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Top Kidney Patient Group Shares National Reuters Pharma Award

New Market-Driven Approach to Patient Engagement, Clinical Trial Design, and Diverse Trial Recruitment Accelerates Innovation and Health Solutions

American Association of Kidney Patients Expands Research and Policy Impacts

Washington, D.C.: The American Association of Kidney Patients (AAKP), the oldest and largest independent kidney patient organization in the U.S., and Bayer were recently honored with the national 2024 Reuters Pharma Award in Driving Health Equity. AAKP and Bayer were recognized for a new market-driven approach to patient engagement, clinical trial design, and diverse trial recruitment that accelerates kidney innovation and expands consumer choice of kidney health solutions.

For Bayer, AAKP developed and engaged a Standing Patient Council that provided a systematic co-development approach to trial design, trial site selection, trial-related information and forms, and recruitment and retention strategies. The Standing Patient Council was representative of the diverse kidney disease population and their insights shaped tactics used to successfully enroll Black and Hispanic kidney patients at sustained levels that exceeded clinical trial expectations. The AAKP and Bayer joint award submission was entitled “*Defining the Value of Patient Engagement through Patient Advocacy Groups: Bayer’s New Blueprint for Clinical Trial Development and Recruitment/Retention Strategies to Drive Patient Diversity Solutions.*”

AAKP President Edward Hickey, III, stated, “AAKP is very proud of the patients who participated in the Standing Patient Council and clinical trial as well as our shared recognition by Reuters with a 2024 Pharma Award. Our partnership with Bayer has been highly successful and we appreciate their ongoing commitment to kidney medicine and their sophisticated understanding of the longstanding unmet patient needs for advanced therapies to prevent, slow, and cure this devastating disease. Together, we have demonstrated a common sense and market-driven approach to respectfully and substantively involve all kidney patients in the research and clinical trials that may impact their lives and livelihoods. We hope more companies follow our example and lean forward to involve the diverse kidney patient community in all

aspects of the product development lifecycle.” Hickey is a U.S. Marine Corps Veteran and has served as a senior staff professional in the U.S. House of Representatives and as a senior appointee in multiple presidential administrations.

In 2019, as the groundbreaking [Executive Order on Advancing American Kidney Health](#) was announced, AAKP declared the next ten years, 2020 to 2030, as *The Decade of the Kidney™* to maintain growing momentum behind the bipartisan national policy commitment to address the unmet kidney patient needs. During The Decade of the Kidney™, AAKP and its allies have also moved to hold federal government officials accountable for policies that foster, and not hinder, greater research, development, and patient access to new kidney drugs, diagnostics, and devices. AAKP has publicly targeted barriers caused by federal government regulatory and payment decisions, referred to as Government Determinants of Health (GDoH) as well as coverage and payment decisions made by insurers that either knowingly or unwittingly interrupt, delay, or deny timely patient access to new innovations. In America and across the globe, kidney patients and advocacy organizations have broadened their impact on innovation through alliances with like-minded research professionals, kidney medicine experts, pharmaceutical and medical device companies, and investors who view their insights as a catalyst for transcending status quo, high mortality kidney care.

Through its Center for Patient Research and Education, founded in 2014, AAKP has built unique capacities to rapidly fulfill academic, government, and medical device and pharmaceutical industry requests to engage kidney patient experts. The Center supports AAKP’s efforts to speed up the utilization of unique patient insight data across both the product development lifecycle and within regulatory and payment decisions. Since its launch, AAKP has dramatically expanded its membership databases, social media recruitment, and analytics tools. The organization now services dozens of requests every year for clinical trial awareness and recruitment campaigns, patient advisory boards, technical evaluation panels, focus groups, patient surveys, clinical research, and public policy research. AAKP leaders and staff provide expert advice to organizations and companies on how to work meaningfully with patients as co-investigators and partners and offers [online training](#) for patients on how to be equally effective collaborators.

