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MEDIA CONTACT:
Jennifer Rate
Marketing & Communications Manager
jrate@aakp.org
(813) 400-2394

GLOBAL KIDNEY SUMMIT MOBILIZES PATIENTS FOR CARE INNOVATION

DECADES OF PATERNALISM AND HIGH MORTALITY DIALYSIS CHALLENGED

KIDNEY PATIENT CONSUMERS DEMAND CARE CHOICE AND ACCESS

WASHINGTON, D.C. – The American Association of Kidney Patients (AAKP), the largest independent kidney patient organization in the USA, and its strategic partners at The George Washington University (GW) School of Medicine & Health Sciences (SMHS) hosted their 4th Annual Global Summit on Kidney Innovations entitled “Global Kidney Patient Voice™ - The Key to Accelerating Innovations,” on August 23-24, 2022. Since 2019, the Summit has grown its reach to nearly 90 countries and audiences in the tens of thousands and is now the largest patient-led innovations summit in the world. For 2022, the Summit engaged new participants from Nepal, Bosnia and Herzegovina, Iraq, and Kazakhstan. The 2022 event included 15 sessions and over a combined 60 [patient expert](#), government, medical, and industry speakers. All 2022 Global Summit presentations will be available OnDemand through the [AAKP website](#) and [AAKP YouTube Channel](#) and will continue to reach additional viewers across the world to increase the AAKP and GW SMHS reach exponentially of this year’s Global Summit content.

The 2022 Summit showcased the massive worldwide shift in patient expectations, advocacy, science, innovation, and public policy related to kidney diseases and treatments. Kidney disease medicine and treatments are undergoing the greatest transformations in decades as patients organize to impact policy and accelerate research as new companies and investors enter the field. Status quo kidney care, especially in-center dialysis, is a legacy of the last century defined by extremely high burdens, including patient disability and mortality, loss of work and dependency on unemployment assistance, and steep costs to taxpayers and societies. COVID-19 has exacerbated existing disease burdens for patients and remains a serious threat to the kidney patient population globally. Kidney patients are extremely vulnerable to COVID-19 due to the multiple chronic conditions they manage, compromised immune systems, and, for kidney transplant recipients, immune suppression therapies that limit the effectiveness of COVID-19 vaccines and therapeutics.

The Summit is a key component of AAKP’s [Decade of the Kidney™](#) initiative, launched in 2019 to organize patients internationally to become more involved in kidney research, clinical trials, industry-led innovations and public policy, and to deliver new life-saving treatments within the lifetime of most patients. AAKP is linking and coordinating patient consumers and patient advocacy organizations across the globe to elevate kidney disease as a health, policy, economic, and workforce priority. AAKP and allied professional organizations support innovations and care choices aimed at earlier disease detection and safer and more patient-centered treatments that prevent or slow disease progression. AAKP and its allies advocate for pre-emptive organ transplants, home dialysis, artificial implantable and wearable organs, and xenotransplants.

In the past several years, the U.S. Food and Drug Administration and regulatory bodies across the globe have approved new, safe therapies that improve kidney patient quality of life while reducing disease burdens.

AAKP trains and mobilizes patients to overcome barriers to care choice and access, especially government policies and provider and insurance company practices that intentionally thwart patient care choice and access to timely treatments and new innovations. In the U.S., AAKP recently launched its [Patient Voice Patient Choice™](#) initiative to hold elected leaders, the Centers for Medicare and Medicaid Services (CMS), and health insurance companies fully accountable for decisions that interfere with patient choice and access (www.patientvoicepatientchoice.org). AAKP is working with patients across the globe to establish similar accountability initiatives within their own countries.

