

FOR IMMEDIATE RELEASE July 3, 2024

MEDIA CONTACT:

Jennifer Rate
Director, Communications and
Digital Operations
jrate@aakp.org
(813) 400-2394

Independence Day Celebrated Across Kidney Community

July Fourth Marks New Highpoint in 2024 Voter Registration Campaign

Non-Partisan KidneyVoter™ Drive Fueled by Federal Policy Disarray

Washington, D.C. – On the Fourth of July, American Independence Day, the American Association of Kidney Patients (AAKP) announced the rapid success and growing impact of its 2024 non-partisan <u>KidneyVoter™</u> registration drive. On June 19, Flag Day, AAKP kicked off its 2024 drive, titled "<u>50 States in 50 Days."</u> As the largest and oldest fully independent kidney patient organization in the nation, AAKP's non-partisan voter registration program engages all people impacted personally and professionally by kidney diseases, kidney failure, and kidney transplant concerns.

For 2024, AAKP has set a target of engaging over 500,000 KidneyVoters™, building on the success of its 2020 goal of engaging over 100,000 KidneyVoters™. As a part of the "50 States in 50 Days" initiative, AAKP has already engaged a record number of kidney community members through grasstops and grassroots efforts across Illinois, Massachusetts, New Jersey, New York, Oregon, Pennsylvania, and Virginia. Interest in the nonpartisan effort has accelerated among kidney patients, organ donors and donor families, kidney care professionals, researchers, and employees of start-up and well-established companies across the medical industry. Over 37 million people are impacted by kidney disease in the United States, nearly one in seven adults, almost 600,000 people receive life-saving kidney dialysis, and over 90,000 people are awaiting a kidney transplant.

AAKP will soon engage kidney community members in the states of Arizona, Georgia, Michigan, Maine, Nevada, North Carolina, and Wisconsin. AAKP utilizes a sophisticated suite of digital and grassroots targeting tools and leverages data gained from online education programs and signature events, legislative awareness campaigns, and issue action campaigns

through AAKP's <u>Patient Choice Patient Voice™ program</u>. AAKP formally launched the KidneyVoter™ registration and mobilization program in <u>2019</u> after first testing various technologies and tactics in 2018 through AAKP's national grassroots and online networks. The program is housed in AAKP's Center for Patient Engagement and Advocacy and coordinates several message campaigns, including "<u>I AM A KIDNEYVOTER</u>™."

AAKP Executive Director Diana Clynes stated, "AAKP began our 2024 KidneyVoter™ drive in the state of New York in honor of our six dialysis Patient Founders who received their care at Kings County Hospital. Beginning in 1969, these brave individuals harnessed the power of patient voices and patient votes to increase their independence from kidney disease and to prevent avoidable deaths among their fellow Americans. By 1973, their pioneering advocacy before the U.S. Congress and White House resulted in dialysis and transplant coverage for every American suffering from kidney failure. AAKP will never forget its advocacy roots or the lesson that citizen participation in elections and the officials we elect to serve us have profound and lasting implications for the future of kidney medicine, patient lives, and patient livelihoods." AAKP Patient Founders led the national grassroots effort that drove Congress to enact changes to the Social Security Act in 1972 to cover dialysis and transplantation. The bipartisan changes were included in Congressional legislation signed by President Richard Nixon in 1973. The benefit, paid by U.S. taxpayers and responsible for saving millions of lives, is commonly known as the End-Stage Renal Disease Program (ESRD), administered by the Centers for Medicare and Medicaid Services (CMS).

AAKP defines kidney disease as both a workforce and health care issue and labels federal government decisions that knowingly or unwittingly harm kidney patients as Government Determinants of Health (GDoH). Multiple federal agencies under the U.S. Department of Health and Human Services (HHS) are currently behind in their commitments and uncoordinated in their approaches to adequately address the decades-long demands of the kidney community. HHS agencies have failed to improve kidney disease screening and prevention recommendations, approve new clinical endpoints to jumpstart a new generation of transplant drugs and align CMS payment regulations to better support patient access to new, FDAapproved drugs, diagnostics, and devices. In one example of GDoH, a decision made by a CMS Medicare Advisory Contractor (MAC) in 2023, publicly defended by the CMS Administrator, has resulted in a 50% reduction in molecular blood tests for organ health surveillance used among kidney transplant patients on Medicare since 2017. AAKP is committed to transforming kidney care beyond the status quo and outdated, high-mortality dialysis care and its associated high levels of unemployment, disability, and dependency. The organization is heavily involved in research and advocacy efforts related to artificial implantable and wearable organs and xenotransplantation.

AAKP advocacy leaders have received numerous awards for their policy efforts before the Executive Branch and Congress. AAKP patient and care partner volunteers received recognition from President Donald Trump in 2020 and President Joe Biden in 2022 through the President's Volunteer Service Award (PVSA) program. AAKP leaders provide unique patient viewpoints to government leaders on a regular basis and have elevated kidney community concerns during the past several presidential transitions (read 2020 and 2021 articles).

AAKP is nationally and globally recognized for leadership in disease education, research partnerships, inclusive clinical trials, and policy advocacy before the U.S. Congress, White House, and international institutions, including the United Nations and the World Health Organization (WHO). AAKP's national and global strategy rests on three core principles: advancement of patient consumer care choice and access to new innovations; protection of the patient and doctor relationship from third-party interference, especially by non-kidney experts; and aggressive support of regulatory and payment policies that accelerate, not impede, advancement of kidney medicine research and patient access to kidney innovations.

###

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. 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.