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Kidney Group Unveils Risk Campaign During National Safety Month

Innovation and Engagement Transform Infection Prevention and Disaster Readiness

Government Leaders and Care Providers Must Involve Patients in Continuity Plans

WASHINGTON, D.C. – During June, <u>National Safety Month</u>, the American Association of Kidney Patients (AAKP), the largest independent kidney patient organization in the U.S., rolled out a new, year-long safety awareness and public education campaign titled *"Every Patient Safe."* The multi-faceted campaign focuses on the unique risks and unmet safety needs of America's highly vulnerable kidney patients and kidney transplant recipients. Those risks include ongoing susceptibility to serious COVID infection and premature death, increased vulnerability to healthcare-acquired infections (HAIs) and catheter-related bloodstream infections (CRBSIs) among hemodialysis patients, future pandemics, and disruptions caused by sudden natural and unnatural disasters.

AAKP President Edward Hickey, III, a kidney patient, stated, "Our *Every Patient Safe* campaign will engage patients, medical professionals, industry, and policymakers to raise awareness of kidney patients' ongoing unmet safety needs across multiple care settings and under very dynamic scenarios. We applaud the ongoing efforts of medical professionals to provide safe and timely care to their kidney patients. Yet, we share a common concern that the lessons learned during COVID and recent disasters regarding kidney patient vulnerabilities will be forgotten, and serious mistakes will be repeated. Every level of government and every sector of the health and pharmaceutical delivery system must understand the unique risks involved with kidney care, and they must engage both patients and professionals in planning for ongoing and future threats." Hickey is a U.S. Marine Corps Veteran and has served as a senior appointee in multiple presidential administrations, including as Senior Advisor for Homeland Security to the Director of the U.S. Civil Service and a senior staff professional in the U.S. House of Representatives.

On May 10, 2023, as White House and U.S. Department of Health and Human Services (HHS) senior appointed officials announced the end of the COVID-19 Public Health Emergency, AAKP issued a statement entitled <u>"Don't Forget Kidney Patients – Their Vulnerabilities Remain."</u> Over 37 million people

are impacted by kidney disease in the United States, nearly 1 in 7 adults, and almost 600,000 people receive life-saving kidney dialysis. Over 250,000 people are living with a kidney transplant, and over 90,000 people with kidney failure are on the waitlist for a kidney transplant. The COVID-19 pandemic has been and continues to be devastating to the kidney patient community, with unprecedented numbers of hospitalizations for severe illness and premature deaths among both immunocompromised dialysis patients and immunosuppressed kidney transplant recipients (see *American Journal of Kidney Disease (AJKD)*, Executive Summary, U.S. Renal Data System 2023 Annual Data Report: Epidemiology of Kidney Disease in the United States https://www.ajkd.org/article/S0272-6386(24)00048-9/pdf).

The *"Every Patient Safe"* campaign will feature a series of risk awareness and infection prevention resources, patient tools, OnDemand educational programming, and engaging social media content. AAKP has tested several new platforms that will allow kidney patients to better use their own social media networks to share information with fellow patients and medical professionals. AAKP will also leverage the campaign to escalate demand for greater patient care choice and access to new, safe FDA-approved products that mitigate patient risks from life-threatening HAIs and CRBSI infections. The campaign will also highlight key lessons learned from the COVID pandemic and how rapid adoption of technology, including telemedicine and suites of remote medical monitoring tools and devices, can create a more nimble and resilient health delivery system for high-risk kidney patients under any disaster scenario.

As part of the campaign launch, AAKP expanded its emergency preparedness resources to support kidney patients, care partners, and families in planning for natural and unnatural disasters through the stand up of a comprehensive emergency preparedness web page, accessible through AAKP's national website at https://bit.ly/AAKPEmergencyPreparedness, which includes top tips for readiness, various checklists, and necessary items kidney patients must have in personal emergency kits. Also available are links to resources with our federal and non-government partners, including Healthcare Ready and Kidney Community Emergency Response.

