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**LARGEST KIDNEY GROUP THANKS PRESIDENT TRUMP FOR SIGNING
PANDEMIC RELIEF AND TRANSPLANT DRUG COVERAGE**

Transplant Drug Reform A Milestone in First Year of AAKP's Decade of the Kidney™

Washington, D.C.: The American Association of Kidney Patients (AAKP), the largest and oldest kidney patient organization in the United States, released the following statement upon President Donald J. Trump's signing of bipartisan, Congressionally authorized immunosuppressive drug coverage provisions for kidney transplant patients. The provisions were included in Congressional actions related to the COVID-19 pandemic relief package and \$1.4 trillion omnibus spending bill. AAKP patient volunteers used the organization's sophisticated communications systems to drive Congressional action and mobilize the most comprehensive national grassroots campaign in its 50-year history, the effort included, coordinated local virtual kidney patient networks, text messages, emails, and multiple social media platforms. In 2018, AAKP launched the first [kidney patient voter registration campaign](#) in the kidney community, "Kidney Voters," which expanded exponentially in 2020 and has provided unique data insights to better target kidney patient voices in national policy debates and Congressional deliberations. AAKP will engage and educate over 500,000 "Kidney Voters" by 2024.

The new coverage provisions end the current, arbitrary 36-month limit on transplant drug coverage for kidney transplant recipients—a massive policy reversal that kidney patient advocates, transplant professionals, and allied members of the kidney community have fought to change for two decades. Kidney transplant patients must take a lifetime course of immunosuppressive drugs to keep their transplanted kidneys working and to prevent organ rejection. Interruptions to drug coverage have serious impacts on transplant recipients; can

lead to organ rejection; and a return to high cost, high mortality dialysis—a comparatively less ideal treatment for kidney failure. The Congressional Budget Office reports that the policy change will positively impact hundreds of kidney transplant patients every year and save taxpayers hundreds of millions of dollars over the next ten years.

AAKP STATEMENT

“The American Association of Kidney Patients extends our appreciation to President Trump for signing pandemic relief for Americans in desperate need and for extending immunosuppressive drug coverage to kidney transplant patients. In 2019, President Trump and HHS Secretary Alex Azar, consistent with insights shared by kidney patients and the medical allies with whom they met, initiated a bold reform vision for the outdated, status quo kidney care system through the *Executive Order on Advancing American Kidney Health*. We are pleased Congress also listened to kidney patients and their medical allies and took bipartisan action to support the reform vision. The extension of immunosuppressive drug coverage and elimination of the current, arbitrary 36-month limit removes a long-standing barrier to increased kidney donation, kidney transplantation, and patient care choice. The signing of this bill marks a historic milestone for the first year of the AAKP initiated and led Decade of the Kidney™ and we will closely monitor implementation. In memory of all patient advocates who worked for this policy change, and whose lives ended before they could witness this victory, AAKP will expand our capacities to organize, train, and mobilize kidney patients to achieve even greater transformations to status quo kidney care in the years ahead.”

In 2019, upon the signing of President Trump’s *Executive Order on Advancing American Kidney Health*, AAKP launched [The Decade of the Kidney™](#), a strategic effort to organize kidney patient consumers nationally and globally to drive policies to support greater patient care choice, accelerate timely access to treatment options including preemptive kidney transplants, drive innovations including artificial implantable and wearable kidneys, expand kidney precision medicine and research, and prevent kidney injury and disease. AAKP has been a staunch defender of kidney patient care choice and defines quality kidney care as a treatment that best aligns with patient aspirations, including the ability to work full-time or part-time and have a career, to start a family, own a home, and retire securely. AAKP and its allies have worked against corporate dialysis industry efforts in Congress to deny kidney patient consumers their right to care choice and access to treatment innovations and spearheaded kidney patient efforts that helped defeat the controversial Dialysis Patients Demonstration Act. AAKP is currently organizing kidney patients nationwide to defeat another dialysis industry backed bill that limits kidney patient care choice, the “BETTER” Kidney Care Act.

In a statement ([read announcement](#)) issued December 21, 2020, U.S. Senate passage of immunosuppressive drug coverage, AAKP thanked Senate Majority Leader Mitch McConnell (R-KY), Senate Minority Leader Chuck Schumer (D-NY), Senator Bill Cassidy (R-LA), Senator Dick Durbin (D-IL), and Senator Joe Manchin (D-WV) and their Senate colleagues for listening to the voices of kidney patients and reversing the current, arbitrary 36-

month limit on transplant drug coverage. Similarly, AAKP issued a statement ([read announcement](#)) on December 8, 2020, after the U.S. House of Representatives passed similar language. AAKP thanked Speaker Nancy Pelosi (D-CA), Minority Leader Kevin McCarthy (R-CA), Representatives Ron Kind (D-WI), Michael Burgess (R-TX), Jimmy Panetta (D-CA), Jason Smith (R-MO), and all other Congressional Members for respect for kidney patient insights on the need for immunosuppressive drug coverage. AAKP leaders have also recognized the role of U.S. Secretary of Health and Human Services Alex Azar, Comptroller General of the United States Gene Dodaro, and Congressional Budget Office Directors Phillip Swagel, predecessor Keith Hall, and their staffs for respecting the unique insights and life experiences of patients who have fought to maintain their transplants amidst the loss of immunosuppressive drug coverage.

In November of 2020, over 25 AAKP kidney advocates were recognized with the President's Volunteer Service Award (PVSA) for their ongoing advocacy for kidney transplants and response to the COVID-19 pandemic ([read announcement](#)). AAKP patient volunteers provide an independent patient view on kidney issues through sophisticated virtual platforms, international patient group partnerships, clinical journal editorials, television, radio, social media, and a growing [Patient Ambassador Initiative](#). At the start of the COVID-19 pandemic, AAKP transitioned all 2020 events to free virtual access, prioritized COVID-19 topics, and leveraged tactics to engage a wider audience. In the past eight months, AAKP has broadcasted expert COVID-19 insights through one [global](#) and two [national virtual events](#), a dozen [webinars](#), and launched advocacy campaigns to [highlight disparities](#) in minority and kidney patient representation in COVID-19 clinical trials and vaccine distribution protocols. Viewership for 2020 AAKP programs now exceeds 80,000 people across 70 countries and is growing rapidly. International and national program faculty have included 90 medical practitioners and researchers, and 60 patient experts. The [AAKP Global Summit on Kidney Innovations](#), conducted in partnership with The George Washington University School of Medicine and Health Sciences, alone reached over 20,000 patients and professionals worldwide in July of 2020.

AAKP Board Members and patient members play key roles in top federal initiatives including: the National Institutes of Health/National Institute of Diabetes and Digestive and Kidney Diseases (NIH/NIDDK) Kidney Precision Medicine Project (KPMP); the U.S. Food and Drug Administration (FDA) Patient Engagement Advisory Committee (PEAC), the Kidney Health Initiative (KHI), a partnership between the FDA and the American Society of Nephrology as well as the U.S. Department of Health and Human Services Kidney Innovation Accelerator, or KidneyX.

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Established in 1969, AAKP maintains a national and global network of patient advocates, kidney researchers, medical innovation leaders and policy influencers. From 1969-1973, AAKP patients led the effort in the U.S. Congress, alongside senior White House officials, to establish the End Stage Renal Disease Program (ESRD),

which has saved over a million lives through modern dialysis coverage as administered by the Centers for Medicare and Medicaid Assistance. For more information, visit www.aakp.org. Follow AAKP on social media: [@kidneypatient on Facebook](#), and [@kidneypatients on Twitter](#).