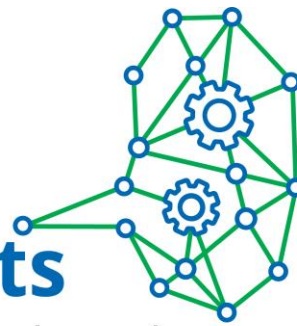


Kidney Patients

Mobilizing for Innovation & Independence



AAKP 46th National Patient Meeting

September 24, 2021

Time	Event	Session Title	Moderator	Speaker(s)
8:00 a.m. – 10:00 a.m.	Sponsor Hall Open	<p>Visit this year's Sponsors & Exhibitors!</p> <p><i>Earn points and win prizes by attending sessions, downloading booth material, watching company videos, engaging with vendors, and more!</i></p>		
10:00 a.m. – 11:00 a.m.	<p>Welcome</p> <p>Poster Presentation</p> <p>General Session</p>	<p>Welcome to the AAKP 46th Annual National Patient Meeting: <i>Mobilizing for Innovation & Independence</i></p> <p>The Decade of the Kidney™: Bridging Oceans with Patients' & other Stakeholders' IDEAS</p> <p>Global Kidney Voices™: Leading the Charge - Kidney Patients Driving Global Innovation and Independence</p>	<p>Paul T. Conway, AAKP Chair of Policy & Global Affairs; ABIM Nephrology Specialty Board; former dialysis patient, current transplant recipient</p> <p>Richard Knight, AAKP President, former dialysis</p>	<p>Diana Clynes, AAKP Executive Director</p> <p>Fokko Wieringa, PhD, (2021 <i>KidneyX Artificial Kidney Prize Winner</i>); Principal Scientist, IMEC, The Netherlands; Dutch Kidney Foundation; Member, The Kidney Health Initiative (EU)</p> <p>Julianna Blum, PhD, Co-Founder & Executive Vice President, Corporate Development,</p>

		<i>Session presented by The Decade of the Kidney™</i>	patient, current transplant recipient	<p>Humacyte</p> <p>Kathleen Tighe, Vice President, Head, U.S. Public Affairs and Patient Advocacy - Rare Diseases, Sanofi Genzyme</p> <p>Rosemarie Sellati, Global Head of Patient Advocacy-Transplant, Novartis</p> <p>Melissa Penn, JD, MPH, Deputy Director of Advocacy, Bayer Pharmaceuticals, Inc.</p> <p>Daniel Wilson, MD, Senior Medical Director, Bayer Pharmaceuticals</p>
Wellness Break (5 min)				
11:05 a.m. – 12:05 p.m.	General Session	Trending Issue: Innovation Starts with Research: Including Patients at the Table	Suzanne Ruff, AAKP Treasurer, living donor	<p>Melissa West, Senior Director for Strategic Relations and Patient Engagement, Alliance for Kidney Health, American Society of Nephrology</p> <p>Claudia Dahlerus, PhD, Assistant Research Scientist, Nephrology, Internal Medicine, Michigan Medicine, University of Michigan – Kidney Epidemiology and Cost Center</p> <p>Elisa Gordon, PhD, MPH, Professor, Department of Surgery-Division of Transplantation, Center for Health Services and Outcomes Research, and Center for Bioethics & Medical Humanities, Northwestern University Feinberg School of Medicine</p> <p>Wendy L. St. Peter, PharmD, FCCP, FASN, FNKF, Professor, College of Pharmacy, University of Minnesota</p>

