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**KIDNEY PATIENTS AND DOCS ASK CONGRESS TO EXPAND KIDNEY R & D PLUS
TELEHEALTH FLEXIBILITIES**

***Kidney Patient Consumers Expand National and Global Impact on Legislative, Regulatory, and
Coverage Actions***

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 kidney professional organization, for a virtual 2021 Capitol Hill Annual Kidney Community Advocacy Day on September 22, 2021. AAKP has a fifty-year history of Congressional and White House advocacy that began in the late 1960s and includes a historic event when an AAKP patient founder, Shep Glazer, dialyzed in front of the U.S. House Ways and Means Committee. Glazer and allied medical experts successfully demonstrated to Congress how innovations in kidney research and treatment could save lives, help people return to work, and serve as a critical bridge to better long-term therapies like kidney transplantation. Congress, inspired by Glazer's example, authorized dialysis treatment for every American suffering from kidney failure in 1972. President Richard Nixon signed the authorizing legislation in 1973 and established the modern End Stage Renal Disease (ESRD) program. The ESRD program is administered by the Centers for Medicare and Medicaid Assistance (CMS) and has saved over a million lives since it was initiated.

AAKP is a national leader in efforts to expand the use of patient insight information in all Congressional and federal agency discussions and decisions ([read article](#)) and leads a growing global patient consumer and allied expert network working to expand kidney patient consumer choice and access to innovations, including artificial kidneys ([read here](#)).

For the Capitol Hill Annual Kidney Community Advocacy Day, patients and doctors conducted over 150 virtual meetings among key Congressional offices representing dozens of states. Key priorities raised during the Congressional virtual visits included: a request for over \$2 billion in funding to accelerate advances in kidney disease research and innovation at the National Institutes for Diabetes, Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) ([read here](#)); \$25 million for KidneyX, a collaborative between ASN and the U.S. Department of Health and Human Services (HHS); and support for the CONNECT for Health Act (H.R. 2903/S. 1512) designed to enable permanent patient access to telehealth services that have temporarily been made available by CMS due to the COVID-19 pandemic. The CONNECT for Health Act removes outdated home and originating site restrictions, allowing kidney patients far greater independence and more freedom to manage their care as well as greater access to home dialysis options. Advocates also raised the need patients and living organ donors have identified for greater Congressional protections for living kidney donors so that a decision to give the gift of life does not jeopardize employment or subject donors to life and disability insurance discrimination ([read here](#)). In 2018, AAKP, the American Society of Transplant Surgeons, the American Society of Transplantation, and allied kidney community organizations successfully worked with the U.S. Department of Labor to secure employment protections for living organ donors, protections which have yet to be formalized through Congressional legislation. The 2018 protections were extended through a [formal opinion letter](#) from the Department of Labor stating that Family Medical Leave Act (FMLA) coverage

extends to organ donation and that eligible employees are entitled to unpaid and job-protected leave because related care procedures such as overnight and in-patient and follow-up care qualify.

For the virtual Congressional visits, AAKP joined allies including the Renal Physicians Association, Alport Syndrome Foundation, the American Kidney Fund, the American Nephrology Nurses Association, the American Society of Diagnostic and Interventional Nephrology, the American Society of Pediatric Nephrology, the American Society of Transplant Surgeons, the American Society of Transplantation, Home Dialyzors United, IGA Nephropathy Foundation of America, the National Kidney Foundation, the Oxalosis and Hyperoxaluria Foundation, the Polycystic Kidney Disease Foundation, the Rare Kidney Disease Foundation, the Renal Pathology Society, the Society for Transplant Social Workers, and the Veterans Transplant Association. In 2019, AAKP declared 2020-2030 *The Decade of the Kidney*[™] (www.decadeofthekidney.org) to prioritize national and international government, academic, and private sector investments in kidney disease research and to support the development of new diagnostics, devices, and biologics to combat the disease. Since 2018, AAKP has been training patient advocates in policy analysis and grassroots tactics to support its *KidneyVoters*[™] initiative (<https://bit.ly/KidneyVoters>), the first and largest non-partisan voter registration effort in the kidney stakeholder community which aims to mobilize 500,000 *KidneyVoters*[™] by 2024.

The September 22 Congressional visits built on over 100 similar meetings AAKP executed on May 21 in partnership with the Renal Physicians Association (RPA). Highlighting the strategic importance of kidney patients and doctors working together to advance investments in kidney research and innovation, RPA President Tim Pflederer, MD, stated, “RPA greatly values our now over ten-year partnership with AAKP for Capitol Hill Day. The kidney patient-nephrologist combination in advocating on issues such as access to appropriate care, lifetime immunosuppressive drug coverage, and promotion of innovation in chronic kidney disease care is unsurpassed. We look forward to many years of joint advocacy with AAKP on issues affecting kidney patients and their physicians.” The online engagement and impact of kidney patient and medical professional advocacy days is leveraged through AAKP’s Center for Patient Engagement and Advocacy, which enlists patients across the nation via smart phones and iPads in a simultaneous contact campaign with local Congressional offices outside Washington, D.C.

AAKP President Richard [Knight](#), a former hemodialysis patient and current 14-year transplant recipient stated, “We appreciate our ongoing collaboration with ASN and allied kidney community stakeholders like the RPA. We believe our combined efforts to increase investments in kidney research and innovation, along with the advancement of telemedicine, can make a substantive impact on kidney disease and improve patient consumer outcomes, especially among rural communities and communities of color that are disproportionately impacted by kidney disease and COVID-19.” Knight is a small business consultant and business strategy instructor at Bowie State University (BSU) as well as a former Congressional staff member and liaison to the Congressional Black Caucus.

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, healthcare professionals, and the larger kidney community on a long-term, research-based framework for addressing kidney disease and methods of treatment.” [Hickey](#) serves as the Director of Staff Attorneys at the national law firm of O’Melveny & Myers and is the newly named Co-Chair of *O’Melveny Salute*, the firm’s internal veterans advisory group representing all branches of the military. 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.

AAKP Chair of Policy and Global Affairs Paul T. Conway, a 24-year kidney transplant patient and former dialysis patient stated, “Congress took an important first step in creating legal protections for living organ donors through the Living Donor Protection Act. Bill sponsors have been working to strengthen their legislation and progress has been made. Kidney disease is a health, disability, and workforce issue that costs taxpayers and the economy \$130 billion in annual Medicare spending, including over \$50 billion just to manage kidney failure and dialysis care. *The Decade of the Kidney*[™] is a time for a renewed commitment to saving lives

through increased innovation, more living kidney donation, and the realignment of regulatory and payment barriers that prevent safe kidney innovations from entering consumer markets and becoming more accessible to kidney patient consumers." [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.

Current NIH/NIDDK 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 2021 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](#).

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 www.aakp.org for more information.