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GLOBAL KIDNEY INNOVATION SUMMIT ACCELERATES INTERNATIONAL CONSORTIUM

Patient Needs and Insights Drive New Era of Global Kidney Research,
Discovery, and Personalized Treatments

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 and Health Sciences (SMHS) continue to make a unique impact in the international battle against kidney diseases. Their 2021 annual *Global Summit on Kidney Disease Innovations* focused on expanding patient consumer choices and improved health outcomes, engaged a combined audience of over 20,000 viewers across 80 countries, exceeded their 2020 virtual attendance record established at the height of the COVID-19 pandemic, and continues to draw viewers worldwide to their [online content](#). *The Global Summit* is a key component of AAKP's [The Decade of the Kidney™](#), an AAKP global initiative ([read article](#)) launched in 2019 for the 2020-2030 decade to help U.S. and international policymakers better address the devastating human and societal costs of kidney diseases based on patient-defined priorities.

The Global Summit has accelerated engagement in an expanding international consortium of influencers, led by patient consumers and advocates, committed to a new era in kidney medicine marked by more inclusive clinical trials, greater use of patient insight data, personalized medicine, and disruptive technologies including artificial implantable and wearable kidneys. The patient-led consortium includes academic and medical researchers, clinical trial designers, innovators, capital market investors, companies, non-governmental and faith-based organizations, as well as elected and appointed government leaders across the globe. Kidney patients worldwide are demanding an end to outdated dialysis care, characterized by staggeringly high mortality rates, and greater access to new

products and solutions aimed at detecting, preventing, and treating kidney diseases earlier and in ways that improve quality of life and decrease dependency and disease-related unemployment. They are also organizing and coordinating their policy and grassroots efforts in a sophisticated effort to advance more common sense regulatory and payment reforms that prioritize patient needs and fully support the timely entry of new, safe products into global consumer markets. Based on the ongoing success and rapidly expanding interest in *The Global Summit*, AAKP and GWU have already opened pre-registration for the May 2022 [Global Summit on Kidney Disease Innovations](#). All 2021 *Global Summit* virtual presentations are available OnDemand through the [AAKP website](#) and [AAKP YouTube channel](#).

Dr. Dominic Raj, Co-Chair of *The Global Summit*, a Professor of Medicine, Biochemistry and Genetics and Biostatistics and Epidemiology, and Director of the Division of Kidney Diseases and Hypertension at the George Washington University School of Medicine and Health Sciences, stated, “As a researcher in molecular biology and genetics, I seek to personalize medicine by genes and molecular pathways, but I think it is more important to personalize by patient needs. This, I believe, is the key take home message from *The Global Summit* and I am very proud of my colleagues across the globe who are actively incorporating the unique insights of kidney patients in their research and discovery of new therapies to prevent and treat the growing spread of kidney diseases.”

Hilde Vautmans, Member of the European Parliament (MEP), Chair of MEP Kidney Health, and Deputy Coordinator for the Committee on Foreign Affairs for a Renew Europe (EU) provided a [virtual presentation](#) in which she praised kidney patients worldwide for their efforts to work alongside government leaders in the fight against kidney diseases. Further, Vautmans invited greater cooperation among elected leaders in the European Parliament and the U.S. Congress, especially among like-minded members of the U.S. Congressional Kidney Caucus, stating “This battle is difficult. And I can speak from experience here, but [...] change is possible [...] but we can and have to act more. In Europe but also in the United States. I always say we need more awareness, more funding and more innovation. Today I want to add a fourth element and that is collaboration, because as we all are aware and all are witnessing, diseases know no borders. So, let’s work together [...] We share a common goal, on both sides of the Atlantic: We must further improve the lives of people with Kidney Disease!”

