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Kidney Patients Remind Congress and Payers: Your Decisions Impact Our Lives and Innovation

Largest Kidney Patient Meeting Shows Patient Determination for Change

Washington, D.C. – The American Association of Kidney Patients (AAKP), the largest independent kidney patient organization in the USA, conducted its 47th Annual National Patient Meeting, [*“Patient Consumers: Leaders for Research and Innovation.”*](#) September 21-23, 2022. This year’s meeting highlighted expanding kidney patient impacts on all aspects of innovations in kidney medicine, including research, clinical trials, product design, market delivery, and timely patient access to new drugs, devices, and diagnostics. The virtual meeting broke all previous engagement records and drew patients from 46 states and territories. The agenda featured 25 sessions and over 60 patient expert, government, medical, and industry speakers. All 2022 National Patient Meeting presentations will be available OnDemand through the [AAKP website](#) and [AAKP YouTube Channel](#) in the coming days.

AAKP is mobilizing kidney patients to engage elected leaders in Congress, appointed officials in the Executive Branch, and other policy decision-makers to address barriers and risks to greater patient care choice and innovations in kidney medicine, including future cures and new treatments. AAKP has cited the lack of alignment among new, safe U.S. Food and Drug Administration (FDA)-approved kidney treatments and payment and reimbursement decisions made by the Centers for Medicare and Medicaid Services (CMS) and private insurers as a key barrier. The organization also believes the ongoing lack of alignment exacerbates disparate care outcomes, negatively impacts taxpayers, and poses a serious risk to private sector expansions and investments in kidney research, clinical trials, and product development.

In June of 2022, AAKP publicly called out Humana for interfering with patient member access to a new kidney medical innovation that delays the progression of Diabetic Kidney Disease (DKD) and kidney failure ([read now](#)). AAKP has voiced similar concerns regarding the intransigence of United Healthcare (UHC) to provide their patient members timely access to the same therapy, as well as UHC’s unnecessary appeals hurdle that further delays patient access. AAKP is conducting a national campaign to address payment barriers through its [Patient Voice Patient Choice™](#) initiative. Visit AAKP’s Action Center at <https://bit.ly/AAKPTakeAction> to learn more.

AAKP has also cited the use of Quality Adjusted Life Year (QALY) methodologies, such as those advocated by the Cambridge, Massachusetts-based Institute for Clinical Economic Review (ICER), as

another threat to patient choice, timely access to new medicines, and private sector engagement in kidney research and treatments. AAKP is a member of the [Partnership to Improve Patient Care \(PIPC\) coalition](#), a collaboration of over 150 chronic disease and patient rights organizations that oppose wider use of QALY measures by insurers and governments due to their lack of substantive patient insight data and discriminatory impact on the most vulnerable patient populations in America.

The AAKP Annual Meeting program featured top federal and major university researchers and experts in the field of kidney medicine and highlighted the disproportionately high incidence and mortality rates of kidney diseases among minority and underserved communities. Researchers included Dr. Jenna Norton and Dr. Raquel Greer from the National Institutes of Health (NIH) / National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); Dr. Prabir Roy-Chaudhury, University of North Carolina Kidney Center; Dr. Claudia Dahlerus, University of Michigan – Kidney Epidemiology and Cost Center (UM-KECC); Dr. Rohan S. Paul, Washington University in St. Louis and the George Washington Transplant Institute in Washington, D.C.; Dr. Kamyar Kalantar-Zadeh, University of California Irvine School of Medicine; Dr. Elisa Gordon, Northwestern University; Dr. Keith C. Norris, University of California Los Angeles; and Dr. Katina Lang-Lindsay, Alabama Agricultural and Mechanical University.

The Annual Meeting also included top experts on the application of patient preference data and patients insights on future kidney products, federal regulatory decisions, and research priorities, such as [Zach Cahill](#), Senior Artificial Kidney Product Specialist with the American Society of Nephrology (ASN) and the Kidney Health Initiative (KHI); Dr. Michelle Tarver, Deputy Director, Office of Strategic Partnerships and Technology Innovation Program and Director for Patient Science, Digital Health Center of Excellence, Center for Devices and Radiological Health (CDRH), Food & Drug Administration (FDA); and Dr. Harold I. Feldman, Deputy Executive Director for Patient-Centered Research Programs Patient-Centered Outcomes Research Institute (PCORI).

Attendees learned about national efforts to elevate scientific truth in medicine and medical practices from Dr. Richard Baron, President of the American Board of Internal Medicine (ABIM). Dr. Baron discussed the need for ongoing professional certification and competence and encouraged patients and advocates to hold the medical community accountable for maintaining certification and quality standards. Patients were also encouraged to become more involved in the global push for a kidney Emoji to increase global awareness of kidney diseases through the power of social media by Dr. Edgar Lerma, a nephrologist and hypertension expert who serves as Clinical Professor of Medicine at the University of Illinois at Chicago. Dr. Lerma is leading the charge to gain approval for a kidney Emoji alongside AAKP and other national kidney organizations. AAKP has endorsed this effort through articles appearing in the February 2022 American Society of Nephrology *Kidney News* ([read now](#)) and a joint article in the August 2022 *American Journal of Kidney Diseases*, the official journal of the National Kidney Foundation ([read now](#)).

