



FOR IMMEDIATE RELEASE:

April 16, 2021

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KIDNEY PATIENTS AND DOCS ASK CONGRESS TO EXPAND RESEARCH AND INNOVATION

Amidst COVID-19, Largest American Kidney Organizations Back Strategic Funding for NIH and KidneyX

Washington, D.C.: The American Association of Kidney Patients (AAKP), the largest kidney patient organization in America, partnered with the American Society of Nephrology (ASN), the world's largest renal professional organization, to host their 9th Annual Kidney Health Advocacy Day on April 14th. The event centered on two specific Congressional kidney funding requests, \$25 million for the KidneyX, a collaborative between ASN and the U.S. Department of Health and Human Services (HHS), and an additional \$285 million for the National Institutes of Health (NIH), each designed to accelerate groundbreaking advances in kidney disease research and innovation. Together, the organizations conducted dozens of joint, virtual meetings among key Congressional offices representing twenty-five states. The reach of the Kidney Health Advocacy Day event was further amplified as patients - including many undergoing dialysis treatments in real-time, families, living kidney donors, and renal doctors across the nation, engaged through AAKP's Center for Patient Engagement and Advocacy via smart phones and iPads in a simultaneous contact campaign with Congress. AAKP is a national leader in efforts to expand the impact of patient insight information in all Congressional and federal agency discussions and decisions ([read article](#)).

AAKP President Richard Knight, a former hemodialysis patient and current 14-year transplant recipient stated, "We appreciate our ongoing collaboration with ASN and believe our shared views provide a unique doctor and patient perspective to Congress on how they can make a substantive impact on kidney disease and improve patient outcomes, especially among communities of color who are disproportionately impacted by both this disease and COVID-19." Knight is a small business consultant and business strategy instructor at Bowie State University (HBCU) as well as a former Congressional staff member and liaison to the Congressional Black Caucus.

Congressional leaders were asked to accelerate innovations in kidney treatments by providing an investment in FY22 of \$25 million to support the KidneyX prize competition aimed at supporting the development of artificial kidney technologies, including wearable and implantable artificial kidneys, and other novel innovations. KidneyX launched the Artificial Kidney Prize in 2020 as a long-term commitment to the development of an artificial kidney and the first round of prizes will be awarded in FY21. Parallel sign-on letters in support of the \$25 million KidneyX request are circulating in the House and Senate, led by multiple leaders including Rep. Suzan DelBene (D-WA), Rep. Larry Bucshon (R-IN), Senator Ben Cardin (D-MD), and Senator Todd Young (R-IN). Learn more about KidneyX by watching a presentation hosted during an AAKP Global Summit on Kidney Innovations, held in partnership with the George Washington University School of Medicine & Health Sciences. ([Watch OnDemand](#) or [click here to download slide presentation](#))

Additionally, Congressional leaders were asked to provide an additional \$270-285 million in FY22 to support kidney research efforts at the National Institutes of Health (NIH), particularly those at the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK). AAKP formulated the NIH request to keep pace with medical research cost inflation, to make-up for lost NIH kidney research grant funding due to the impacts of COVID-19 on NIH operations, and to substantively increase investments in kidney health research to lead to

more discoveries to slow and prevent kidney failure, determine long-term impacts of COVID-19 on kidneys, and address health disparities.

In 2019, AAKP declared 2020-2030 *The Decade of the Kidney*™ (www.decadeofthekidney.org) and substantial increases in Federal, academic, and private sector investments in kidney disease research were identified as a top priority to combat the disease, spur innovation, expand patient consumer treatment choice, and to better serve communities most impacted, especially communities of color. A recent AAKP kidney patient and stakeholder survey, conducted under the AAKP Center for Patient Research and Education, indicated overwhelming support for additional and substantial long-term increases to the NIH budget for kidney research. In 2020, AAKP initiated a national patient consumer grassroots education campaign to lay the groundwork for greater investments in kidney research across all sectors. AAKP has increased its education campaign on the link between kidney research and health outcomes through its *KidneyVoters*™ initiative (<https://bit.ly/KidneyVoters>), the first and largest voter registration effort in the kidney stakeholder community.