AAKP has a very long history of collaboration with the American Society of Nephrology (ASN), the Renal Physicians Association (RPA), the American Society of Transplant Surgeons (ASTS), the American Society of Transplantation (AST), and multiple other kidney stakeholders to raise awareness of a wide range of safety issues for kidney patients and the need to build resiliency into the health system for kidney care and future threats. In collaboration with ASN, AAKP has participated in ASN's COVID-19 and Other Emerging Threats initiative alongside members of ASN's Excellence in Patient Care team. AAKP also works closely with the Centers for Disease Control and Prevention (CDC) and, in 2016, was a founding member of the <u>CDC's</u> Making Dialysis Safer Coalition. AAKP partners with the CDC to help prevent HAIs and CRBSIs among kidney patients and also raises awareness of the CDC's Chronic Kidney Disease Surveillance initiative. AAKP is a formal liaison organization to the CDC's Health Infections Practices Advisory Committee (HICPAC) and is represented by AAKP's Chair of Policy and Global Affairs, Paul T. Conway, a former agency chief of staff for the U.S. Department of Homeland Security (DHS).

Additional campaign topics featured throughout the year include aging and kidney disease, the risk of slips/falls, and what kidney patients need to know when going into the hospital. During the campaign in July 2024, AAKP will also announce a call for applications for its annual <u>AAKP Patient Safety Award</u>, which recognizes specific and impactful leadership and activities that exemplify the Association's strategic goal of advancing patient safety through innovations and specific measures within health systems, both nationally and globally, that inspire actions to improve overall patient safety. Each year, the AAKP provides the kidney patient community with invaluable resources they can use to prepare for both natural and

unnatural emergencies and was recognized in 2021 by the former Governor of the State of Arizona, Douglas A. Ducey, for AAKP's partnership with the Arizona Department of Health ADVICE Collaborative.

According to the 2023 Annual Report of the United States Renal Data System (see summary and tables - https://usrds-adr.niddk.nih.gov/2023/end-stage-renal-disease/4-vascular-access), the "landscape of vascular access in the U.S. is not encouraging" and "the percentage of individuals who die within 18 months of starting HD is nearly twice as high among patients initiating with a catheter than among those initiating with a fistula." The COVID-19 pandemic exacerbated, but was not the sole cause, of the increased utilization of catheters among dialysis patients due to limited access to hospital operating rooms for permanent access placement. Over the past decade, AAKP has advocated for improved patient access to fistulas, which often require full access to outpatient surgical facilities, and has championed greater patient access to a series of new innovations that improve safety and reduce infection risks among patients who depend upon both fistulas and catheters for their life-saving dialysis care. In multiple instances, the Centers for Medicare and Medicaid Services (CMS) has stymied innovation and patient access to new devices and drugs approved by the U.S. Food and Drug Administration (FDA) that could improve patient safety and care outcomes. In these instances, CMS has interpreted payment and reimbursement guidelines to limit the wider use of innovations among dialysis patients and dialysis providers, despite federal data collected by HHS documenting unmet patient safety needs and improved dialysis access.

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About the American Association of Kidney Patients (AAKP): Since 1969, AAKP has been a patient-led organization driving policy discussions on kidney patient care choice and medical innovation. In 2018, AAKP established the first and largest U.S. kidney voter registration program, *KidneyVoters*[™]. Over the past decade, AAKP patient advocates have helped advance lifetime transplant drug coverage for kidney transplant recipients (2020); the presidential Executive Order on Advancing American Kidney Health (2019) new job protections for living organ donors under the Family Medical Leave Act (FMLA) via the U.S. Department of Labor (2018); and Congressional legislation allowing HIV-positive organ transplants for HIV-positive patients (2013). Follow AAKP on social media at @kidneypatient on Facebook, @kidneypatients on Twitter, and @kidneypatients on Instagram, and visit www.aakp.org for more information.