				Christine Broderick , Engagement Officer, Patient Centered Outcomes Research Institute (PCORI)
Wellness Break (5 min)				
12:10 p.m. – 12:50 p.m.	General Session	Hot Topic: Coronavirus and Kidney Patients Update – A CDC Expert Session	Janice Lea, MD, MSc, FASN, AAKP Board of Director, Executive Committee	Shannon Novosad, MD, MPH, LCDR , Medical Officer, Division of Healthcare Quality Promotion, Centers for Disease Control and Prevention (CDC)
Wellness Break (5 min)				
12:55 p.m. – 1:35 p.m.	General Session	Hot Topic: Delta Virus, Vaccines, & Kidney Patients: Ongoing Threats to Weak Immune Systems and Kidney Transplants	Erin Kahle, MPA, CNP, AAKP Director of Patient Insights, Data Analytics, & Advocacy	Robert Montgomery, MD, DPhil, FACS , Chair of the Department of Surgery, Director of the NYU Langone Transplant Institute, Heart Transplant Recipient
Wellness Break (5 min)				
1:40 p.m. – 2:05 p.m.	General Session	Disease Management: Veterans Affairs Responds to Kidney Disease <i>Session presented by the AAKP Veterans Health Initiative</i>	Edward V. Hickey, III, USMC, AAKP Vice President; Chair, AAKP Veterans Health Initiative; caregiver; current kidney patient	Paul Palevsky, MD , Professor of Medicine, University of Pittsburgh School of Medicine; Deputy Director of the VA Kidney Disease and Dialysis Program; President, National Kidney Foundation
2:05 p.m. – 3:05 p.m.	Sponsor Hall Open	Visit this year's Sponsors & Exhibitors! <i>Earn points and win prizes by downloading booth material, watching company videos, engaging with vendors and more!</i>		
2:30 p.m. – 2:55 p.m.	Sponsor Spotlight	Natera: Unlocking Answers to Your Kidney Management with Genetic Testing		Phil Gauthier, MD, MBA , Transplant Nephrologist and Senior Medical Director, Natera Trudy McKanna, MS , Certified Genetic Counselor, Director of Medical Education, Natera

2:30 p.m. – 2:45 p.m.	Sponsor Spotlight	BD: James and Brandy: An EndoAVF Story		
Wellness Break (5 min)				
3:05 p.m. – 3:45 p.m.	Breakout Session A	<p>Disease Management: Rare Diseases and Understanding the Implications of Genetic Testing</p> <p><i>This session is proudly sponsored by Travers Therapeutics.</i></p>	Catherine Campbell, AAKP Ambassador, current ESRD patient, seeking a living donor transplant	<p>Richard Nelson, Founder and Chair, Rare Kidney Disease Foundation</p> <p>Anna Greka, MD, PhD; Institute Member, Director of the Kidney Disease Initiative, Broad Institute of MIT</p>
3:05 p.m. – 3:45 p.m.	Breakout Session B	<p>Disease Management: Advancements in Diabetic Kidney Disease Treatment</p> <p><i>This session is proudly sponsored by Baxter.</i></p>	Jonathan Traylor, AAKP Ambassador, transplant recipient	Stephen Fadem, MD, FACP, FASN ; Chair, AAKP Medical Advisory Board; Clinical Professor of Medicine, Baylor College of Medicine, Section of Nephrology
3:05 p.m. – 3:45 p.m.	Breakout Session C	<p>Advocacy & Engagement Training: How to be an effective participant in clinical trials and research efforts</p> <p><i>This session is proudly sponsored by Sanofi-Genzyme.</i></p>	Melissa Bensouda, AAKP Ambassador, home hemodialysis patient	Scott Toner , President and Founder, BridgeView Strategies, former AAKP Board of Director
Wellness Break (5 min)				
3:50 p.m. – 4:30 p.m.	Breakout Session A	<p>Disease Management: Advancements in AKI: New Research in Acute Kidney Injury</p> <p><i>This session is proudly sponsored by Mallinckrodt Pharmaceuticals.</i></p>	Richard Knight, AAKP President, former dialysis patient, current transplant recipient	<p>Ivonne H. Schulman, MD; Program Director, Translational and Clinical Studies of Acute Kidney Injury; National Institutes of Health (NIH); National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); Division of Kidney, Urologic and Hematologic Diseases (KUH)</p> <p>Kaleab Z. Abebe, PhD, Associate Professor of Medicine, Biostatistics, and Clinical and Translational Sciences; Director, Center for Clinical Trials and Data Coordination; Director, Center for Research and Health Care Data Center; University of Pittsburgh</p>

