AAKP
American Association
of Kidney Patients
aakp.org

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LATE SUMMER READING LIST RELEASED BY LARGEST KIDNEY PATIENT ORGANIZATION

Editorials Present Patient Insights on Innovation, Covid-19, Organ Donation, Transplants, and Dialysis

Washington, D.C. - The American Association of Kidney Patients (AAKP), the nation's largest kidney patient organization, today released a curated, late summer reading list featuring editorials by AAKP-affiliated patient authors and links to companion, open access research articles published in the *Clinical Journal of the American Society of Nephrology (CJASN)*. 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 and recipient of AAKP's National Journalism Award, CJASN launched a first-in-kind initiative (read here) designed to further engage kidney patients and caregivers in the kidney research enterprise and to share their unique insights and perspectives on unmet needs with CJASN's audience of nephrologists and disease experts across the globe.

Mrs. Diana Clynes, AAKP Executive Director, stated, "As a result of Dr. Mehrotra's leadership and the efforts of CJASN, with the full support of the American Society of Nephrology, kidney patients across the disease spectrum have had opportunities to share their unique insights with a wide global audience of medical professionals and researchers while gaining open access to the latest developments in the battle against kidney diseases. AAKP is very grateful to CJASN for their leadership in elevating patient insights and their deep respect for the urgency patients have for innovation and better health outcomes. We encourage every family experiencing kidney disease, and the general public, to read these editorials and articles to gain a better practical understanding about how kidney diseases impact patients and why all people of goodwill should join the fight against this devastating condition."

In 2019, AAKP launched *The Decade of the Kidney™*, an international patient consortium aimed at mobilizing patient consumers and their allies to push leaders and decision makers for greater investments in kidney research and more sensible regulatory and payment policies designed to accelerate innovations in kidney drugs, diagnostics, and devices, including artificial kidneys. Through AAKP's Center for Patient Research and Education, the Association provides original kidney patient survey data and expert advice to a broad spectrum of leaders in government, industry, think tanks, and academia who are responsible for recruiting patients for research studies, technical evaluation panels, advisory committees, clinical trials, as well as efforts to incorporate patient insight data across the product development lifecycle, including regulatory and payment decisions. AAKP conducts the largest kidney patient meeting in the United States, hosted virtually this year on September 24-25, 2021, which features the latest expert findings in kidney research and new developments in kidney diseases. The annual meeting will include special skill building workshops for patient advocates and families such as *Being an Effective Participant in Clinical Trials and Industry Research Efforts*, *Top Ten Things to Know to be Effective on Camera – from Zoom to Media Interviews*, and grassroots organizing efforts including *I am a Kidney Voter™*, which highlights the importance of voter registration. The 2021 Patient Meeting provides FREE registration. Click here to learn more and register today. Past AAKP meetings have featured specific skill workshops for patients and caregivers interested in writing for medical journals like CJASN including *How to Write, Co-Author, and Publish in Medical Journals*. Click here to watch OnDemand.

Late Summer Reading List

COVID-19 and Kidney Disease

"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

Care Management, Nomenclature, and Technology

"12 Tips to Nephrology Teams Supporting Patients with Advanced Kidney Disease," 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

"Patients with Kidney Disease: Ready to Use Smartphones for Health Care Delivery," Dale Rogers*, AAKP Secretary, Ambassador, former 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

Kidney Transplantation

"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

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 their website at https://aakp.org/.