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MEDIA CONTACT:

Jennifer Rate
Marketing & Communications Manager
jrate@aakp.org
(813) 400-2394

SUMMER READING LIST RELEASED BY LARGEST KIDNEY ADVOCACY GROUP

Patient Insights on Care Choice, Innovation, Covid-19, and Kidney Replacement Therapies

Washington, D.C. - In advance of the July 4th Independence Day weekend, the American Association of Kidney Patients (AAKP), the nation's largest independent kidney patient organization, released their annual summer reading list featuring articles by AAKP-affiliated patient authors. The list includes links to patient editorials; companion, open access research articles published in the *Clinical Journal of the American Society of Nephrology (CJASN)*; and national news articles on kidney issues referencing AAKP.

Mrs. Diana Clynes, AAKP Executive Director, stated, "Based on the success of our [2021 Spring Reading List](#), we have released an extended version for 2022 that features articles authored by AAKP-affiliated patients on issues ranging from care choice, innovation, transplantation, COVID-19, and dialysis. AAKP is very grateful to CJASN Editor, Dr. Mehrotra, and the entire CJASN publishing team for their leadership in elevating patient insights and their deep respect for the urgent needs of kidney patients. We encourage everyone interested in the firsthand insights of kidney patient consumers to read these editorials and articles to gain a greater appreciation for the burden of kidney disease and why all people of goodwill should join the fight for disease prevention and treatment innovations."

In 2017, under the leadership of CJASN Editor-In-Chief Rajnish Mehrotra, MD, MS, FASN, the David S. and Nayda Utterberg Endowed Professor of Medicine at the University of Washington, CJASN launched a [first-in-kind initiative](#) designed to fully engage kidney patients and caregivers in the kidney research enterprise. Through Patient Voice Editors and Patient Voice Editorials, patients have shared their unique insights and perspectives with CJASN's international audience of nephrologists and disease experts. AAKP awarded Dr. Mehrotra with the association's National Journalism Award for his efforts to elevate the patient voice and his lifelong contributions as a national champion for patient care choice and the alignment of kidney treatments to support patient aspirations.

As part of the AAKP-initiated [Decade of the Kidney™](#), AAKP national and global patient advocates have been aggressively involved in writing and research to increase kidney disease awareness, build support for treatment innovations, and advance common-sense regulatory and payment policies. AAKP is leading an [international patient consortium](#) to mobilize patient consumers and their allies to push leaders and decision makers for greater investments in kidney research designed to accelerate innovations in kidney drugs, diagnostics, and devices, including artificial kidneys. Within the U.S., AAKP has launched its [Patient Voice Patient Choice™](#) initiative to engage kidney patient consumers in efforts to eliminate unnecessary barriers erected by insurers or government policies that block access to new, FDA-approved kidney therapies, diagnostics, and devices. For more information and to take part in current patient access campaigns, visit www.patientvoicepatientchoice.org.

AAKP is nationally recognized for both its educational programming and grassroots advocacy programs. In 2018, AAKP launched the first voter registration program in the kidney community, [KidneyVoter™](#), and has announced a goal of registering over 500,000 KidneyVoters™ by the 2024 election year. KidneyVoters™ are Americans whose lives and families have been impacted by kidney disease, along with those whose careers are in the fields of kidney medicine, research, and private sector companies dedicated to advancing new therapeutics, devices, and diagnostic tools.

Summer Reading List

AAKP in the News

“Patients with Vulnerable Immune Systems Worry Vaccine May Put Them in Peril,” Kaiser Health News, Aaron Bolton

<https://bit.ly/3xB9wRv>

“Majority of Arizona Dialysis Centers Facing Health Violations,” KVOA, Chorus Nylander

<https://bit.ly/3EnXlsT>

“Repeat Safety Violations, Critical Resource Shortages Put Arizona Dialysis Patients at Heightened Risk,” Arizona Center for Investigative Reporting, Shaena Montanari

<https://bit.ly/3vyokOu>

“Vulnerable Patients Prepare to Navigate Post-Pandemic World,” National Journal, Erin Durkin

<https://bit.ly/3rDihXx>

“Chronic Kidney Disease: Forging Patient Centered Solutions,” The Hill, featuring Richard Knight, *AAKP President, former dialysis patient, current transplant recipient*

