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**STATEMENT**

**AMERICAN ASSOCIATION OF KIDNEY PATIENTS COMMEMORATES JUNETEENTH**

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

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**To all Friends and Allies of American Kidney Patients:**

Today, June 19<sup>th</sup>, marks the celebration of Juneteenth, or Freedom Day, which honors the emancipation of the last remaining enslaved African Americans in the Confederacy in 1865 - more than two years after President Abraham Lincoln signed the Emancipation Proclamation on January 1, 1863.

Juneteenth is a unique annual opportunity to reflect on the deep historic significance and ongoing relevance of this day in our nation's history. Often referred to as America's second Independence Day, Juneteenth is a time for every American to celebrate African American freedom, acknowledge African American contributions to our shared history, and recognize continued African American achievement across all areas of society. The legacy of Juneteenth reminds us of the importance of hope during uncertain times and perseverance in the face of adversity.

As AAKP observes Juneteenth, we renew our call for substantive change and innovation in kidney medicine, during this *Decade of the Kidney™*, with a focus on addressing the disproportionately negative impact of kidney disease—including unacceptably high mortality rates and unmet patient needs—among Black and Brown Americans.

Today, an estimated 37 million Americans are living with kidney diseases, and more than 800,000 have kidney failure and require dialysis or a transplant to survive. Alarmingly, kidney disease and its many comorbidities, including diabetes and hypertension, are appearing at younger ages—especially within Black and Brown communities. AAKP has long identified kidney disease as both a healthcare and workforce issue, capable of undermining lives and livelihoods by accelerating unemployment, dependency, and disability. Once again, it is Black and Brown communities that often bear the greatest and unexcusable burden of this condition.

This Juneteenth, please join AAKP in declaring that the time to transcend high mortality, high cost kidney care is now. Our nation can no longer afford – nor should hardworking Americans be asked to support – a status quo kidney care system that fails patients and their families. We must recommit to advancing:

- Proactive disease screening for Americans most at-risk for kidney disease and kidney failure. The United States Preventative Services Task Force (USPSTF) has failed to meaningfully address this issue for over two decades and has consistently ignored the advice of the American kidney community – including the expert voices of patients. Their inaction is a national embarrassment. The USPSTF remains out-of-touch with the nation’s commitment to prevent known disease risks and burdens to both patients and taxpayers.
- Development of more new drugs and therapies that prevent or slow disease progression – and a patient-centered federal Medicare payment system prioritizes long-term patient health – not medical paternalism and lack of care choice.
- Advancement of innovative technologies—including artificial implantable and wearable organs and xenotransplants—that can break the cycle of outdated dialysis treatments, disability and dependency, and prevent premature deaths.

AAKP defines high-quality care as a patient’s ability to choose, and have timely access to, the treatments and prevention services that align with their health goals and life aspirations. When government decisions on regulation and payment systems disrupt innovation and reduce access to new diagnostics, therapies, and devices, we call this a Government Determinant of Health (GDoH). GDoH exacerbates health disparities and places the most vulnerable patients at even greater risk. AAKP will continue to shine a light on GDoH and on the role of any elected or appointed official who fails in their duty to address the needs of the American people—the people they serve.

Thanks to public and private investments in research, science, and innovation, we are in a Golden Era of kidney medicine. With continued support from American taxpayers and the U.S. Congress, we believe historic advancements in kidney care and cures will become reality before the end of this Decade of the Kidney™. If we break down barriers to access, these advancements will benefit all people living with kidney diseases—particularly Black and Brown communities—helping them pursue their freedom and the American Dream.

We can achieve this vision and overcome any obstacle if we hold fast to our hope and never forget our shared history. America is a nation that, united in purpose, can accomplish anything, including the defeat of kidney diseases.

As AAKP joins friends and allies in observing Juneteenth, we thank you for the compassion and concern you show toward individuals and families impacted by this complex, chronic condition. We ask for your prayers for those who are gravely ill and for those we've already lost. And we ask that you continue to stand with us, raise your voices, and remain strong in the fight for kidney patients—especially those who have historically paid the highest price.

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### **About Edward V. Hickey, III, USMC**

In addition to managing his own kidney disease, Mr. Hickey has served as a care partner for family members living with kidney conditions. Before becoming President of AAKP, he held the roles of Vice President and Secretary and has served as Chair of AAKP's Veterans Health Initiative (VHI) since 2017.

Mr. Hickey's distinguished public service career includes positions on Capitol Hill as an Administrative Assistant, as a Special Assistant at the U.S. Department of Commerce, and—following the September 11, 2001 terror attacks—as Senior Advisor for Homeland Security to the Director of the Office of Personnel Management (OPM) under President George W. Bush. At OPM, he also served as liaison to Veteran Service Organizations (VSOs), including the Vietnam Veterans of America, AMVETS, Veterans of Foreign Wars, and the American Legion. He has worked closely with elected officials and staff in both the U.S. House and Senate, as well as the White House, advocating for veterans' rights and stakeholder interests during reforms to U.S. Civil Service laws.

**About AAKP:** Founded in 1969, the American Association of Kidney Patients is the oldest and largest independent kidney organization in the nation. AAKP is a staunch and unapologetic advocate for the principles of patient consumer care choice, the protection of the patient/doctor relationship from third party interference and more intelligent federal regulatory and payment policies that support innovation in kidney diagnostics, medicines, and devices. AAKP believes informed patients are intelligent consumers of healthcare and that patients can speak for themselves on all matters ranging from care quality to public policies that impact their lives and livelihoods.

Over the past decade, AAKP patient members and advocates have helped advance the passage of the bipartisan law modernizing the Organ Procurement and Transplant Network (OPTN) via greater competition and oversight (2023); lifetime transplant drug coverage for kidney transplant recipients (2020); contributed patient insights and lived experiences to inform President Trump's [Executive Order on Advancing American Kidney Health](#) (2019); supported new job protections for living organ donors under the Family Medical Leave Act (FMLA) via the U.S. Department of Labor (2018); and advocated for Congressional legislation allowing HIV-positive organ transplants for HIV-positive patients (2013).