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Kidney Patients Expand Impact as Kidney Voters™ in 2020

Washington, D.C. - The American Association of Kidney Patients (AAKP), the oldest and largest independent kidney patient organization in the nation, today thanked kidney patient volunteers, their families, and kidney community allies for exercising their influence through voter registration and engagement as self-identified Kidney Voters™ through AAKP's [I Am A Kidney Voter initiative](#) ([#KIDNEYVOTER](#) and [#IAmAKidneyVoter](#)) in the 2020 election ([Read: 2020 and Kidney Voters: AAKP Members Flex Growing Muscle](#)).

In 2018, AAKP developed and launched the first non-partisan kidney community voter education, registration, and turnout drive that had ever been attempted. In 2019, AAKP launched [The Decade of the Kidney™](#) upon the signing of the White House Executive Order on Advancing American Kidney Health Initiative. This strategic effort organizes kidney patient consumers nationally and globally to further drive policies that prevent kidney injury and disease, and support greater patient care choice, innovation, and timely access to care and new treatment options. Based on the grassroots tactics and online technologies refined by AAKP in 2018 and 2019, the [I Am A Kidney Voter initiative](#) has expanded rapidly to include all sectors of the kidney community, including medical professionals such as nephrologists and transplant surgeons, researchers, and workers across the medical industry and policy-influencers. AAKP estimates that their expanded platforms will engage close to 500,000 Kidney Voters™ by the 2022 election cycle while expanding kidney patient consumer demand for full immunosuppressive drug coverage for transplanted kidneys, new diagnostics to detect kidney disease far in advance of current standards, new biologics and precision medicine to treat and slow kidney disease progression, as well as bioengineered and artificial wearable and implantable kidneys to ease transplant waiting times.

AAKP Executive Director Diana Clynes stated, "For over 50 years, kidney patients have led efforts to gain greater life-saving care coverage, including the historic 1973 Congressional and White House decisions to provide dialysis and transplant coverage for those with kidney failure. Today, kidney patients are co-investigators and equal partners in nearly every single major research and innovation initiative that is occurring in kidney diseases. By educating and organizing themselves as Kidney Voters, kidney patients have become an equivalent force in the policy and legislative arena, and going forward, elected leaders at all levels would be wise to include patients and their insights in

policy deliberations that impact their kidney health and innovation. They would be equally wise to reassess their past dependency on status quo special interests who claim to speak for kidney patients yet lack any real insights on the burdens of managing kidney disease."

The objectives of the [I am a Kidney Voter initiative](#) are to remind elected leaders about the importance of the independent kidney patient voice in all policy, regulatory, and legislative decisions that may impact their care choices, and that kidney patients should not be ignored on issues related to access to new care options, including new diagnostics, biologics, and devices. Over the past ten years, patients and policymakers have collaborated to advance the science of patient insights, which is translated into Patient Preference Insights (PPI), Patient Reported Outcome (PRO) data, and Real-World Evidence (RWE). Federal agencies, led by the U.S Food and Drug Administration (FDA) and the National Institutes of Health (NIH) and including the Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Centers for Medicare and Medicaid Services (CMS), Center for Medicare and Medicaid Innovation (CMMI), Department of Defense (DOD), and the Veterans Affairs Administration (VA), have each elevated kidney patients in research, clinical trial, policy, and payment deliberations. Patients play key leadership roles in many federal efforts, including the NIH/National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Kidney Precision Medicine Project, where the patient-led Community Engagement Committee crafted patient consent forms and ongoing enrollment processes; and at the FDA, where patients led the Patient Engagement Advisory Committee (PEAC) for the Center for Medical Devices and Radiological Health and contributed expertise through multiple other FDA formats.

AAKP patient members have been outspoken defenders of patient care choice and innovation, and fierce opponents of legislative efforts, largely led by large corporate dialysis providers, to intentionally limit patient care choice and independence through forced patient enrollment in care plans that ignore patient care preference for greater access to transplantation and home dialysis. AAKP patient members and allies vigorously opposed and helped defeat corporate dialysis industry-supported efforts in Congress to pass the 2017-2018 Dialysis Patients Demonstration Act (DPDA), sponsored by former Senators Dean Heller (R-NV) and Bill Nelson (D-FL). The DPDA legislation limited patient care choice and increased the role of dialysis providers in kidney transplant decisions. Similarly, AAKP patient members and allies are opposed to the current BETTER Kidney Care Act (H.R. 8254/S. 4574), sponsored by Senators Todd Young (R-IN) and Kyrsten Sinema (D-AZ), along with Representatives Earl Blumenauer (D-OR) and Jason Smith (R-MO-8), which is supported by the corporate dialysis industry and is built on the same foundation and follows the same anti-patient choice policy footsteps as the failed Dialysis Patients Demonstration Act.

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About the American Association of Kidney Patients (AAKP): AAKP was founded in 1969 by six kidney dialysis patients in Queens County Hospital in New York who were committed to helping save the lives of fellow kidney patients across America. AAKP grew and from 1969-1973, AAKP patients led efforts in the U.S. Congress, and with White House officials, to establish the End Stage Renal Disease Program, which has saved over a million U.S. lives through modern dialysis coverage. For more

information, visit www.aakp.org. Follow AAKP on social media at [@kidneypatient](https://www.facebook.com/kidneypatient) on Facebook and [@kidneypatients](https://twitter.com/kidneypatients) on Twitter.