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COVID-19 SPURS HUGE VIRTUAL CONGRESSIONAL CONTACT WITH KIDNEY PATIENTS AND TOP DOCTORS

Washington, D.C.: The American Association of Kidney Patients (AAKP), the largest kidney patient organization in America and the fully independent voice for kidney patients, partnered with the Renal Physicians Association (RPA) to host their annual Capitol Hill Day on June 26. The effort, conducted virtually and coordinated across social platforms and email, set a record for single day contacts by both organizations. Prior to the congressional visits, the U.S. Centers for Disease Control and Prevention (CDC) listed chronic kidney disease (CKD) patients, patients with organ transplants, and those on immunosuppressive medications at high-risk for COVID-19.

Patients and renal professionals discussed key issues including the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act (S. 3353 / H.R. 5534) and the Living Donor Protection Act (S. 511 / H.R. 1224) as well as telemedicine flexibilities extended by CMS during the coronavirus pandemic. AAKP has been heavily involved in educating living organ donors on the protection precedents set by the 2018 executive branch extension of organ donor protections through the U.S. Department of Labor's Wage and Hour Division.

Over 100 advocates participated in 135 congressional visits with elected leaders and staff representing 35 targeted states and the District of Columbia. The kidney doctors who participated included many on the frontlines of the COVID-19 pandemic, many of whom have witnessed the devastating impacts and fear of the disease among their highly vulnerable patients. Doctors were joined by patients, family members, and caregivers.

AAKP also activated its national membership through its AAKP Center for Patient Engagement and Advocacy, including fellow patients in the middle of dialysis treatments, to use smart phones and iPads to submit letters to Congress. Thousands of letters were sent to Capitol Hill, demonstrating that COVID-19 has actually increased patient engagement as AAKP forecasted in its March release (<https://aakp.org/coronavirus-expands-kidney-patient-virtual-engagement-with-white-house-and-congress/>).

"Our 2020 Capitol Hill Day, in partnership with AAKP, was the largest RPA Hill Day ever, and this happened in no small part because of the technological ability to bring doctors and patients together virtually; this will likely be part of a hybrid approach in the future," states Robert Blaser, Director of Public Policy with RPA. Blaser is a highly respected kidney legislation expert and a recipient of the AAKP President's Award for his efforts on behalf of kidney patients and their families.

AAKP President Richard Knight, a former in-center hemodialysis patient and current 14-year transplant recipient stated, "Patients and doctors have a timely view on how Congress can immediately help improve

kidney patient outcomes, especially among hard hit minority communities, in the midst of the coronavirus pandemic. We believe our combined voices will lead Congress to put aside their differences and prioritize measures that can save patient lives immediately.” Knight is heavily involved in national kidney policy and serves as the Co-Chair of the Community Engagement Committee for the National Institutes of Health/NIDDK Kidney Precision Medicine Program (KPMP).

Paul T. Conway, Chair of AAKP Policy and Global Affairs and a 23-year transplant recipient stated, “AAKP expanded our national and international virtual engagement technologies prior to the COVID-19 pandemic and the investments have made a strategic difference in this crisis for kidney patients and their doctors. As allies, we will continue to raise a coordinated voice on critical issues including the need for greater representation of minority populations and kidney patients in COVID-19 vaccine clinical trials.” Conway serves as AAKP liaison to the Federal Health Infection Control Practices Advisory Committee, (HICPAC), a Federal Advisory Committee appointed to provide advice and guidance to the CDC and Department of Health and Human Services (HHS) regarding the practice of infection control and strategies for surveillance, prevention, and control of healthcare-associated infections, antimicrobial resistance, and related events in healthcare settings.

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About the American Association of Kidney Patients (AAKP): AAKP is among the strongest advocates for kidney patient consumer care choice and treatment innovation. 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 virtual platforms and social networks are internationally known for their impact. In 2019, AAKP, in collaboration with the *George Washington University School of Medicine and Health Sciences*, utilized virtual capacities to livestream the [Inaugural Global Summit on Kidney Disease](#), engaging over 10,000 kidney patients, health system administrators, and medical experts in over 50 countries. Also in 2019, AAKP announced the start of the [Decade of the Kidney™](#) upon the signing of the Executive Order on *Advancing American Kidney Health Initiative*. Since 2018, AAKP has conducted the largest virtual kidney voter registration drive in the nation, the [“I am a Kidney Voter” campaign](#), which has registered patients in every state. AAKP fights for policies to increase early disease detection; increase kidney transplantation and pre-emptive transplantation; protect the patient/physician relationship; promote research and innovation; and eliminate of barriers for patient access to available treatment options.