Dr. Barbara L. Bass, Vice President for Health Affairs, Dean of the GW SMHS, and CEO of the George Washington Medical Faculty Associates, opened this year's Global Summit. The first session featured AAKP International Ambassadors representing Nepal, India, Germany, Australia, and Canada who are working within their own nations to elevate patient insights and patient engagements in public policy, clinical trials, and medical innovations. Patients moderated all sessions and were joined by international experts including: [Dr. Raymond Vanholder](#), MD, PhD, Professor of Medicine, University of Ghent and Clinical Head of the Nephrology Division of the Ghent University Hospital, Belgium, and President, European Kidney Health Alliance (BELGIUM); [Dr. Murray Sheldon](#), MD, Associate Director of Technology and Innovation, U.S. Food and Drug Administration (FDA), Center for Devices and Radiologic Health (CDRH) (USA); **Dr. Michael T. Osterholm**, PhD, MD, Regents Professor and McKnight Presidential Endowed Chair in Public Health and Director of the Center for Infectious Disease Research and Policy, University of Minnesota (USA); **Jack Fisher**, Technical Officer, Global Coordination Mechanism on Non-Communicable Diseases, Global Non-Communicable Disease Platform, Deputy Director General's Office, World Health Organization, Geneva (SWITZERLAND); **Dr. Manikkam Suthanthiran**, MD, Stanton Griffis Distinguished Professorship in Medicine, Professorships in Biochemistry and Surgery in Medicine, Cornell University Medical College, Founding Chairman of the Department of Transplantation Medicine, and Chief of Nephrology and Hypertension at New York-Presbyterian/Weill Cornell Medical Center, Co-Chair, Executive Transplantation Council of the Multi-Organ Program of Columbia and Cornell, New York-Presbyterian Hospital (USA); **Dr. Robert A. Star**, MD, Director, Division of Kidney, Urologic, and Hematologic Diseases, Section Chief, Renal Diagnostics and Therapeutics Unit, Kidney Diseases Branch, National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health (USA); **Dr. Benno Kitsche**, MD, Specialist in Internal Medicine, Nephrology, and Hypertension, DHL, Chairman, Board for the further development and promotion of home dialysis, KfH Board of Trustees for Dialysis and Kidney Transplant (GERMANY); **Melissa Flathmann**, Consumer Reviewer Administrator, Peer Review and Science Management, Congressionally Directed Medical Research Program, U.S. Department of Defense (USA); **Ann M. Dodelin**, MA, Consumer Reviewer Administrator, Sr., Peer Review and Science Management, Congressionally Directed Medical Research Program, U.S. Department of Defense (USA); **Dr. Fokko Wieringa**, PhD, (*2021 KidneyX Artificial Kidney Prize Winner*), Principal Scientist, IMEC, The Netherlands, Dutch Kidney Foundation, Member, Kidney Health Initiative (NETHERLANDS).

AAKP President [Richard Knight](#), a 16-year kidney transplant recipient, stated, "Kidney disease is a devastating disease that is rapidly expanding and negatively impacting patients, families, and economies throughout the world. Future innovations in kidney medicine depend upon greater patient engagement through fully inclusive clinical trials and research. As stated in my opening remarks, educating people about kidney disease prevention and their choice of treatments and new innovations is a humanitarian act." Knight serves on the NIH/NIDDK Advisory Council, is Co-Chair of the Strategic Plan Stakeholder Engagement Subgroup, and Co-Chair of the Community Engagement Committee for the Kidney Precision Medicine Project (KPMP).

Dr. Dominic Raj, Director of the Division of Kidney Diseases & Hypertension, The George Washington University School of Medicine and Health Sciences, and Co-Chair of the Global Summit, stated, "We have witnessed a resurgence in drug development for kidney disease over the last five years with a significant increase in drugs in the pipeline and clinical trials. The current movement in nephrology is driven by the increasing societal and economic burden imposed by CKD as well as scientific advances that have enabled the discovery of new drug targets."

[Paul T. Conway](#), a 42-year kidney patient, Co-Chair of the Global Summit, and AAKP Chair of Policy and Global Affairs, stated, “AAKP is fortunate to have created a global platform to share patient insights, expand patient impact on innovation policies, and actively support courageous professionals and companies working to expand care choice and treatment innovations. Kidney patient consumers have the will and capacities to transcend status quo care, and we are executing that vision. But, as we celebrate our progress, we stand in full support of fellow kidney patients who live under regimes that reject universal human rights and are hostile to requests by patients to have a voice and choice in their own treatments and outcomes.” Conway is a former Chief of Staff of the United States Department of Labor and serves on the Nephrology Specialty Board of the American Board of Internal Medicine (ABIM).

AAKP’s [Decade of the Kidney™](#) has garnered widespread international attention and support. 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 before the European Parliament in Brussels. AAKP leaders joined patients and elected officials from across the EU to discuss patient demands for greater innovations, including artificial organs and access. For the past year, AAKP has also been actively engaged with the World Health Organization (WHO) in a new engagement framework to elevate the lived experiences and sense of urgency shared by patients across the world within WHO deliberations and agenda setting.

AAKP and GW SMHS thanks its 2022 Global Summit sponsors: Gold Level, Novartis; Silver Level, Kibow Biotech; Bronze Level, Horizon Therapeutics and Travere Therapeutics; Patron Level, Mallinckrodt Pharmaceuticals; and Supporting Level, Talaris Therapeutics. Information on the 2023 Global Summit will be listed at <https://aakp.org/programs-and-events/global-summit/> as it becomes available.

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About the American Association of Kidney Patients (AAKP): Since 1969, AAKP has been a patient-led organization driving policy discussions on kidney patient consumer care choice and treatment innovation. 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.

About the GW School of Medicine and Health Sciences: Founded in 1824, the GW School of Medicine and Health Sciences (SMHS) was the first medical school in the nation’s capital and is the 11th oldest in the country. Working together in our nation’s capital, with integrity and resolve, the GW SMHS is committed to improving the health and well-being of our local, national, and global communities. Visit their website at smhs.gwu.edu.