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Kidney Patients Cite Insurance and Payment Issues as Critical Barriers to FDA Approved Care Innovations

Patients and Taxpayers Forced to Absorb Preventable Costs

Patient Voice Patient Choice™ Campaign Engages Private Insurers and CMS

WASHINGTON, D.C. – The American Association of Kidney Patients (AAKP), the nation's largest independent and patient-led kidney organization, unveiled an aggressive consumer engagement and mobilization campaign to help patients engage their commercial insurers and the Centers for Medicare and Medicaid Services' (CMS) on coverage decisions that undermine patient access to new and safe care innovations approved by the U.S. Food and Drug Administration (FDA). The [AAKP Patient Voice Patient Choice™](http://www.patientvoicepatientchoice.org) campaign provides a sophisticated, interactive platform for patients, care partners, and others of goodwill to quickly identify and understand barriers impacting care choice and timely access to new treatments (www.patientvoicepatientchoice.org). The campaign includes tactics such as social media, letters to insurers and shareholders, online petitions, Congressional contact software, and voter registration tools.

In the United States, AAKP and allied kidney medical professionals, along with bipartisan leaders in the U.S. Senate and House of Representatives, have pushed to increase kidney research funding and to accelerate policies that remove barriers to treatment innovation. In the past several years, the FDA has increased substantive patient engagement, listened closely to patient concerns, and has approved several long-awaited and safe advancements in kidney care. The FDA's approvals have sparked massive, renewed interest in kidney medicine among existing and start-up pharmaceutical and medical device companies. The FDA's approvals have also created tremendous hope among patients and families suffering from the devastatingly high personal and financial costs of kidney diseases and related conditions such as diabetes, pruritus, and other debilitating ailments. Newly approved innovations include improved dialysis

technologies, including those used in home dialysis, which help patients gain greater independence, including the ability to pursue aspirations for full-time and part-time work.

However, access to new kidney innovations has been severely curtailed by intentionally cumbersome insurance policies and cost controls that interfere with the ability of kidney doctors to prescribe the right treatment at the right time. These same payer policies often force highly vulnerable patients and their caregivers to navigate lengthy and complicated appeals processes. Unfortunately, many of these appeals offer little hope of a reversal, despite growing medical evidence that new therapies improve health outcomes beyond status quo kidney treatments. Nationally, intensifying patient frustrations toward insurers and barriers to timely treatment access have fueled bipartisan Congressional support for [H.R. 3173 Improving Seniors' Timely Access to Care Act](#), sponsored by Congressional Kidney Caucus Co-Chair Representative Suzan DelBene (D-WA) and supported by Caucus Co-Chair Larry Bucshon (R-IN). AAKP also supports H.R. 3173. AAKP supports the efforts of Representatives DelBene and Bucshon to increase care choice and access for patients.

AAKP President Richard Knight, [a national kidney advocate](#), stated, "Kidney patient consumers and their allies have worked for many years to bring new treatments to market and to end disparate care. They are not about to sit idly as payer policies and red tape block timely access to care options that prevent further suffering or more serious illness. AAKP has organized patient consumers and they will raise their voices and exercise their votes to hold insurers, elected leaders, and other decision makers publicly accountable for their indifference toward highly vulnerable kidney patients." At a June 14, 2022, virtual event, *The Hill Live: Chronic Kidney Disease – Forging Patient-Centered Solutions*, Knight and AAKP thanked companies that have already been responsive to kidney patient concerns. Knight and AAKP also called out Humana for their ongoing lack of responsiveness to kidney patient concerns and for Humana's byzantine policies that block diabetic kidney disease (DKD) patients from gaining full access to a new treatment that slows DKD progression ([WATCH HERE](#)). Knight is a former dialysis patient, current 16-year transplant recipient, and a former U.S. 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, stated, "AAKP is increasingly concerned that access-related issues are interfering with gains in kidney medicine during The Decade of the Kidney™. We strongly encourage responsible leaders in the insurance industry and at CMS to elevate these issues internally and weigh the ongoing defense of restrictive policies against the long-term costs borne by patients, taxpayers, and the nation when new treatments are walled off from patients in serious need. Defending status quo healthcare in an era of innovation is never a sustainable position." [Hickey](#) is a former Administrative Assistant on Capitol Hill and was involved in the first comprehensive Congressional initiative on brain diseases. He has served in two presidential administrations, including roles as a liaison to national 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 42-year kidney patient who has lived with a kidney transplant for the past 25 years, stated, "The alignment of insurer and federal payment decisions to new, federally-approved and safe kidney therapies and devices is pivotal to sustained private sector involvement in kidney innovations and improved health outcomes. If current payer policies fail to evolve, advances in kidney care are in jeopardy, and both patients and American taxpayers will continue to bear the long-term costs of avoidable and unnecessary

kidney disease complications and kidney failure. AAKP patient members and our allies find this situation totally unacceptable and are already taking action.” [Conway](#) is a former Chief of Staff of the U.S. Department of Labor and the U.S. Office of Personnel Management, which administers the Federal Employees Health Benefits Program (FEHBP), the world’s largest employer-sponsored group health insurance program.

The Patient Voice Patient Choice™ campaign is another element of [AAKP’s Decade of the Kidney™](#) initiative (www.decadeofthekidney.org), launched in 2019. The initiative aims to widen national and global kidney patient involvement in decisions that impact disease research and the development of innovations, including safe new drugs, devices, and transformative technologies including artificial wearable and implantable kidneys and xenotransplants. For the past four years, AAKP, in partnership with the George Washington University School of Medicine and Health Sciences, has also led the [Global Summit on Kidney Disease Innovations](#), one of the largest patient-led innovation conferences in the world with engagement in over 80 countries. In June of 2022, the European Kidney Health Alliance (EKHA) formally expanded its ongoing involvement in The Decade of the Kidney™ initiative by including it in the theme of their annual European Kidney Forum in the European Parliament in Brussels. AAKP also conducts the largest voter registration drive in the kidney community, the [KidneyVoter™ program](#).

Kidney disease has an incredibly alarming and growing impact on Americans and their families and a disproportionate impact across minority, underserved, and rural communities. The human burdens and costs to patients, their families, and the American taxpayer are immense. Up to 37 million Americans are estimated to have kidney disease, and according to the [Centers for Disease Control \(CDC\)](#), 90 percent of patients are unaware that they suffer from the disease. Kidney disease and kidney failure exact a heavy toll on patients, families, and the American taxpayer, with Medicare costs alone estimated at \$120 billion dollars. Status quo kidney care is characterized by late disease diagnosis, outdated dialysis technologies, disparate treatment access, long waiting times for organ transplants, and extremely high mortality rates.

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About the American Association of Kidney Patients (AAKP): In 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.