

# 5<sup>th</sup> Annual Global Summit on Kidney Disease Innovations

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The Honorable Alex M. Azar II  
*24th U.S. Secretary of Health and Human Services (2018-2021)*

Acceptance of the Global Kidney Leadership & Innovation Award  
5<sup>th</sup> Annual Global Summit on Kidney Disease Innovations  
The American Association of Kidney Patients and the George Washington University School of  
Medicine and Health Sciences  
June 28, 2023  
Washington, DC

Thank you very much Ed and Dr. Raj for this deeply meaningful award. I am greatly honored to receive the inaugural Global Kidney Leadership and Innovation award in kidney medicine at the 5<sup>th</sup> Annual Global Summit on Kidney Disease Innovations.

Ed, I would like to thank you for your past service to America as a public servant on Capitol Hill, in two presidential administrations and as a United States Marine. I have tremendous respect for the work you and AAKP are doing to aid military service members and veterans with kidney diseases, and their families, through AAKP's close collaborations with the Departments of Defense and Veterans Affairs.

Dr. Raj, I know that both you and Dean Barbara Bass are deeply committed to applied research and patient-centered medicine and are making significant advancements in the field of kidney medicine and related illnesses here at George Washington University. I believe the vision that you and AAKP's former president Paul Conway bring as Co-Chairs of the Global Summit has been critical to raising international attention to the burdens of kidney disease and the need for greater patient care choice in preventative therapies and treatments.

Equally important, this Summit has brought a tremendous spotlight to the valiant efforts medical professionals, researchers and private sector industries are engaged in to bring new kidney care innovations to global consumer markets. Over 840 million people suffer from kidney disease and kidney failure across the globe. Here in the U.S., over 37 million people suffer from kidney disease, over 700,000 live with kidney failure, and nearly 100,000 await a kidney transplant.

Clearly, the need for regulatory and payment policies that encourage medical innovations has never been greater.

When I was first notified of the decision to grant me this recognition, I had several immediate reflections. The first was very personal. For those that may not be aware, my father experienced kidney failure, and I was able to witness the entire continuum of kidney disease in America, from diagnosis to center-based dialysis, to home peritoneal dialysis, to a paired-donor-exchange transplant, to hospital dialysis and eventually to death while on dialysis in the hospital. For the patients and caregivers listening and watching us today from across the globe, I want you to know that I truly understand the burdens you manage and your journey.

I think each of you has great courage and determination to face this disease and to continue the pursuit of your dreams and aspirations. Your disease does not define who you are – and it should never be used to either control or limit what you attempt to achieve as individuals.

My second reflection was on the many discussions and meetings I have conducted over the years within the kidney community. I thought of the many accomplishments the kidney community has achieved over the past several years – just as Ed Hickey recounted in his generous introduction. I consider myself fortunate to have contributed to these victories for kidney patients and kidney medicine.

In my professional roles, I have met a wide array of experts here in America and overseas in specialty medical fields related to kidney disease. They included nephrologists, transplant surgeons, cardiologists, endocrinologists as well as the nurses, techs and social workers who spend most of their time caring directly for kidney patients.

I have consulted with dozens of leaders from transplant centers, private and non-profit dialysis providers as well as entrepreneurs and executives leading research and innovation in the fields of kidney diagnostics, devices and drugs.

And, of course, as the Secretary of Health and Human Services, I led the many federal agencies responsible for researching kidney disease and treatments, paying for the complications of kidney disease, paying for and regulating the kidney transplantation system, and incentivizing and developing new kidney products and bringing them quickly to market and getting them reimbursed by Medicare and Medicaid.

It is not an overstatement to say that I have had access to, and continue to work closely with, some of the most knowledgeable kidney disease experts in the world.

Yet, among all these experts, there is one group whose knowledge, sense of urgency and clarity about the burdens of kidney disease rises above all others.

Who are these experts? They are the patients I have had the privilege to meet and learn from directly. Among them were the patient advocacy leaders I welcomed around my conference table as my team and I led the development of the most significant changes to kidney care in the United States in 50 years. Their insights were indispensable to the creation of common-sense

solutions – including the 2019 Executive Order on Advancing American Kidney Health. I am proud to say the patient leaders of AAKP were regular contributors to these discussions.