				Marla Levy , a proud survivor of four open heart surgeries, Acute Kidney Injury (AKI), and Chronic Kidney Disease (CKD)
3:50 p.m. – 4:30 p.m.	Breakout Session B	Disease Management: Race in Kidney Disease Research and Diagnosis <i>This session is proudly sponsored by Medtronic.</i>	David Rodriguez, AAKP Board of Director, Executive Committee, Ambassador, current transplant recipient	Keith C. Norris, MD, PhD , Professor of Medicine, UCLA Division of General Internal Medicine and Health Services Research
3:50 p.m. – 4:30 p.m.	Breakout Session C	Advocacy & Engagement Training: Patient Voice, Patient Choice – I am a KidneyVoter™ <i>This session is proudly sponsored by Horizon Therapeutics.</i>	Diana Clynes, AAKP Executive Director	Erin Kahle, MPA, CNP , Director of Stakeholder Operations
Wellness Break (5 min)				
4:35 p.m. – 4:45 p.m.		Close of Day Remarks		Edward V. Hickey, III , USMC, AAKP Vice President; Chair, AAKP Veterans Health Initiative; caregiver; current kidney patient
4:45 p.m. – 5:45 p.m.	Sponsor Hall Open	Visit this year's Sponsors & Exhibitors! <i>Earn points and win prizes by downloading booth material, watching company videos, engaging with vendors and more!</i>		
4:45 p.m. – 5:15 p.m.	Sponsor Spotlight	CareDx: Kidney Transplant? There's an app for that!		Koren Axelrod , Senior Business Analyst, Digital Products, CareDx, Inc. Patrick O. Gee, Sr., PhD, JLC , Founder & CEHD, iAdvocate, Inc., AAKP Ambassador, Kidney Transplant Recipient Alexandra Flaxman , Engagement Manager, CareDx, Kidney Transplant Recipient

				Victor M. Blanco , Outreach & Education Transplant Coordinator, Texas Transplant Center, Kidney Transplant Recipient
5:15 p.m. – 12:00 a.m.		<p>Check out the AAKP After Hours Resources!</p> <p>Stop by the Networking Lounge!</p> <p><i>Click on the tabs found on the navigation bar at the top of the event platform.</i></p>		

September 25, 2021

Time	Event	Session Title	Moderator	Speaker(s)
8:00 a.m. – 10:00 a.m.	Sponsor Hall Open	<p>Visit this year's Sponsors & Exhibitors!</p> <p><i>Earn points and win prizes by attending sessions, downloading booth material, watching company videos, engaging with vendors and more!</i></p>		
10:00 a.m. – 11:10 a.m.	Welcome	Welcome to Day 2 of the AAKP 46th Annual National Patient Meeting: Mobilizing for Innovation & Independence		Diana Clynes, Executive Director
	General Session	The Evolving Transplant Landscape: How the Association of Organ Procurement Organizations is Embracing Stakeholder Viewpoints	Richard Knight, AAKP President, former dialysis patient, current transplant recipient	Jon Snyder, PhD , Director, Scientific Registry of Transplant Recipients (SRTR); Director, Transplant

				<p>Epidemiology, Hennepin Healthcare Research Institute</p> <p>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</p> <p>Jan Finn, President, Association of Organ Procurement Organizations (AOPO); CEO, Midwest Transplant Network</p>
Wellness Break (5 min)				
11:15 a.m. – 12:00 p.m.	General Session	Trending Issue: Innovations in Alternative Therapies to Dialysis (Implantable and Wearable)	Melissa Bensouda, AAKP Ambassador, home hemodialysis patient	<p>Shuvo Roy, PhD; (2021 <i>KidneyX Artificial Kidney Prize Winner</i>); Technical Director, The Kidney Project; Professor, Departments of Bioengineering and Therapeutics Sciences and Surgery</p> <p>William H. Fissell, MD; Medical Director, The Kidney Project; Associate Professor of Clinical Medicine, Vanderbilt University Medical Center</p> <p>Janis Naeve, Managing Director, Amgen Ventures</p> <p>Victor Gura, MD, Founder & Innovator, Wearable Artificial Kidney (WAK 3.0), Cedars-Sinai Medical Center Los Angeles</p>
Wellness Break (5 min)				
12:05 p.m. – 12:40 p.m.	General Session	Trending Issue: Innovations in Alternative Therapies to Dialysis (Xenotransplantation)	Dale Rogers, AAKP Secretary, Ambassador, former dialysis patient, current transplant recipient	David K.C. Cooper, MD, PhD , (2021 <i>KidneyX Artificial Kidney Prize Winner</i>); co-director, Xenotransplantation Program, University of Alabama, Birmingham School of Medicine
Wellness Break (5 min)				

