



American Association of Kidney Patients  
aakp.org

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## STATEMENT

### KIDNEY PATIENTS COMMEMORATE JUNETEENTH

**Washington, D.C.:** The American Association of Kidney Patients (AAKP), the largest independent kidney patient organization in America, issued the following statement by AAKP President Edward V. Hickey, III, USMC, in commemoration of Juneteenth:

“To all friends and allies of American kidney patients: today, Monday, June 19, marks the celebration of Juneteenth, or Freedom Day, which honors the emancipation of the last remaining enslaved African Americans in the Confederacy—more than two years after Abraham Lincoln signed the Emancipation Proclamation.

Juneteenth provides each of us with an annual opportunity to reflect on the deep historic significance and ongoing importance of this day in our nation’s history. It is a time for all Americans to celebrate African American freedom, promote African American contributions to our shared history, and recognize continued African American achievement throughout our society.

In 2020, at the start of The Decade of the Kidney™ and in the early days of the COVID-19 pandemic, AAKP celebrated Juneteenth and called for greater change and innovation in kidney medicine to address the disproportionate negative impacts of kidney disease and accompanying unmet patient needs among Black and Brown communities. We said then that more thoughtful patient engagement was needed and defined that as greater inclusion of minorities in research, clinical trials, and disease prevention and treatment education. We also said that we must be united in our resolve to end disparate care and to expand care choices for all kidney patients because every kidney patient has the right to pursue their dreams and aspirations.

In the years that followed, COVID-19 exacted a high toll in innocent American lives. Among the most devastated populations were immunocompromised kidney patients on dialysis and immunosuppressed kidney transplant patients—especially people from Black and Brown communities. Mortality rates for kidney patients have been unprecedented and deeply troubling, and have brought renewed national attention to the shortcomings of status quo kidney care. Today, more than 37 million Americans are living with kidney diseases and over 800,000 have kidney failure

and need dialysis or a transplant to live. Alarming, kidney disease is occurring at younger ages, especially in Black and Brown communities.

We believe far more needs to be done to address kidney disease and to accelerate timely innovations—and time is of the essence. Failures to align regulatory and payment decisions in a common sense manner delay timely patient access to new diagnostics, devices, and drugs. This situation is made worse when the federal government tolerates Medicare Advantage programs that market to disadvantaged communities while simultaneously discriminating against highly vulnerable kidney patients by denying immediate access to medically-advised kidney therapeutics that can delay disease progression and help avoid the need for dialysis or kidney transplantation. These failures exacerbate underlying disparities in patient outcomes and create additional burdens for patients related to employment, disability, and dependency. The time is now to address and end these failures.

The pursuit of freedom never ends, and our shared history is a reminder of what can be achieved when we are united in purpose. One purpose we should never lose sight of is how we can secure freedom from disease. As a kidney community, we must unite and work to bring more stakeholders and government officials into the discussions about how to transcend status quo kidney care and how we can cure and end kidney diseases.

As AAKP joins our friends and allies in celebration of Juneteenth, we thank you for the ongoing empathy and care you have for all patients. Please keep up the fight for all impacted by kidney disease, especially for the people most disproportionately impacted by its unique burdens. AAKP remains a steadfast and dependable ally in this noble cause.”

In addition to managing his own kidney disease, Mr. Hickey has been a care partner to others with kidney disease within his own family. Before becoming President of AAKP, Mr. Hickey held the positions of Secretary and Vice President of AAKP and continues to serve as the Chair of the Veterans Health Initiative. His distinguished public service career includes posts on Capitol Hill as an Administrative Assistant, a Special Assistant at the United States Department of Commerce, and following the terror attacks of September 11, 2001, the Senior Advisor for Homeland Security for the Director of the Office of Personnel Management (OPM) under President George W. Bush. At OPM, Mr. Hickey also served as liaison to Veteran Service Organizations nationwide, including the Vietnam Veterans of America, AMVETS, the Veterans of Foreign Wars, and the American Legion. He has coordinated extensively with elected leaders and staff in the U.S. House and Senate as well as the White House to represent the veteran stakeholder interests in the preservation of veterans’ legal rights during reforms to U.S. Civil Service laws.

**The American Association of Kidney Patients (AAKP)** is the oldest and largest fully-independent kidney patient organization in the United States and the strongest advocate for kidney patient consumer care choice. From 1969-1973, AAKP patients led the effort in the U.S. Congress and with senior White House officials to establish the End-Stage Renal Disease Program, which has saved over a million lives through modern dialysis coverage. AAKP announced the start of the Decade of the Kidney™ in June of 2019, and since 2018, has conducted the largest voter education and registration drive in history among kidney patients, caregivers, and healthcare professionals aimed at increasing the kidney patient voice in policy decisions as Kidney Voters. AAKP fights for patient care choice, early detection, increased kidney transplantation and pre-emptive transplantation, protection of the patient/physician relationship, promotion of research and innovation, and the elimination of barriers for patient access to available treatment options.

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**FOR MORE INFORMATION:**

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