AAKP Vice President and Chair of the AAKP [Veterans Health Initiative](#), Edward V. Hickey, III, USMC, a chronic kidney patient, stated “AAKP appreciates the Congressional commitment to kidney disease and their demonstrated interest in working directly with kidney patient experts and professionals on a long-term, research-based framework for addressing kidney disease and treatment.” Hickey is a former Congressional staff member who was involved in the first comprehensive Congressional initiative on brain diseases. He has served in two presidential administrations, including roles as liaison to Veteran Service Organizations, such as the Vietnam Veterans of America, AMVETS, the Veterans of Foreign Wars, and the American Legion.

Current NIH/NIDDK funded research efforts include the groundbreaking [Kidney Precision Medicine Project \(KPMP\)](#), a research consortium led by an equal partnership of kidney research and patient experts. KPMP is designed to better understand and discover new means to treat chronic kidney disease (CKD) and acute kidney injury (AKI) through kidney tissue samples altruistically provided by patient research collaborators. Learn more about the KPMP from Dr. Jonathan Himmelfarb, Co-Director of the University of Washington Center for Dialysis Innovation (CDI) and Director of the Kidney Research Institute (KRI), from his presentation at the 2020 AAKP Global Summit on Kidney Innovation: [Emerging Research with Global Implications: Identification & Diagnosis of Kidney Diseases – The Kidney Precision Medicine Project](#). NIH is also heavily involved in patient-centered research related to APOL1 genetic variants, a key risk factor for CKD and kidney failure among African, Caribbean, and Latin Americans, and a factor related to disparate kidney health outcomes. Learn more about [APOL1 research](#) in an AAKP webinar featuring Dr. Barry I. Freedman, Wake Forest School of Medicine and Principal Investigator, APOLLO Scientific Data and Research Center, along with fellow research and patient colleagues – [Who is at risk: Understanding the connection between APOL 1 gene and kidney disease](#).

AAKP Chair of Policy and Global Affairs Paul T. Conway, a 24-year kidney transplant patient and former dialysis patient stated, “Kidney disease is a health, disability, and workforce issue that costs taxpayers and the economy \$130 billion in annual Medicare spending, including \$50 billion just to manage kidney failure and dialysis care. Less than one percent of this cost is invested in kidney health research, so *The Decade of the Kidney*™ is a time for all stakeholders, including elected leaders, to think more strategically about saving lives through increased research funding, expanded talent pipelines to draw in experts from more diverse disciplines, and new policies to encourage private investors and market forces to create new technologies and jobs that target disease prevention, detection, and treatment.” Conway has served in three presidential administrations and is a former Chief of Staff of both the U.S. Department of Labor and the U.S. Office of Personnel Management with a background in labor, workforce and health policy implementation and stakeholder relations.

More than 37 million Americans are living with kidney diseases, which for nearly 800,000 Americans progresses to kidney failure, a life-threatening condition for which there is no cure. This under-recognized epidemic disproportionately affects communities of color. For instance, Black Americans comprise 13 percent of the U.S. population but represent 33 percent of Americans receiving dialysis, the most common therapy for kidney failure. The COVID-19 pandemic is especially deadly for kidney patients. Americans with kidney

diseases are the most at risk among Medicare beneficiaries for severe outcomes from COVID-19, including hospitalization and death, and COVID-19 damages the kidneys of as many as 50 percent of all hospitalized COVID-19 patients, even those without a prior history of kidney diseases.

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About the American Association of Kidney Patients (AAKP): Since 1969, AAKP has been the largest kidney patient organization driving policy discussions on kidney patient consumer care choice and treatment innovation. By 1973, AAKP patients had collaborated with the U.S. Congress and White House to provide dialysis coverage for any person suffering kidney failure, a taxpayer-funded effort that has saved over one million lives. 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). AAKP virtual platforms and social networks are internationally known for their impact. Follow AAKP on social media at [@kidneypatient](#) on Facebook and [@kidneypatients on Twitter](#) and visit at www.aakp.org.