



**FOR IMMEDIATE RELEASE:**  
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## **STATEMENT**

### **Ending the COVID-19 Public Health Emergency:**

#### **DON'T FORGET KIDNEY PATIENTS – THEIR VULNERABILITES REMAIN**

**Washington, D.C.** - As the COVID-19 public health emergency comes to an end, the American Association of Kidney Patients (AAKP), as the oldest and largest patient-led kidney patient advocacy organization in the nation, offers a simple request, on behalf of the millions of immunocompromised kidney disease and dialysis patients and immunosuppressed kidney transplant patients, to policymakers: "Don't you forget about me." AAKP welcomes the many successes America has achieved in the battle against COVID-19 and the opportunity many Americans now have to once again pursue their aspirations. The end of the public health emergency (PHE) was made possible by the ingenuity and dedication of researchers, scientists, medical professionals, public servants, pharmaceutical industry workers, and the enormous generosity of American taxpayers. It has also come after the loss over one million innocent American lives and tens of thousands more who remain debilitated from long COVID.

We also remind government leaders and health insurance executives that science and data show today is not "a different day" for everyone. Highly vulnerable kidney patients have the same worries today that they did yesterday. COVID-19 is not an equivalent threat as the annual flu for this patient community. COVID-19 remains a serious concern for immunocompromised kidney disease and dialysis patients and immunosuppressed kidney transplant patients, many of whom suffer from multiple chronic conditions. Over the past three years, according to federal government data and medical research, COVID-19 has ravaged these unprotected patient populations with some of the highest premature death and mortality rates of any sector of our society.

Based on our ongoing concerns for patients, we offer the following recommendations:

**1.) Align Federal Regulatory and Payment Policies for Vaccine Innovation:**

Federal regulatory and payment polices should encourage, not hinder, the next generation of safe vaccines and therapeutics to protect and treat immunocompromised and immunosuppressed kidney patients, for whom few effective treatment options exist, to prevent severe illness and death.

**2.) Foster Innovation in Transplant Drugs via the FDA Immediately:**

The Secretary of Health and Human Services (HHS) should monitor the U.S. Food and Drug Administration's (FDA) progress in adopting new clinical endpoints and/or secondary endpoints for the advancement of new immunosuppressive drug medications for kidney transplant recipients. This is an unmet need for patients and essential for future transplant drug innovation and reduced transplant patient vulnerability. Immunosuppression therapies used today rely upon endpoints that are 20 to 40 years old, which completely fail to consider long-term graft survival and patient quality of life. Instead, the FDA relies upon a clinical measure based on one year of transplant organ graft failure, a woefully inadequate and outdated measure given the advances in transplant patient survival far beyond the first year. Moreover, unmet needs in this area include antibody mediated rejection and BK virus nephropathy, which currently have no effective FDA approved therapies.

### **3.) Formalize Telemedicine Flexibilities:**

Telemedicine practices, a core element of patient-centered medicine, and associated waivers established by the Center for Medicare and Medicaid Services (CMS) in response to COVID-19, must be made permanent so that kidney patients can continue to exercise maximum patient care choice in the selection of their providers and the safe setting for the care they receive.

### **4.) Expand Home Dialysis Options:**

Home dialysis, which increased during COVID-19 as a patient preference and a comparatively safer alternative to in-center hemodialysis, should be supported and encouraged across the HHS agencies. Increased home dialysis access (hemodialysis and peritoneal dialysis), along with earlier kidney disease detection and innovation in transplantation, was a recommendation within the 2019 *Executive Order on Advancing American Kidney Health* and should remain a top HHS policy priority.

### **5.) Protect the Rights of Kidney Patients Under the ADA:**

The HHS Office of Civil Rights should closely monitor ongoing kidney patient access to critical life-saving procedures in hospitals and healthcare settings, especially when kidney patients contract COVID-19 and need emergency interventions to remain alive. In 2020, [HHS Assistant Secretary for Civil Rights](#) reminded hospitals and hospitalists, in writing, that the rights of kidney patients under the Americans with Disabilities Act (ADA) must not be violated during the COVID-19 pandemic. This happened in response to media reports, and concerns raised by kidney patient advocates and nephrologists, that multiple dialysis patients were denied life-saving treatments in direct contradiction to their expressed desire to live. This was a dark chapter in medicine for kidney patients that will never be forgotten by the kidney patient community and must never be repeated.

### **6.) Expand Data Transparency, Assess Costs to People, Facilitate Accountability:**

All current federal data related to kidney patients since the onset of the COVID-19 pandemic (including data on the CMS 2728 Medical Evidence Form and 2746 Death Notification Form, as well as data previously included in CROWNWeb) must be made available to researchers and the public, within appropriate HIPPA and disclosure standards. It is of great importance that a true picture of how kidney patients have been impacted be established, including COVID-related infections, COVID-related injuries including acute kidney injury (AKI), premature deaths (in all healthcare settings and at the individual facility level), and other data related to COVID-19. Data transparency improves public and patient trust in government and will aid researchers and scientists in their efforts to prepare for future pandemics and to gauge the true magnitude of the COVID-19 pandemic and resulting loss of innocent life, injury, and long COVID.

AAKP is committed to improving kidney patient care choice and access to innovations in COVID-19 therapeutics and treatments. We will continue to advocate for all kidney patients and their families, never forgetting the innocent friends, family members, and kidney allies who lost their lives or had their lives forever altered by this terrible disease.

[Click here](#) to watch OnDemand AAKP's panel discussion, "COVID-19 Concerns for Immunosuppressed Kidney Transplant Patients as the National Public Health Emergency Ends," which took place on March 9, 2023, [World Kidney Day](#), during AAKP's National Kidney Patient Consumer Policy Roundtable: Timely Issues Impacting Kidney Transplant Patients, Drug Innovation, and Living Organ Donors. Esteemed participants included Edward V. Hickey, III, USMC, AAKP President, Chair of the Veterans Health Initiative, former senior U.S. Congressional staff member, and kidney patient; Paul T. Conway, AAKP Chair of Policy and Global Affairs; former Chief of Staff, U.S. Department of Labor; former dialysis patient, 26-year kidney transplant patient (moderator); Jeffery Silberzweig, MD, FASN, Chief Medical Officer and Vice President for Hospital Services, The Rogosin Institute; Professor of Clinical Medicine, Weil Cornell Medicine; Co-Chair American Society of Nephrology (ASN) COVID-19 Response Team; Lisa Glasser, MD, U.S. Medical Affairs Head, Vaccines and Immune Therapies, AstraZeneca; and Glenda V. Roberts, Director of Patient Engagement & External Relations, Kidney Research Institute, Center for Dialysis Innovation, Department of Medicine, Division of Nephrology, University of Washington; Board Member, Kidney Health Initiative (KHI); Transplant Subcommittee Member, American Society of Nephrology (ASN) COVID-19 Response Team; AAKP Ambassador; former dialysis patient, current kidney transplant recipient.

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Since 1969, AAKP has driven national policy discussions on kidney patient consumer care choice and treatment innovation. In 2018, AAKP established the largest U.S. kidney voter registration program, KidneyVoters™. Over 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). Follow AAKP on social media at [@kidneypatient](#) on Facebook, [@kidneypatients](#) on Twitter, and [@kidneypatients](#) on Instagram, and visit [www.aakp.org](http://www.aakp.org) for more information.