Kidney Medicine Long Overdue for Change and Innovation

National Summit Unites Voices of Patients, Industry, and Medical Experts

WASHINGTON, DC, UNITED STATES, July 2, 2021 /EINPresswire.com/ -- The American Association of Kidney Patients (AAKP) recently hosted its 4th Annual Public Policy Summit (https://bit.ly/AAKPPolicySummit2021) 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. AAKP 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.

The American Association of Kidney Patients Logo

The Policy Summit educates federal and state policymakers on kidney policy issues and opportunities for innovation as identified by kidney patient consumers and their patient-centered allies. Since 2018, the event has evolved from an audience in the hundreds to a virtual audience in the thousands. Status quo kidney care is characterized by late disease diagnosis, outdated dialysis technologies, disparate treatment access, long waiting times for organ transplants, and extremely high mortality rates.

The 2021 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. At the event, AAKP awarded an AAKP President's Medal (https://bit.ly/GriffinPRodgersAward) to Griffin P. Rodgers, MD, Director, National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), at the National Institutes of Health (NIH) for his outstanding commitment to patient-centered research and superior efforts as a U.S. civil servant in response to the COVID-19 pandemic and the fight against kidney diseases.

The key issues discussed were: 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; 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. Access the full agenda (https://bit.ly/PolicySummitAgenda2021) and view presentations OnDemand. The 2021 AAKP Annual Policy Summit was supported by sponsors including: Baxter Healthcare; CareDx, Inc.; Sanofi Genzyme; Travere Therapeutics; Akebia Pharmaceuticals; Bayer; CSL Behring; Natera; Otsuka Pharmaceuticals; Ardelyx; Horizon Therapeutics; Novartis; AstraZeneca; and patient advocates nationwide.

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, “AAKP believes policy and innovation should be informed and shaped by the people whose lives are at risk and 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. We are grateful to all who have helped 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.

In 2019, AAKP launched The Decade of the Kidney™ (https://bit.ly/DecadeofTheKidney), 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.

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About the American Association of Kidney Patients (AAKP): Founded in 1969, AAKP has been the largest kidney patient organization driving policy discussions on kidney patient consumer care choice and innovation. In 2018, AAKP launched their nonpartisan KidneyVoters™ program (https://bit.ly/KidneyVoter), the first, and now the largest, voter registration initiative serving kidney stakeholders. AAKP announced plans to register a half million kidney patients and other people of goodwill by the 2024 election cycle. Follow AAKP on social media at @kidneypatient on Facebook and @kidneypatients on Twitter, and visit www.aakp.org.

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