Kidney Patients
Mobilizing for Innovation & Independence
AAKP

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American Association of Kidney Patients
aakp.org

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Kidney Patients Launch Education and Voter Registration Drive for Independence Day

Kidney Patriots™ Mobilize to Fight Disease Risks and Push for Care Innovation

WASHINGTON, D.C. – The American Association of Kidney Patients (AAKP), the nation's largest kidney patient organization, today unveiled a patient and family education and voter registration campaign for the July 4 Independence Day holiday weekend. The effort will encourage kidney patients and their families, including potential living organ donors and transplant recipients, to safely enjoy the weekend while being fully aware of the ongoing risks posed to chronic disease and immunosuppressed people by COVID-19 and the emerging Delta variant (Watch OnDemand AAKP COVID-19 Mutation Strains webinar). Patients and families are being asked to think of themselves as KidneyPatriots™, and to look out for themselves and their communities so they can stay healthy and truly independent. Further, kidney patients and their families are being asked to register to vote, as AAKP expands their nonpartisan KidneyVoters™ program and efforts to mobilize a broad and diverse national constituency committed to fighting kidney diseases, policies to accelerate earlier detection and care innovation, and federal efforts to research COVID-19 impacts and vaccine effectiveness among kidney patients, especially transplant patients.

In 2018, as part of its national policy and engagement strategy, AAKP launched the nonpartisan KidneyVoters™ program (see video here), the first, and now the largest, voter registration initiative serving every sector of the kidney stakeholder community. The program is an important effort to involve patients, medical professionals, and other people of goodwill in the public dialogue and policy process as it pertains to the future of kidney care. The KidneyVoters™ campaign has already engaged tens of thousands of Americans who believe kidney patients and organ donors should be at the table when policy, regulatory, and coverage decisions are made that impact their lives, their ability to stay independent, employed, and fully insured, as well as their consumer choice of treatment innovations. Based on the 2020 success of the KidneyVoters™ program as a mobilization and membership recruitment tool, AAKP has announced plans to register 500,000 kidney patients and other people of goodwill committed to the fight against kidney diseases by the 2024 election cycle.

Up to 37 million Americans are estimated to have kidney disease, and according to the Centers for Disease Control (CDC), 90 percent of patients are unaware that they suffer from the disease. Kidney disease and kidney failure exact a heavy toll on patients and families, as well as the American taxpayer, with Medicare costs alone estimated at nearly $120 billion dollars. Status quo kidney care is characterized by late disease diagnosis, outdated dialysis technologies, disparate treatment access, long waiting times for organ transplants, and extremely high mortality rates. Change within the field of kidney care has been challenging over the past 50 years due to the comparative lack of federal research investments compared to other diseases, limited capital investments and innovation, as well as entrenched special interests that have, historically, been involved in efforts to lobby Congress to protect status quo care through laws that limit kidney patient consumer care choices and stifle the creative forces of competition and innovation. AAKP is the largest patient organization involved in efforts to expand patient consumer care choice of treatments, early disease detection, preemptive transplantation, and disruptive new care models and innovations including home dialysis and remote medical monitoring and the creation of an artificial wearable or implantable kidney.

AAKP President Richard Knight, a national kidney advocate, stated, “AAKP has always prioritized patient independence over dependency in both kidney disease management and treatment care choices so that patients have the maximum flexibility to maintain either full-time or part-time work as they determine. COVID-19 remains an ongoing threat to kidney patients, and we are committed to making certain that innovations that have provided greater safety during the pandemic, such as new home dialysis technologies and virtual care, remain in place and are made even more accessible. In honor of July 4, we are encouraging all kidney patients to be safe, get better informed about kidney disease and COVID-19 risks, and mobilize to make certain patient concerns remain at the forefront of elected leaders and their staffs." Knight is a former dialysis patient, current 14-year transplant recipient and is a former U.S. Congressional staff member and liaison to the Congressional Black Caucus.

AAKP Vice President and Chair of the AAKP Veterans Health Initiative Edward V. Hickey, III, USMC, a kidney disease patient, stated, "Independence Day is an important time to celebrate the principles that unite us as a nation and to remind each of us that no matter how difficult the challenges are that confront America, people of goodwill can come together to solve large problems. Kidney disease impacts Americans in every community, and during this *Decade of the Kidney*™, the time is now for each of us to learn more about the risks it poses, who is most vulnerable, and to hold our elected leaders accountable for making it a national priority." Hickey is a former Congressional staff member who was involved in the first comprehensive Congressional initiative on brain diseases. He has served in two presidential administrations, including roles as a liaison to Veteran Service Organizations, such as the Vietnam Veterans of America, AMVETS, the Veterans of Foreign Wars, and the American Legion.

AAKP Chair of Policy and Global Affairs Paul T. Conway, a 40-year kidney patient and transplant recipient, stated, “Americans share a common spirit of independence and an innate instinct to fight against anything that encroaches upon our ability to work, achieve, and pursue our aspirations. Yet, kidney disease and the underlying vulnerabilities it creates, left untreated or without more care innovation, can dampen that spirit, damage careers, and make dreams elusive. AAKP hopes kidney patients pay attention to the ongoing risks to their health posed by COVID-19 and the Delta variant, safely enjoy the holiday, and ask their friends to join the fight against this deadly disease and in support of greater advances in care innovation." Conway has served as the Chief of Staff of the U.S. Department of Labor and in multiple policy positions under three U.S. presidents and three state governors.

AAKP works closely with federal government officials, medical researchers, industry leaders, and investors who are committed to re-establishing kidney patient consumers to their rightful place at the center of all kidney health, innovation, research, and policy decisions. The organization provides original kidney patient population survey data and expert advice to leaders in government, industry, think tanks, and academia involved in standing up and recruiting patients for technical evaluation panels, in-person and virtual focus groups, formal advisory committees, clinical trials, and efforts to include substantive patient insight data across the product development lifecycle.

In 2019, AAKP launched The Decade of the Kidney™, a patient-led initiative designed to increase patient care choice and access to new care options, federal kidney disease research funding, increased living kidney donation and transplants, legal protections for living organ donors facing insurance discrimination, greater home care and telemedicine options, and the availability of artificial implantable or wearable kidney. The next generation of kidney diagnostics, biologics, and devices are being informed and driven by the science of unique patient insights, real world evidence (RWE), and patient reported outcome data (PRO). Research, industry, and patient advocates are working closely with career, appointed, and elected federal officials to make certain that patient insight data is also being incorporated into federal frameworks for regulatory and payment decisions so that life-saving treatments reach consumers safely and without unnecessary delays or unnecessary barriers.

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About the American Association of Kidney Patients (AAKP): Since 1969, AAKP has been the largest kidney patient organization driving policy discussions on kidney patient consumer care choice and treatment innovation. 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 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 www.aakp.org for more information.