



School of Medicine  
& Health Sciences



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## **Kidney Patients Expand Worldwide Impact on Medical Innovations**

### ***Patient-Led Global Summit on Science, Policy, and Care Choice Drives Optimism***

**WASHINGTON, D.C.** – The American Association of Kidney Patients (AAKP), the largest independent kidney patient organization in the USA, and its strategic partner, The George Washington University (GW) School of Medicine & Health Sciences (SMHS), hosted their 5<sup>th</sup> Annual *Global Summit on Kidney Disease Innovations* on June 28-29, 2023. The *Global Summit* encourages participants to collaborate to advance science and medical innovation, advocate for more common-sense regulatory and payment policies, and to remove barriers to new life-saving treatments and cures. AAKP believes patients have a valid and rightful voice in the medical and policy decisions that impact their lives.

The 5<sup>th</sup> anniversary meeting was a key milestone event for AAKP and the GW/SMHS. The event doubled its reach from 50 countries in 2019 to over 100 countries in 2023, with audiences in the tens of thousands through real-time and OnDemand programming. Over the course of the past five years, the *Global Summit* has conducted a cumulative total of over 75 expert sessions, involving over 250 speakers from 40 countries, while generating 80 hours of broadcast quality filmed programming. The *Global Summit* is the largest patient-led kidney innovations summit in the world.

Kidney disease is both a global healthcare and workforce issue. Over 840 million people suffer from kidney disease and failure worldwide. In the United States, over 37 million people suffer from the disease, over 700,00 live with kidney failure, and nearly 100,000 await a kidney transplant. The cost of kidney disease in America alone is estimated at over \$100 billion annually. This cost does not include the additional high costs to patients, families, and taxpayers of unemployment, disability, dependency, and premature death. Those costs are often a direct consequence of burdensome and outdated status quo treatments, especially dialysis. AAKP believes the full, true costs of legacy kidney technologies are grossly underestimated and should be weighed as new technologies emerge. AAKP works closely with [U.S. Congressional leaders](#) to ensure patient access to kidney innovations.

The [2023 Global Summit agenda](#) focused on advancements in diabetic kidney disease, endocrinology, metabolic diseases, cardio-renal syndrome, and unmet patient needs for new

transplant drugs, artificial implantable and wearable kidneys, and xenotransplants. Topics were covered during 14 sessions involving a total of 60 [patient experts](#), government, medical, and industry speakers, resulting in over 16 hours of broadcast quality filmed programming. This year's speakers were drawn from over 20 countries including India, Switzerland, Croatia, Zambia, Ethiopia, Spain, Netherlands, Germany, Sweden, Canada, Israel, Hong Kong, Australia, Kenya, Belgium, Ukraine, France, and the United Kingdom. For 2023, the *Global Summit* gained new audiences across Norway, Dominican Republic, Oman, Sierra Leone, South Africa, Tanzania, Ukraine, Yemen, Israel, Croatia, Hong Kong, as well as the Commonwealth of the Northern Mariana Islands, including Saipan. An international panel on unplanned events impacting kidney patients provided timely lessons learned from responses to earthquakes, hurricanes, and the war in Ukraine. 2023 participants were also able to curate their learning experience through an "After Hours" educational program of over 70 additional professionally-produced AAKP expert webinars and over 30 patient-authored editorials.

The 2023 program included significant firsts. The inaugural [Global Kidney Leadership and Innovation Award](#) was presented to The Honorable Alex M. Azar, II, the 24<sup>th</sup> Secretary of the U.S. Department of Health and Human Services (HHS), marking the fourth anniversary of the historic, bipartisan 2019 U.S. presidential [Executive Order on Advancing American Kidney Health](#). Secretary Azar, a caregiver whose father was a kidney dialysis patient and kidney transplant recipient, was the architect of the Executive Order, widely regarded as the largest shift in American kidney policy in 50 years. Secretary Azar and his team regularly welcomed kidney advocates to the policy table, including AAKP leaders, as they developed principled policies to transform status-quo kidney care through expanded patient care choice, patient-centered medicine, and long-overdue innovations in kidney diagnostics, drugs, and devices. In 2019, to further organize and mobilize domestic and international support for kidney research and innovation, AAKP launched [The Decade of the Kidney™](#). The initiative has been strongly embraced by patients, industry, and professionals, along with senior Members of the European Parliament, the European Kidney Health Alliance, and the European Kidney Patient Federation. AAKP will announce an array of new international partners over the next year.

During his remarks at the award presentation, Secretary Azar ([read full remarks](#)) ([watch award presentation and remarks](#)) said, "The best way to create sound policy and to improve kidney care here in the U.S. and around the globe is to work directly with the stakeholders most impacted by disease. This means patients and not simply health systems or providers. It is vitally important for public officials—either appointed or elected—to listen closely to patients because government works for the people, not the other way around." He continued by saying, "The lesson is clear—the organized voice of kidney patients can change status-quo medicine and is key to advancing the next generation of kidney care treatments and cures. I strongly encourage industry to lean forward and work with patients as partners as new devices and therapies are developed."

