights, and Effective Patient Engagement</p>
<p>Paul T. Conway, AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient</p>	<p>Trust Patient Insights at Both the Individual and National Level</p>	<p>Kidney Policy, Patient Insights, and Effective Patient Engagement</p>
<p>Nichole Jefferson, AAKP Ambassador, former dialysis patient, current transplant recipient</p>	<p>How Community Engagement is Enhancing NIDDK Research</p>	<p>Kidney Policy, Patient Insights, and Effective Patient Engagement</p>
<p>Richard A. Knight, AAKP Immediate Past President, former dialysis patient, current transplant recipient</p>	<p>A Participant-Centered Approach to Understanding Risks and Benefits of Participation in Research Informed by the Kidney Precision Medicine Project</p>	<p>Kidney Policy, Patient Insights, and Effective Patient Engagement</p>

Catherine Campbell, DNP, RN, MBA, CHC, CCM, FACHE, AAKP Ambassador, current transplant recipient		
Artemeshia “Meshia” Adams, AAKP Ambassador	Race and Evaluation for a Kidney Transplant	Kidney Transplantation
David Rodriguez, AAKP National Board Member, Ambassador, former dialysis patient, current transplant recipient	Kidney Disease Burden and Kidney Transplantation: A True Story	Kidney Transplantation
Richard A. Knight, AAKP Immediate Past President, former dialysis patient, current transplant recipient	An Evolving Continuum of Care for the Kidney Disease Patient Will Help the Transplant Center Patient Navigator	Kidney Transplantation
Kevin Fowler, AAKP Ambassador, transplant recipient	Accountability of Dialysis Facilities in Transplant Referral	Kidney Transplantation
STAT News, Glenda V. Roberts, AAKP Ambassador, kidney transplant recipient	Understanding my racial heritage — thanks, Ancestry.com — could have gotten me a kidney transplant earlier	Kidney Transplantation
Melissa Bensouda, current home hemodialysis patient	Optimizing Use of Deceased Donor Kidneys: Organ Waste While We Continue to Wait	Kidney Transplantation
Michael Jack Lennon, AAKP Ambassador, transplant recipient	Getting a Kidney: Where is the Patient Choice	Kidney Transplantation
Stephen Z. Fadem, MD, FASN, FACP; Chair, AAKP Medical Advisory Board	Dialysis, Transplantation, and Work: Honoring the Original Intent	Kidney Transplantation
James Myers, AAKP National Board Member, Ambassador, former dialysis patient, current transplant recipient	Patient Experiences with Home Dialysis	Dialysis Care
Daronta Briggs, AAKP Ambassador, transplant recipient	Disparities in Health Outcomes with Dialysis in the United States Vary by Race	Dialysis Care

Jonathan Haydak, AAKP Ambassador, former home dialysis patient, current transplant recipient	Patient Priorities for Research Involving Peritoneal Dialysis	Dialysis Care
Edward V. Hickey, III, USMC, AAKP President, Chair, AAKP Veterans Health Initiative, current chronic kidney disease patient Paul T. Conway, AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient	Inclement Weather and Dialysis Patients: Warning Flags for Emergency Managers and Public Officials	Dialysis Care

Presentations and Webinars featuring AAKP allied subject matter experts

AAKP, Allies & Medical Expert Filmed Segments on Clinical Trials, Diversity, & Inclusion	<ul style="list-style-type: none"> • 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) • Raising Awareness of Kidney Disease in Minority Communities (Click to Watch) • Race in Kidney Disease Research and Diagnosis (Click to Watch) • Innovation Starts with Research: Including Patients at the Table (Click to Watch) • 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)
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<p>AAKP, Allies & Medical Expert Filmed Segments on Patient Engagement in Research and Innovation</p>	<ul style="list-style-type: none"> • The High Value of Your Lived Experiences: Why Researchers Want and Need Patient Involvement (Click to Watch) • Patient Insights and Lived Experiences: Expanding Impact within Federal Agencies (Click to Watch) • Calling All Researchers! Learn about funding opportunities available now through the CDMRP (Click to Watch) • • Moving from Intention to Action: a WHO Framework for Meaningful Engagement of People Living with NCDs and Mental Health conditions (Click to Watch) <ul style="list-style-type: none"> ○ Intention to Action series: People Power (Read Now) ○ WHO Framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions (Read Now) • How Patient Consumers are Leading Global Demand (Click to Watch) • The Decade of the Kidney™: Bridging Oceans with Patients’ & Other Stakeholders (IDEAS) (Click to Watch) • Global Kidney Patient Voice™: Leading the Charge - Kidney Patients Driving Global Innovation and Independence (Click to Watch) • Innovation Starts with Research: Including Patients at the Table (Click to Watch)
<p>AAKP, Allies & Medical Expert Filmed Segments on Patient Care Choice and Access to Treatments</p>	<ul style="list-style-type: none"> • Patients Re-Define Shared Decision Making (SDM) for Kidney Treatment: Moving Beyond the Limited Medical and Social Work Models (Click to Watch) • Misalignments in Federal Regulatory and Payment Decisions Determine Patient Access to Vital Innovations (Click to Watch) • The Long and Winding Road...FDA’s Decades-Long Effort to Jumpstart the Next Generation of Transplant Drugs (Click to Watch) • Transplant Diagnostic Testing - The 2023 HHS/CMS Policy Change that Disrupted Transplant Professionals and Medicare Transplant Patients and Contradicted Stated Presidential Commitments (Click to Watch) • The Great Flaw: How Quality Adjusted Life Years (QALYs) Promote Ethical Problems and Impede Access to Therapies and Drug Innovation (Click to Watch) • How Payment Policies Can Disrupt or Impact Patient Care Choice and Access (Click to Watch)
<p>AAKP, Allies & Medical Expert Filmed Segments on Early Detection, Identification, and Intervention of Kidney Diseases</p>	<ul style="list-style-type: none"> • Metabolite Found in Urine Predicts Kidney Failure from Type 2 Diabetes 5 to 10 Years Early (Click to Watch) • Kidney Disease Screening – How the Federal Government Could Uphold its Commitment to Patients and Taxpayers for Earlier Kidney Disease Detection and Timely Intervention (Click to Watch)