AAKP President [Richard A. Knight](#) stated, “AAKP’s Annual Patient Meeting continues to serve the kidney community as a vitally important educational event and on ramp for patient participation in the most important research, clinical trials, and new product developments occurring in the kidney space. Patients want new therapies and fewer barriers to innovation and are working collaboratively with medical professionals and industry to achieve these goals.” Knight is a 16-year kidney transplant recipient and serves as Co-Chair of the Community Engagement Committee for the NIH/NIDDK Kidney Precision Medicine Project (KPMP), the largest taxpayer-supported kidney science initiative.

[Edward V. Hickey, III, USMC](#), AAKP Vice President and Chair, [Veterans Health Initiative](#), stated, “This year’s meeting was unparalleled and patients have made their intention to remove barriers to innovation and access very clear. The expanding reach and impact of patients is central to the [Decade of the Kidney™](#), and their insights and lived experiences are already leading to new

treatments, including artificial kidneys.” Hickey is a former senior Congressional aide and has served in multiple presidential administrations, including appointed roles in the U.S. Department of Commerce and the Office of Personnel Management.

[Paul T. Conway](#), AAKP Chair of Policy and Global Affairs, states, “Kidney patients, researchers, medical professionals, and industry leaders are united in their determination to transcend status quo kidney care and its exceedingly high human and taxpayer costs. Innovation will only succeed when there is a genuine and shared approach to patient-centered care. Unfortunately, some payers lag far behind in their knowledge of advancements in kidney medicine and the sophisticated role patients are playing in both innovation and national policy.” Conway is a 25-year transplant patient, former Chief of Staff for the U.S. Department of Labor, and has served in three presidential administrations.

The 2022 Annual Patient Meeting also gained viewers from Algeria, Australia, Bolivia, Canada, Croatia, Denmark, Italy, Jamaica, Japan, Kenya, and the United Arab Emirates. International participants will be invited to join AAKP Global™ initiatives, which train patients to impact kidney innovation and market access within their own countries and through the World Health Organization (WHO). Since 2021, AAKP has provided expertise to the WHO on the development of a new engagement framework designed to elevate the lived experiences and insights of people living with non-communicable diseases, including kidney patients, within WHO deliberations and agenda setting ([Watch OnDemand](#)).

AAKP defines quality kidney medicine as timely access and patient consumer choice of new treatments that empower patients to better manage their health and to fully pursue their aspirations, including part-time or full-time work. AAKP advocates for earlier disease detection, pre-emptive kidney transplants, artificial organs, and greater utilization of home hemodialysis and peritoneal dialysis—consistent with the patient-backed 2019 *Executive Order on Advancing American Kidney Health*. In the United States alone, an estimated 37 million people have chronic kidney disease (CKD), including 800,000 with kidney failure, whose kidney care costs the American taxpayer over \$100 billion a year. Those costs do not include the additional expense to the nation and patients stemming from workforce dropout, disability, and dependency caused by the illness and 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 for infection.

The AAKP thanked its 2022 National Patient Meeting sponsors at all levels, including: Platinum Level, Calliditas Therapeutics, Horizon Therapeutics, Medtronic, Natera, Novartis Pharmaceuticals, and Otsuka Pharmaceuticals. Gold Sponsors included Akebia Therapeutics, Amgen, AstraZeneca, and BI Lilly. Silver sponsors included Bayer Pharmaceuticals, CareDx, Chinook Therapeutics, Mallinckrodt Pharmaceuticals, Travere Therapeutics, and Vertex Pharmaceuticals. Bronze Sponsors included Aurinia Pharmaceuticals, CVS Kidney Care, Sanofi, and Eurofins – Transplant Genomics; and Patron Sponsors included BD, eGenesis, and Talaris Therapeutics.

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About the American Association of Kidney Patients (AAKP): Since 1969, AAKP has been the premier patient-led organization driving policy discussions on kidney patient consumer care choice and treatment innovation. AAKP members represent all disease states, ethnicities, and demographic indicators. By 1973, AAKP patients had collaborated with the U.S. Congress and White House to secure dialysis coverage for any person suffering kidney failure, a taxpayer-funded effort that has saved over one million lives. In 2018, AAKP established the largest U.S. kidney voter registration program, KidneyVoters™. 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). Follow AAKP on social media at [@kidneypatient](#) on Facebook, [@kidneypatients](#) on Twitter, and [@kidneypatients](#) on Instagram, and visit www.aakp.org for more information.