American Association
of Kidney Patients
aakp.org

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PHARMA, RESEARCH, AND MEDICAL LEADERS SAY KIDNEY PATIENTS ARE KEY TO CARE INNOVATION

Kidney Patient-Led Policy Summit Targets Regulatory and Reimbursement Barriers to New Treatments

WASHINGTON, D.C. – The American Association of Kidney Patients (AAKP) recently hosted its 4th Annual Public Policy Summit entitled *Patient Voice & Patient Choice: Patients At the Policy Table Today Determine Tomorrow's Innovations and Care Choices*. Founded in 1969, AAKP is the oldest and largest fully independent kidney patient organization in the U.S. and is both a nationally and internationally recognized leader in the advancement of kidney patient consumer care choice, disease education, substantive patient engagement strategies, and the mobilization of grassroots kidney advocate networks.

AAKP works closely with federal government officials, medical researchers, industry leaders, and investors who are committed to re-establishing kidney patient consumers to their rightful place at the center of all kidney health, innovation, research, and policy decisions. The organization provides original kidney patient population survey data and expert advice to leaders in government, industry, think tanks, and academia involved in standing up and recruiting patients for technical evaluation panels, in-person and virtual focus groups, formal advisory committees, clinical trials, and efforts to include substantive patient insight data across the product development lifecycle.

This year's Policy Summit highlighted challenges and opportunities for researchers and companies involved in safely bringing new, or expanding, kidney care innovations to consumer markets. The event featured over 34 experts on kidney disease innovation and patient consumer insight data drawn from the pharmaceutical, medical device, diagnostic, research, and medical professional communities. The consistent messages shared among all 2021 presenters included the need to slow the spread of kidney disease, expand policies that honor full patient consumer care choice, and the need for better coordination across Federal regulatory and payment agencies to ensure new technologies enter the consumer market. The next generation of kidney diagnostics, biologics, and devices are being informed and driven by the science of unique patient insights, real world evidence (RWE), and patient reported outcome data (PRO). Research, industry, and patient advocates are working closely with career, appointed, and elected federal officials to make certain that patient insight data is also being incorporated into federal frameworks for regulatory and payment decisions so that life-saving treatments reach consumers safely and without unnecessary delays or unnecessary barriers.

Among the key issues discussed were: the comparative health and safety benefits of home dialysis and telehealth/telemedicine during and beyond the COVID-19 pandemic; updates on the KidneyX prize-winning artificial kidney initiative entitled *The Kidney Project*; diabetic kidney disease; diagnostics to detect kidney transplant failure and strategies to reduce donated kidney discard rates; smarter alignment of federal regulations and payment policies to support breakthrough treatments and innovations; continuity of care for secondary hyperparathyroidism; Medicare patient access to all federally-approved kidney disease related therapeutics; the emerging role for pharmacists as formal members of the kidney patient medical care team; and the serious threat Quality Adjusted Life Year metrics (QALY's) pose to both medical innovation and timely patient access to new or existing chronic disease therapeutics. Click here to access the full agenda and view presentations OnDemand.

AAKP launched the Annual Policy Summit in 2018 on Capitol Hill as an in-person and simulcast event targeted to Washington, D.C., decision makers and influencers. The goal was to educate decision makers on kidney policy issues and opportunities for innovation as identified by kidney patient consumers and their patient-centered allies, beyond issues typically promoted In Congress by special interests that financially benefit from status quo kidney care. Since the inaugural 2018 event, the Policy Summit has evolved from an audience in the hundreds to a virtual audience in the thousands at both the federal and state level. As a part of AAKP's national policy education and kidney advocate mobilization strategy, in 2018, AAKP also launched their nonpartisan *KidneyVoters™* program, the first, and now the largest, voter registration initiative serving every sector of the kidney stakeholder community including medical professionals and like-minded members of the pharmaceutical industry. Based on the 2020 success of *KidneyVoters™* as mobilization and membership recruitment tool, AAKP has announced plans to register a half million kidney patients and other people of goodwill committed to the fight against kidney diseases by the 2024 election cycle.