<https://bit.ly/3OTSRy5>

“Immunocompromised patients worry vaccine exemptions put them in peril,” Montana Public Radio, Aaron Bolton

<https://bit.ly/3Agqt53>

“A COVID Surge Is Overwhelming U.S. Hospitals, Raising Fears Of Rationed Care,” NPR, Will Stone

<https://n.pr/3y9yk1B>

COVID-19 and Kidney Disease

“COVID-19 and Palliative Care: Observations, Extrapolations, and Cautions,” Edward V. Hickey, III, USMC, *AAKP Vice President; Chair, AAKP Veterans Health Initiative, current chronic kidney disease patient*, and Paul T. Conway, *AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient*

<https://bit.ly/PVHickey2>

“An Honorable and Ongoing Fight: Protecting Organ Transplant Recipients against COVID-19 in the Age of Disinformation,” Paul T. Conway, *AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient*

<https://bit.ly/ConwayPV2>

“The Early Days: The Post Kidney Transplant Recipients’ COVID-19 Journey,” Glenda V. Roberts, *AAKP Ambassador, kidney transplant recipient*, and Patrick Gee, PhD, *AAKP Ambassador, former home dialysis patient, current transplant recipient*

<http://bit.ly/GeeRobertsPV>

“Age, Comorbid Conditions, and Racial Disparities in COVID-19 Outcomes,” Co-Authored by Janice Lea, MD, MSC, FASN, *AAKP National Board Member*
<https://bit.ly/3yxmPCQ>

Care Management, Nomenclature, and Technology

“12 Tips to Nephrology Teams Supporting Patients with Advanced Kidney Disease: An Advocate’s Dozen,” Edward V. Hickey, III, USMC; *AAKP Vice President; Chair, AAKP Veterans Health Initiative, current chronic kidney disease patient*
<http://bit.ly/HickeyPV>

“A Patient’s View on Exercise and ESKD,” Nichole Jefferson, *AAKP Ambassador, former dialysis patient, current transplant recipient*
<http://bit.ly/JeffersonPV>

“Nephrology Nomenclature: How to Accelerate Patient Anxiety, Suppress Engagement, and Mire the Advance of Medical Innovation,” Paul T. Conway, *AAKP Chair of Policy and Global Affairs, former home dialysis patient, current transplant recipient*
<http://bit.ly/PTConroyPV>

“Patient Perspective of Smartphone-Based Apps for CKD Self-Care,” Dale Rogers, *AAKP Secretary, Ambassador, former dialysis patient, current transplant recipient*
<http://bit.ly/CJASNRogersPV>

“Patients with Kidney Disease: Ready to Use Smartphones for Health Care Delivery,” Lana Schmidt, *AAKP National Board Member, former home dialysis patient, current transplant recipient*
<http://bit.ly/PVSchmidt>

Kidney Policy, Patient Insights, and Effective Patient Engagement

“A Patient’s Perspective on Advancing American Kidney Health Initiative,” Richard A. Knight, *AAKP President, former dialysis patient, current transplant recipient*
<http://bit.ly/KnightAAKH>

“Legitimization and Incorporate of Patient Preferences,” Paul T. Conway, *AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient*, and Richard A. Knight, *AAKP President, former dialysis patient, current transplant recipient*
<http://bit.ly/PVConwayKnight>

“Trust Patient Insights at Both the Individual and National Level,” Paul T. Conway, *AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient*
<http://bit.ly/ConwayPV>

“The New HHS Kidney Innovation Accelerator,” Kevin Fowler, *AAKP Ambassador, transplant recipient*, and Paul T. Conway, *AAKP Chair of Policy and Global Affairs, former dialysis patient, current transplant recipient*
<http://bit.ly/CandfPV>

“How Community Engagement is Enhancing NIDDK Research,” Nichole Jefferson, *AAKP Ambassador, former dialysis patient, current transplant recipient*
<http://bit.ly/CJN14591218>

“A Participant-Centered Approach to Understanding Risks and Benefits of Participation in Research Informed by the Kidney Precision Medicine Project,” Co-Authored by Richard A. Knight, *AAKP President, former*

dialysis patient, current transplant recipient, and Catherine Campbell, DNP, RN, MBA, CHC, CCM, FACHE, *AAKP Ambassador, current transplant recipient*
<https://bit.ly/3OyomxP>