Patients provided me with a broad and detailed picture of how the consequences of this deadly disease had been managed – and in many cases ignored – for decades. They were candid in their observations that far too many patients, especially people from historically underserved minority communities, were diagnosed with kidney disease in the emergency room, amid medical crisis and kidney failure, as we say, “crashing into dialysis.” This, to me, was a tragedy with massive implications for people, families, and our national healthcare system.

I listened closely as patients described how too few of their fellow patients were informed of their care choices of home dialysis or a kidney transplant. Instead, many patients were presumptively routed to in-center dialysis – and were never informed how this could negatively impact their capacity to keep working and caring for their families and might, instead, force unplanned dependency on limited disability income. My father was a leading surgeon, yet it took over a year for us to learn of the option of peritoneal dialysis that so improved his quality of life.

Transplant patients, including AAKP’s past president Richard Knight, told me stories of how the 36-month limit on federal transplant drug coverage was creating havoc for patients that experienced a subsequent job loss or insurance disruption. Before our 2020 establishment of lifetime immunosuppressive transplant drug coverage, a temporary job loss or insurance disruption often forced transplant patients to choose between daily living expenses and the cost of continuing their transplant drugs. This meant some transplant patients needlessly lost their transplanted kidneys and returned to dialysis, the transplant waiting list, or experienced premature death.

And I listened to patients who had spent years on dialysis and the organ transplant list asking why, in the face of high mortality rates, innovations like artificial wearable, implantable, or regenerative kidneys had yet to appear as a life-saving care option. So we drove forward the Kidney X program to incentivize innovation in kidney care.

These patients understood that kidney disease was not simply a medical issue. They saw it as both an economic and workforce issue. For many, their lives were a testament to the fact that kidney disease denies people the opportunity to pursue part-time or full-time work, the ability to care for their families and the chance to build a secure retirement.

Patient insights – coupled with those of medical experts and other kidney stakeholders – fueled our efforts at HHS to change the narrative of kidney disease and to enact the policy changes necessary to transcend status quo kidney care and begin a new era of patient-centered medicine.

The result was a complete transformation in how we think about and pay for kidney disease management. Earlier disease detection, faster interventions, improved dialysis technologies, greater opportunity for organ transplantation and new transplant drugs, and artificial and regenerative organs are now the future of kidney medicine. These changes will result in the

reduction of patient burdens, unacceptably high mortality rates and unnecessary and wasteful spending associated with episodic and crisis kidney care.

We are already seeing results from the change we made from fee-for-service reimbursement of center-based dialysis to value-based payments in Medicare that reward the type of patient-centered care we all desire. The electronic medical record company Epic reports that as a result of the Advancing American Kidney Health order, we are already seeing earlier diagnosis of kidney disease, which should enable prevention of disease and help reduce the rate at which patients crash into dialysis. We changed the payment structures to incentivize early detection, prevention, and treatment of chronic kidney disease, we incentivized home dialysis options, we incentivized transplantation, improved the rules for living donors, and we changed the rules to make organ procurement organizations more accountable and to improve their performance.

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.

The accomplishments we achieved would not have been possible without the consistent and robust support of patients and patient advocacy organizations. In 2019, AAKP launched The Decade of the Kidney and this Global Summit in order expand international support among kidney patients and other stakeholders for increased kidney research and innovation. 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.

But because in the field of policy there are no permanent victories, only permanent battles – and because policies often change as national leaders and priorities change – kidney patients and their allies must remain fully engaged in the public and policy arena.

You must remain vigilant to preserve the changes in kidney policy and practice that we achieved. And you must hold your elected leaders and governments accountable if you believe they waver in their commitment to advancing the best interests of patients.

Once again – I thank AAKP and the George Washington School of Medicine for this award and for inviting me to your 5<sup>th</sup> Annual Global Summit on Kidney Disease Innovations.

It has been a great honor to appear before you today – your work is critical to the lives of patients across the globe.

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