The 2021 *Global Summit* included over 15 panels featuring over 40 patient and medical experts along with a menu 29 expert videos covering COVID-19 kidney-related issues, diversity in clinical trials, APOL-1 genetic research, diabetic kidney disease (DKD), nutrition, and telemedicine. Executives from top companies in the kidney space underscored the importance and value of patient insights in science, discovery, and the development of new drugs, devices, and diagnostics. Emphasizing the key role patients play in the new era of kidney medicine were leaders from Bayer Pharmaceuticals, Baxter International Inc., bioMérieux, CareDx, Inc., CSL Behringer, Novartis, and Sangamo Therapeutics, Inc. They were joined by key policy and innovation leaders including Barbara L. Bass, MD, Vice President for Health Affairs, Dean of the GW School of Medicine and Health Sciences, and CEO of the GW Medical Faculty Associates (USA); Vivekanand Jha, MBBS, MD, DM, PHD, FRCP, FAMS; Executive Director, The George Institute for Global Health (AU) and President, International Society of Nephrology

(IND); Fokko Wieringa, PhD, Principal Scientist, IMEC of The Netherlands and the Dutch Kidney Foundation (EU) and a member of The Kidney Health Initiative (USA); Murray Sheldon, MD, Associate Director for Technology and Innovations, Center for Devices and Radiological Health, U.S. Food and Drug Administration (USA); Jack Kalavritinos, Founder and Principal, JK Consulting and member of the APCO Worldwide International Advisory Council and Health Advisory Board (USA).

Richard Knight, President of the American Association of Kidney Patients, a former hemodialysis patient and 14-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, and the GW School of Medicine and Health Sciences is an established global leader in this field. I thank Dean Dr. Barbara Bass, Dr. Dominic Raj, and our new European Union ally Hilde Vautmans for their deep respect for patients and their concerted efforts to unite patients, clinicians, and policy-makers in the fight against all kidney diseases." Knight ([read CJASN article](#)) is a former U.S. Congressional staff member and business consultant who serves on the National Institutes of Health (NIH), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Advisory Council, and as the Co-Chair of the Community Engagement Committee for the Kidney Precision Medicine Project (KPMP).

Paul T. Conway, Co-Chair of *The Global Summit* and AAKP Chair of Policy and Global Affairs, a former peritoneal dialysis patient and 24-year kidney transplant recipient, stated, "AAKP and our friend and ally Dr. Dominic Raj envisioned *The Global Summit on Kidney Innovations* as a unique international event aimed at accelerating cooperation among patients, researchers, clinicians, and policy professionals. Kidney patient consumers worldwide demand and deserve far greater care choice and are well aware of the value they bring as partners to pioneers developing the next generation of diagnostics, devices, and biologics. AAKP has expanded our collaborations with patient groups worldwide to advance innovation and to support all who share our sense of urgency and intent to transcend legislative, regulatory, and payment barriers that limit care choice and delay entry of new, safe treatments into the global consumer markets." Conway ([read CJASN article](#)) is a former Chief of Staff of the U.S. Department of Labor and serves on the External Expert Panel of National Institutes of Health (NIH), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), Kidney Precision Medicine Project (KPMP), the American Board of Internal Medicine's Nephrology Specialty Board, and is a Patient Voice Editor for *The Clinical Journal of the American Society of Nephrology*.

AAKP has formal partnerships with the multiple international kidney patient organizations including in support of *The Global Summit*, *The Decade of the Kidney*[™], and the growing international kidney innovation consortium, including: [Argentina-based Asociacion Solidaria de Insuficientes Renales \(ASIR\)](#); [European Kidney Patients' Federation \(EKPF\) and the European Kidney Health Alliance \(EKHA\)](#); and [United Kingdom-based Renal Patient Support Group](#). AAKP will be announcing multiple additional global partnerships throughout the remainder of 2021 and 2022. AAKP leaders and their global allies have carried the key messages of *The Global Summit* into other global forums, including the University of Washington's Center for Dialysis Innovation's recent IDEAS Summit, where Dr. Murray Sheldon of the U.S. Food and Drug Administration conducted a presentation on the [expanding international kidney innovation consortium](#). Future

presentations on the key learnings and messages of *The Global Summit* and the international kidney innovation consortium will be conducted at the [AAKP Annual National Patient Meeting](#) September 24-25, 2021, and at the American Society of Nephrology's, 2021 [Kidney Week](#), November 4-7, the largest kidney professional conference in the world. Voices in support of AAKP's expanding global partnerships and international collaborations include:

Mr. Colm Clifford, kidney patient and AAKP Global Ambassador in the Republic of Ireland: *"Change happens when a collective voice sends a strong message that change is required. This begins from the grassroots. While it may eventually be signed off with the stroke of a pen, it's the strong collective voice that can't be ignored that drives that to happen. In kidney disease, after The Global Summit, I'm confident we really are moving forward and it's an exciting time to be involved."*