AAKP President Richard Knight, a national kidney advocate, stated, “AAKP has invested heavily in grassroots and virtual technologies to help patients and their families engage decision-makers, researchers, scientists, and other influencers through our Centers for Patient Engagement and Advocacy and Patient Research and Education. Through our strategic partnerships with government, academia, and industry, we have been able to connect tens of thousands of new patient voices and their unique patient insights to those responsible for making informed decisions that impact some of the most vulnerable, ill, and underserved populations in the country. AAKP is building our capacities to better organize patients, address inequities, and make certain patients have an even greater impact on issues related to care choice and innovation.” Knight is a former dialysis patient, current 14-year transplant recipient, has served in multiple kidney advocacy roles, and is a former U.S. Congressional staff member and liaison to the Congressional Black Caucus.

AAKP Chair of Policy and Global Affairs Paul T. Conway, a 40-year kidney patient and transplant recipient, stated, “For the past six years, AAKP, alongside like-minded allies and people of goodwill, has purposely driven a modern paradigm shift in how kidney policy is formulated in the United States. We believe that policy and innovation should be informed and shaped by the people whose lives are at risk, on behalf of those whose lives are at risk. We believe kidney patients are experts in kidney disease, with unique insights that are of equal, and in many cases more substantive, weight than those put forward by many of the so-called "experts" who seek to impact kidney care absent any practical experience managing the disease. Progress and innovation in the fight against kidney diseases has been stagnant for decades and patients have paid for inaction and status quo thinking with their lives. This is why AAKP insists kidney patients be at the table when decisions are made about their choice of care treatments, how breakthrough innovations will be regulated and paid for, and how new research investments are prioritized and administered. We are grateful to all who have helped change the paradigm and elevate kidney patients as disease experts and co-investigators because the past practices of crafting kidney policy without patients reflected thinking that was, at best, ignorant and paternalistic, and at the worst, arrogant and elitist.” Conway has served as the Chief of Staff of the U.S. Department of Labor and in multiple policy positions under three U.S. presidents, three state governors, and in support of five presidential transitions.

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. Change within the field of kidney care has been challenging over the past fifty years due to the comparative lack of federal research investments compared to other diseases, limited capital investments and innovation, as well as entrenched special interests that have, historically, been involved in efforts to lobby Congress to protect status quo care through laws that limit kidney patient consumer care choices and stifle the creative forces of a competitive free market. In 2019, AAKP launched *The Decade of the Kidney™*, a patient-led initiative designed to increase patient care choice and access to new care options, federal kidney disease research funding, increased living kidney donation and transplants, legal protections for living organ donors facing insurance discrimination, greater home care and telemedicine options, and the availability of artificial implantable or wearable kidney.

The event was conducted in tribute to former AAKP Board Member Mr. Brian Hess, a nationally known kidney patient advocate whose heroic, lifelong battle against kidney diseases and experiences as a home dialysis and transplant patient encouraged thousands of kidney patients to find their own voice in the policy process and to hold Congress and the White House accountable for policies that increase patient care choice and greater innovation in the fight against the deadly disease. Watch the AAKP tribute video to Mr. Hess here.

The 2021 AAKP Annual Policy Summit was supported by Gold Sponsors Baxter Healthcare, CareDx, Inc., Sanofi Genzyme, and Travere Therapeutics; Silver Sponsors Akebia Pharmaceuticals, Bayer, CSL Behring, Natera, and Otsuka Pharmaceuticals; and Bronze Sponsors Ardelyx, Horizon Therapeutics, and Novartis; and other supporters include AstraZeneca, major research organizations, and patient advocates nationwide.

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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 patient collaborations with the U.S. Congress and White House helped gain passage of dialysis coverage for any person suffering kidney failure, creating the only disease specific, taxpayer-funded entitlement program in America. That program, the End Stage Renal Disease Program (ESRD) administered by CMS, has saved over one million lives. 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 at www.aakp.org.