12:45 p.m. – 1:15 p.m.	General Session	Trending Issue: Artificial intelligence/ Machine Learning (AI/ML) - Enabled Medical Devices: Tailoring a Regulatory Framework to Encourage Responsible Innovation in AI/ML	Edward V. Hickey, III, USMC, AAKP Vice President; Chair, AAKP Veterans Health Initiative; caregiver; current kidney patient	Matt Diamond, MD, PhD, CMO , Digital Health Center of Excellence, U.S. Food and Drug Administration
Wellness Break (5 min)				
1:20 p.m. – 2:10 p.m.	General Session	Hot Topic: Innovations in Home Health - Lessons from COVID-19 and Impact on Future Kidney Care	Jennifer Jones, USMC; AAKP Board of Director, Executive Committee; Ambassador; former transplant recipient; current dialysis patient	Jesse Roach, MD , Senior Medical Director, Health Equity, CVS Kidney Care Mary Gellens, MD , Senior Medical Director, Worldwide Medical Baxter Healthcare, Baxter International Inc. Abi Sundaramoorthy, MD, MBA , Executive Vice President, Clinical Enterprise, Somatus
Wellness Break (5 min)				
2:15 p.m. – 2:45 p.m.	General Session	Under the U.S. Capitol Dome: Current and Emerging Legislative Issues	Paul T. Conway, AAKP Chair of Policy & Global Affairs; ABIM Nephrology Specialty Board; former dialysis patient, current transplant recipient	Peggy Tighe , Principal, Government Relations/Legislation, American Society of Transplant Surgeons (ASTS) Rob Blaser , Director of Public Policy, Renal Physicians Association (RPA)
2:45 p.m. – 3:45 p.m.	Sponsor Hall Open	Visit this year's Sponsors & Exhibitors! <i>Earn points and win prizes by downloading booth material, watching company videos, engaging with vendors and more!</i>		
3:00 p.m. – 3:30 p.m.	Sponsor Spotlight Session	Alliance for Gout Awareness: Here for Patients Like You		Josie Cooper , Executive Director, Alliance for Gout Awareness
3:45 p.m. – 4:30 p.m.	Breakout Session A	Disease Management: AAKP Peer Mentorship Project: Coping with Kidney Disease and Choosing (or	Cecilia Santana, AAKP Ambassador; Stakeholder, Enhanced Patient Engagement to Improve	Janice Lea, MD, MSc, FASN ; AAKP Board of Director, Executive Committee; Professor of Medicine at Emory University; Clinical Director of Nephrology & the Chief Medical Director, Emory

		<p>Changing to) a Treatment Right for You!</p> <p><i>The Enhanced Patient Engagement to Improve Patient-Centered Outcomes among Chronic Kidney Disease (CKD) Project is supported by a Eugene Washington Engagement Award (AAKP-EADI-14537) from the Patient-Centered Outcomes Research Institute (PCORI).</i></p> <p><i>This session is proudly sponsored by BD.</i></p>	<p>Patient-Centered Outcomes among Chronic Kidney Disease (CKD) Project, transplant recipient</p>	<p>Dialysis</p>
3:45 p.m. – 4:30 p.m.	Breakout Session B	<p>Disease Management: Caring for Your Kidney Kid in General and During COVID</p> <p><i>Session presented by the AAKP Pediatric Kidney Pals Initiative</i></p>	<p>Jack Lennon, AAKP Ambassador, transplant recipient</p>	<p>Jens Goebel, MD, Professor of Pediatrics; Section Head (Pediatric Nephrology); Medical Director, Kidney Transplantation Children's Hospital Colorado</p>
3:45 p.m. – 4:30 p.m.	Breakout Session C	<p>Advocacy & Engagement Training: Practical Steps in Sharing YOUR Story to Support Finding a Living Organ Donor</p>	<p>Kent Bressler, AAKP Board of Director, Ambassador, pre-emptive transplant recipient</p>	<p>Risa Simon, AAKP Ambassador; Founder, TransplantFirst Academy, pre-emptive transplant recipient</p>
Wellness Break (5 min)				
4:35 p.m. – 5:30 p.m.	Breakout Session A	<p>Disease Management: Disrupting Disease Progression through Community Engagement</p> <p><i>This session is proudly sponsored by AstraZeneca.</i></p>	<p>Sara Eve Schaeffer, MBA, MA, RD; AAKP Board of Director; Executive Director of CMS' Technical Assistance, Quality Improvement, and Learning (TAQIL), Health Services Advisory Group, Inc. (HSAG)</p>	<p>Barry Smith, PhD, MD; AAKP Board of Director; Founder, Dreyfus Health Policy and Research Center</p>