	<ul style="list-style-type: none"> • Advancements in Diabetic Kidney Disease Treatment (Click to Watch) • Early Identification and Intervention Advancements in Diabetic Kidney Disease (Click to Watch) • 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)
<p>AAKP, Allies & Medical Expert Filmed Segments on Emerging Research in Transplantation and Alternatives to Human Organs</p>	<ul style="list-style-type: none"> • Innovations in Transplantation – Emerging Therapeutics to Meet Patient Needs (Click to Watch) • Advancements in Kidney Transplant Research and Innovation (Click to Watch) • The Future is Here: The Decade of the Kidney™ and Artificial Organs (Click to Watch) • The Evolving Transplant Landscape (Click to Watch) • Artificial Intelligence/Machine Learning (AI/ML) – Enable Medical Devices (Click to Watch) • Innovations in Alternative Therapies to Dialysis (Xenotransplantation) (Click to Watch) • Innovations in Alternative Therapies to Dialysis (Implantable and Wearable Kidneys) (Click to Watch) • The Kidney Project: Updates to an artificial implantable organ (Click to Watch) • 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) <ul style="list-style-type: none"> ○ KidneyX Artificial Kidney Prize (Click to Watch) ○ The Kidney Project (Click to Watch) ○ WAK 3.0 (Click to Watch)
<p>AAKP, Allies & Medical Expert Filmed Segments on Home Dialysis Therapies</p>	<ul style="list-style-type: none"> • Innovations and Research: Advancing Dialysis for Improved Patient Outcomes (Click to Watch) • Patient Voice Patient Choice™ - Changing Government Practices to Support Patient Access to Home Dialysis Therapies – Germany (Click to Watch) • Home Dialysis and CMMI (Click to Watch) • Innovations in Home Health: Lessons from COVID-19 and the Impact on Future Kidney Care (Click to Watch) • Advancing Home Dialysis Care: Aligning Policies Across Agencies (Click to Watch) • A Global Need to Support an Ever-Growing Home Dialysis Community (Click to Watch)

AAKP, Allies & Medical Expert Filmed Segments and Webinars on Veterans and Kidney Diseases	<ul style="list-style-type: none"> • Building a New National Veteran Ambassador Network (Click to Watch) • Disease Management: Veterans Affairs Responds to Kidney Disease (Click to Watch) • VA Kidney Medicine Program (Click to Watch) • How Patient Advocates Can Become Part of and Contribute to the CDMRP Peer Review (Click to Watch)
AAKP, Allies & Medical Expert Filmed Segments on COVID-19	<ul style="list-style-type: none"> • COVID-19: Ongoing Threats to Vulnerable Kidney Patients and Current Research on Long-COVID (Click to Watch) • Home Dialysis: Key Learnings from COVID-19 and the Future (Click to Watch) • Emerging Therapies, COVID-19 Prevention, and the Immunosuppressed (Click to Watch) • Diversity and Inclusion in COVID-19 Trials: Insights and Tactics (Click to Watch) • COVID-19 Concerns for Immunosuppressed Kidney Transplant Patients as the National Public Health Emergency Ends (Click to Watch) • Innovations in Home Health: Lessons from COVID-19 and the Impact on Future Kidney Care (Click to Watch) • Top Health Concerns: COVID-19 Current Efforts on Variants and Need for Vaccinations (Click to Watch) • Top Health Concerns: COVID-19 Implications on Transplant Patients (Click to Watch) • America's Veterans: Kidney Health During COVID-19 (Click to Watch)

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