AAKP has forged strong partnerships with numerous universities and academic centers involved in kidney-related studies. AAKP patients are presently involved in research at the George Washington University School of Medicine and Health Sciences, University of Washington, Emory University, University of Pennsylvania, University of Pittsburgh, University of Michigan, Duke University, Wake Forest University, University of Minnesota/Hennepin Healthcare Research Institute, Northwestern University, University of California San Francisco, Vanderbilt University, University of California Los Angeles, University of Minnesota, Virginia Tech, University of Texas Health San Antonio, and various other institutions. Through the Patient Centered Outcomes Research Institute (PCORI), AAKP patient advocates have been involved in nearly every PCORI-funded kidney research effort since PCORI authorization in 2010 and reauthorization in 2019 ([read now](#)).

At the federal level, AAKP patients are impacting research and development initiatives across the Department of Health and Human Services (HHS), the Department of Veterans Affairs (VA), and the Department of Defense (DOD) via the Congressionally Directed Medical Research Program (CDMRP) and other DOD activities. Further, AAKP has been actively involved in patient engagement initiatives and the development of patient insight data alongside the U.S. Food and Drug Administration (FDA), the Centers for Medicare and Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and multiple other federal agencies. To facilitate greater

veteran involvement in kidney research and innovation and to support the VA kidney medicine program in the U.S. Congress, AAKP launched its [Veterans Health Initiative](#) in 2017 and developed a [formal partnership with the VA](#) in 2023 that aims to improve health outcomes and enhance the overall quality of life for Veterans with kidney diseases.

AAKP leaders and AAKP Ambassadors are also closely involved in leading national kidney innovation partnerships and consortiums including the Kidney Health Initiative (KHI), a partnership of the FDA and the American Society of Nephrology (ASN); the KidneyX Innovation Accelerator, a partnership of the ASN and HHS; and the Kidney Precision Medicine Project (KPMP), a scientific consortium funded by the National Institutes of Health (NIH)/National Institute of Diabetes and Digestive and Kidney Disease (NIDDK). The KPMP is America's largest taxpayer-supported kidney science initiative. Together, these efforts are resulting in significant advancements in kidney care through science, new precision medicine, artificial organs, and human centered product design.

Globally, since 2019, AAKP has organized patient consumers and advocacy organizations to support research and clinical trials through AAKP Global™, which includes its [Annual Global Summit on Kidney Disease Innovations](#), a partnership event with the George Washington University School of Medicine and Health Sciences. The *Global Summit* has evolved into the largest patient-led kidney disease innovations conference in the world and has tens of thousands of attendees across 100 countries. The 6th Annual Global Summit, titled “*Vox Populi: The Time is Now to Prevent and Cure Kidney Diseases*” will be held virtually July 16-17, 2024. [Registration is now open.](#)

In the United States alone, there are an estimated 37 million people who have chronic kidney disease, including 800,000 with kidney failure, and whose kidney care costs the American taxpayer over \$100 billion per year. Those costs do not include the additional expense to the nation and patient stemming from workforce dropout, disability, and dependency caused by this chronic illness and the burdens associated with obsolete, status quo technologies found in dialysis care. Immunocompromised kidney patients and immunosuppressed kidney transplant recipients were among the hardest hit by COVID-19 and despite advances in related therapeutics, they remain at high risk of infection

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About the American Association of Kidney Patients (AAKP): Since 1969, AAKP has been a patient-led organization driving policy decisions related to kidney patient care choice, protection of the doctor-patient relationship, and medical innovation. In 2018, AAKP established the first and largest U.S. kidney voter registration program, *KidneyVoters™*. Over the past decade, AAKP patient advocates have helped advance lifetime transplant drug coverage for kidney transplant recipients (2020); the Presidential *Executive Order on Advancing American Kidney Health* (2019); new job protections for living organ donors under the Family Medical Leave Act (FMLA) via the U.S. Department of Labor (2018); and Congressional legislation allowing HIV-positive organ transplants for HIV-positive patients (2013). Follow AAKP on social media at [@kidneypatient](#) on Facebook, [@kidneypatients](#) on Twitter, and [@kidneypatients](#) on Instagram, and visit www.aakp.org for more information.