Daniel Gallego, President of the European Kidney Patients' Federation (EKPF): *"We are more than happy that the AAKP reached out to us to enforce the collaboration of kidney patients worldwide to really give a push for innovation and new therapies that will enhance quality of life of kidney patients, contributing to expand our daily life activities. EKPF strongly believes that in creating these therapies, patients should be included and in the driver's seat to reach next level therapies. Together we can create and extend a platform that is responsible for the long-overdue innovation that kidney patients are waiting for."*

Raymond Vanholder, President of the European Kidney Health Alliance (EKHA): *"Collaboration for improvement of kidney therapies can really benefit by moving boundaries. We are delighted with the expansion of our international collaboration by teaming up with AAKP. At EKHA we strongly believe in the empowerment of patients to enhance quality of life where possible. We therefore adopted their 'Decade of the Kidney' program to create awareness for the unmet needs of kidney patients. An important part of this collaboration will exist in setting the political agenda at the level of the EU and USA to push for real innovative therapies and corresponding funding to realize them."*

Dr. Maria Eugenia Vivado Duran, President of the Argentina-based Asociación Solidaria de Insuficientes Renales of Buenos Aires; AAKP Global Ambassador: *"ASIR joins together with AAKP in support of the rights of the kidney patients and to share in efforts to further medical innovations that will better prevent and treat kidney diseases and improve the quality of life for kidney patients."* Dr. Vivado Duran, a pediatrician and AAKP Global Ambassador, was diagnosed with kidney disease in 1979 during her second pregnancy. She was on hemodialysis for many years and in 2001, received a kidney transplant from a deceased donor, allowing her to continue working for patients, educating the community, and enjoying her family. She has been president of ASIR for four consecutive terms and does everything in gratitude to her anonymous kidney donor.

Dr. Shahid Nazir Muhammad, Specialist Biomedical Scientist, The University of the West of England (UWE) and Academic Lead, on behalf of The Renal Patient Support Group (RPSG), United Kingdom: *"Future research integrating perceptions to acknowledge CKD as a condition with diverse morbidities and investigations to explore educational needs is mission critical. The Renal Patient Support Group (RPSG) is a place where awareness and research meet and encourages healthcare service and support in*

comprehensible proportions. Innovation is good to an extent. However, timely and targeted education relating CKD and recommendations with a solid focus is where best practice between pediatric and adult nephrology, tackling health inequalities is pinnacle to ensure that CKD patients are not forgotten and become unpeople (disenfranchised), and there is kidney disease awareness on an international level."

Ms. Vasundhara Raghavan, caregiver to a son with kidney disease and the AAKP Global Ambassador in the United Arab Emirates: *"An international consortium of kidney patient organizations will be a catalyst to drive many innovations and bring in much-needed changes in the kidney patient ecosystem. The consortium can help execute cross border treatments for paired kidney transplants possible through an international donor bank. Sharing of best practices, knowledge, and resources will aid the kidney patient community immensely. A collaborative platform such as this will help us gather momentum in kidney research, patient advocacy, and provide financial aid to needy patients. The needs of kidney patients are best expressed by them. They are going through the arduous journey and having firsthand knowledge of what works best for them. Patients driving these discussions will help bring conclusive decisions on policy matters directly impacting them. Through this platform they will have a channel to voice their opinions and get to share their experiences to a wider community. Getting patients involved early on in these discussions is extremely critical and the value addition that they will provide to the conversation will be vastly practical."*

AAKP and GW SMHS thank their 2021 *Global Summit* sponsors. Gold Level: Horizon Therapeutics and Travers Therapeutics; Silver Level: CareDx, Inc.; Patron Level: Hansa Biopharma and Sanofi Genzyme; and Supporting Level: AstraZeneca and Eurofins Transplant Genomics. Information on the 2022 *Global Summit* is available at <https://aakp.org/programs-and-events/global-summit/>.

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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. By 1973, AAKP patients had collaborated with the U.S. Congress and White House to establish dialysis coverage for any person suffering kidney failure, a U.S. taxpayer supported 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. *The Global Summit on Kidney Disease Innovations* is produced by AAKP's national strategic media partner, [Briar Patch Media](#), which provides creative consulting and full-service media video production and post-production for corporations, non-profit organizations, individuals throughout the U.S., and several international locations.

About the George Washington University School of Medicine and Health

Sciences: Founded in 1824, the George Washington University 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.