The *Global Summit* also hosted a special presentation by the World Health Organization that unveiled a new [Global Framework to Engage People Living with Chronic Diseases](#), including kidney disease. The Framework elevates patients and their unique insights within WHO and government policymaking worldwide and is the product of an 18-month, multi-continent collaboration that involved AAKP advocacy experts. The WHO also unveiled their [People Power Series](#) which references the *Global Summit* in one of twelve case studies on impactful patient engagement across the globe. *Global Summit* participants also watched the global premier of the Dutch Kidney Foundation's new film, "*The Urgent Need for an Artificial Implantable Kidney*," detailing the history of dialysis and inventor Dr. Willem Kolff, and with a special message from Mayor Sander de Rouwe of Kampen, the Netherlands.

The vital role of the nursing professions in kidney medicine was highlighted as AAKP awarded their nursing Medal of Excellence. Recipients were: Pamela Hoyt-Hudson, BSN, RN, of Dialysis Clinics, Inc., recognized for her distinguished expertise and record of global impact across 25 countries; and Janae Thompson, BSN, RN, an outstanding member of The George Washington University Hospital Transplant Center Team, recognized for her record of transplant advocacy and community impact serving patients in the heart of America's capital of Washington, D.C.! [Learn more.](#)

[Edward V. Hickey, III, USMC](#), AAKP President, stated, “The *Global Summit* continues to evolve as a trusted education and advocacy event designed to unite people around the shared interest of advancing the science and innovations necessary to improve and save the lives of more kidney patients. We are grateful to Dean Barbara Bass and Dr. Dominic Raj for their ongoing support of this important event through the George Washington University School of Medicine and Health Sciences and look forward to further expansions in our shared reach and impact.” Hickey is a kidney patient and attorney with experience as a senior staff member on Capitol Hill and appointed service under two presidents. He is also Chair of AAKP’s [Veteran’s Health Initiative](#), is engaged in ongoing research with the U.S Department of Veterans Affairs, and involved with veteran service organizations aiding homeless veterans to protect their earned legal rights and benefits.

[Paul T. Conway](#), AAKP’s Chair of Policy and Global Affairs and Co-Chair of the *Global Summit*, stated, “Since 2019, our programming has provided timely insights into the unmet needs of kidney patients while also highlighting the challenges governments, medical professionals, and industry face to advance new treatments and cures. Yet, optimism is high because bold leaders have stepped up for patients. We deeply respect Secretary Alex Azar, Dean Barbara Bass, Dr. Dominic Raj, and the George Washington University School of Medicine and Health Sciences for their courage in rejecting the status quo and advancing future kidney care.” Conway is a 45-year kidney patient and 26-year transplant recipient with appointed service under three presidents, including Chief of Staff of the U.S. Department of Labor. He serves on 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.

[Dr. Dominic Raj](#), Director of the GW/SMHS Division of Renal Disease and Hypertension, and Co-Chair of the *Global Summit*, stated, "Over the course of the past five years, this event has served as a showcase for the interconnected disciplines of science, medicine, and policy, and demonstrated how patient advocates, industry, and government collaborate with them. This is an immensely important strategic concept that impacts millions of lives and drives much needed innovation in nephrology. Through her commitment to excellence and the *Global Summit*, our Dean, Dr. Barbara Bass, continues to transform GW into a world-class educational institution with the capacity to impact patient lives across the world." Dr. Raj was recently named as the Bert B. Brooks endowed Professor at the GW/SMHS.

AAKP and GW/SMHS thanked 2023 Global Summit sponsors—Gold Level: Novartis; Patron Level: Aurinia Pharmaceuticals, Hansa Biopharma, and Horizon Therapeutics. AAKP is committed to providing timely, open access kidney disease education and innovation insights to people anywhere in the world. AAKP’s use of broadcast quality programming across all major events has been made possible through their national strategic media partner, Briar Patch Media, and their team of international and national cable and network television production experts under the leadership of Jonathan St. John. Briar Patch Media collaborates with the highly talented GWU media production team for the *Global Summit*. All 2023 *Global Summit* presentations will be available, free of charge, OnDemand through the [AAKP website](#) and [AAKP YouTube Channel](#).

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**American Association of Kidney Patients (AAKP):** Since 1969, AAKP, as a patient-led organization, has shaped national debates on care choice and medical innovation. In 2018, AAKP established the largest U.S. kidney community voter registration program, *KidneyVoters™*. In the past decade, AAKP has advanced lifetime transplant drug coverage for transplant recipients (2020); new job protections for living organ donors under the Family Medical Leave Act (FMLA) via the U.S. Department of Labor (2018); and Congressional legislation allowing HIV-positive organ transplants for HIV-positive patients (2013). Follow AAKP at [@kidneypatient](#) on Facebook, [@kidneypatients](#) on Twitter, and [@kidneypatients](#) on Instagram, and visit their website at [www.aakp.org](http://www.aakp.org).

**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](http://smhs.gwu.edu).