"Changing Health Disparities in Autosomal Dominant Polycystic Kidney Disease (ADPKD)," Suzanne Ruff, *AAKP Treasurer, Living Kidney Donor*
<https://bit.ly/05790522RuffPV>

Kidney Transplantation

"Race and Evaluation for a Kidney Transplant," Artemeshia "Meshia" Adams, *AAKP Ambassador*
<https://bit.ly/PVAdams>

"Kidney Disease Burden and Kidney Transplantation: A True Story," David Rodriguez, *AAKP National Board Member, Ambassador, former dialysis patient, current transplant recipient*
<https://bit.ly/PVRodriguez>

"An Evolving Continuum of Care for the Kidney Disease Patient Will Help the Transplant Center Patient Navigator," Richard A. Knight, *AAKP President, former dialysis patient, current transplant recipient*
<http://bit.ly/KnightPV>

"Accountability of Dialysis Facilities in Transplant Referral," Kevin Fowler, *AAKP Ambassador, transplant recipient*
<http://bit.ly/FowlerPV>

"Understanding my racial heritage — thanks, Ancestry.com — could have gotten me a kidney transplant earlier," STAT News, Glenda V. Roberts, *AAKP Ambassador, kidney transplant recipient*
<https://bit.ly/3nz69UU>

"Optimizing Use of Deceased Donor Kidneys: Organ Waste While We Continue to Wait," Melissa Bensouda, *current home hemodialysis patient*
<http://bit.ly/BensoudaPV>

Dialysis Care

"Patient Experiences with Home Dialysis," James Myers, *AAKP National Board Member, Ambassador, former dialysis patient, current transplant recipient*
<http://bit.ly/PVMyers>

"Disparities in Health Outcomes with Dialysis in the United States Vary by Race," Daronta Briggs, *AAKP Ambassador, transplant recipient*
<http://bit.ly/BriggsPV>

"Patient Priorities for Research Involving Peritoneal Dialysis," Jonathan Haydak, *AAKP Ambassador, former home dialysis patient, current transplant recipient*
<http://bit.ly/HAYDAKPV>

"A Patient's Perspective on Benzodiazepines, Co-Dispensed Opioids, and Mortality among Patients Initiating Long-Term In-Center Hemodialysis," Cher Thomas, *AAKP Member*
<https://bit.ly/ThomasPV>

Issues and Conditions Associated with Kidney Diseases

"Depression: A Side Effect of CKD," Jennifer Jones, USMC, *AAKP National Board Member, Ambassador, former transplant recipient, current dialysis patient*

<http://bit.ly/PVJones>

“An ADPKD Patient’s View on Screening for Intracranial Aneurysms,” Kevin Fowler, *AAKP Ambassador, transplant recipient*

<http://bit.ly/FowlerPV2>

“A Nutritional Lie or Lifestyle?”, Patrick Gee, PhD, *AAKP Ambassador, former home dialysis patient, current transplant recipient*

<http://bit.ly/GeePV>

“Diet Patterns and Kidney Disease,” Michael Jack Lennon, *AAKP Ambassador, transplant recipient*

<http://bit.ly/LennonPV>

“Appropriate Use of Opioids in Patients with Kidney Diseases,” Dave White, *AAKP Ambassador, former dialysis patient, current transplant recipient*

<http://bit.ly/WhitePV>

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About the American Association of Kidney Patients (AAKP): Founded in 1969, AAKP is the largest kidney patient organization driving policy discussions on kidney patient consumer care choice and treatment innovations. By 1973, AAKP patient collaborations with the U.S. Congress and White House helped gain passage of dialysis coverage for any person suffering kidney failure, creating the only disease specific, taxpayer-funded entitlement program in America. That program, the End-Stage Renal Disease Program (ESRD), administered by CMS, has saved over one million lives. In the past decade, AAKP patients have helped gain lifetime transplant drug coverage for kidney transplant recipients (2020); new patient-centered policies via the White House Executive Order on Advancing American Kidney Health (2019); new job protections for living organ donors under the Family Medical Leave Act (FMLA) from the U.S. Department of Labor (2018); and Congressional legislation allowing HIV-positive organ transplants for HIV-positive patients (2013). AAKP virtual platforms and social networks are internationally known for their impact. Follow AAKP on social media at [@kidneypatient on Facebook](#) and [@kidneypatients on Twitter](#), and visit our website at <https://aakp.org/>.