4:35 p.m. – 5:30 p.m.	Breakout Session B	<p>Disease Management: Advancements in Identification and Diagnosis of Kidney Diseases</p> <p><i>This session is proudly sponsored by Novartis.</i></p>	Erin Kahle, MPA, CNP, AAKP Director of Patient Insights, Data Analytics, & Advocacy	<p>Barry I. Freedman, MD, FACP, Chief of Nephrology, Wake Forest School of Medicine</p> <p>Jonathan Himmelfarb, MD, (2021 KidneyX Artificial Kidney Prize Winner); Co-Director of the University of Washington Center for Dialysis Innovation, Director of the Kidney Research Institute, Professor of Medicine and Adjunct Professor of Bioengineering</p> <p>David Davenport, Personalized Medicine Coalition (PMC), Manager, Public Policy and Secretary to the Board</p>
4:35 p.m. – 5:30 p.m.	Breakout Session C	<p>Advocacy and Engagement Training: Top Ten Things to Know to be Effective on Camera – from Zoom to Media Interviews</p> <p><i>Session presented by Briar Patch Media, AAKP’s strategic national media partner</i></p>	Jim Myers, AAKP Board of Director, Ambassador, former dialysis patient, current transplant recipient	<p>Jonathan St. John, Owner/Senior Editor, Briar Patch Media, LLC</p> <p>Jennifer Rate, AAKP Marketing and Communications Manager</p>
Wellness Break (5 min)				
5:35 p.m. – 5:45 p.m.		<p>Close of Day Remarks</p>		<p>Richard Knight, AAKP President, former dialysis patient, current transplant recipient</p>
5:45 p.m. – 6:45 p.m.	Sponsor Hall Open	<p>Visit this year’s Sponsors & Exhibitors!</p> <p><i>Earn points and win prizes by attending sessions, downloading booth material, watching company videos, engaging with vendors, and more!</i></p>		
		<p>Check out the AAKP After Hours Resources!</p> <p>Stop by the Networking Lounge!</p>		

Click on the tabs found on the navigation bar at the top of the event platform.

*Agenda may be subject to change. Due to topic timeliness, some sessions may be a rebroadcast of AAKP OnDemand content.

**Session start times may be approximate

AAKP After Hours – Featured OnDemand Content

<p>AAKP Addresses Clinical Trials, Diversity, & Inclusion</p>	<ul style="list-style-type: none"> • 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)
<p>AAKP Allies & Medical Expert Filmed Segments on Clinical Trials</p>	<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)
<p>AAKP Allies & Medical Expert Filmed Segments on Diabetic Kidney Disease</p>	<ul style="list-style-type: none"> • 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 Home Dialysis Therapies</p>	<ul style="list-style-type: none"> • 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)

<p>AAKP Allies & Medical Expert Filmed Segments on Emerging Research</p>	<ul style="list-style-type: none"> • 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-hosted COVID-19 Educational Webinar Series</p>	<ul style="list-style-type: none"> • Delta Virus, Vaccines, & Kidney Patients: Ongoing Threats to Weak Immune Systems and Kidney Transplants (Click to Watch) • 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) • Taking Care of Your Dialysis Access During the COVID-19 Pandemic (Click here to Watch) • Fighting Coronavirus Upstream - What Early Stage Kidney Disease Patients Need to Know (Click to Watch) • New American Telemedicine Policies & Utilization in the COVID-19 Era: What Patients Should Know (Click to Watch) • The USA Department of Veterans Affairs Kidney Program's Response to COVID-19 (Click to Watch) • Kidney Patient Mental Health Management During COVID-19: Staying Connected while Staying at Home (Click to Watch) • Kidney Patient Nutrition & COVID-19: The Importance of Keeping it Kidney Friendly (Click Here to Watch) • Clinical Trials: Expanding Opportunities for All Kidney Patients in the Midst of COVID-19 and Beyond (Click to Watch) • Diversity and Inclusion in COVID-19 Trials: Insights and Tactics (Click to Watch)

AAKP Allies & Medical Expert Filmed Segments on COVID-19

- **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](#))
- **How Innovation and Community Engagement Furthers Kidney Research at NIDDK** ([Click to Watch](#))
- **Coronavirus: Treatment Immunosuppressed Populations during a Global Pandemic** ([Click to Watch](#))
- **Coronavirus: Kidney Community Stakeholder Response to Global Pandemic** ([Click to Watch](#))
- **Coronavirus: America's Largest Kidney Innovation Collaborative Responds** ([Click to Watch](#))
- **Coronavirus: Observations of Healthcare Systems Responses to Pandemic (Nonprofit, Private, and VA)** ([Click to Watch](#))
- **Coronavirus: Accelerating the Adoption of Telehealth & Telemedicine** ([Click to Watch](#))
- **Coronavirus: Transitioning Patients from Telehealth & Telemedicine Back to In-person Care** ([Click to Watch](#))