Kidney Patients and Physicians Call for Accelerated Innovation at Kidney Health Advocacy Day 2018

By Zachary Kribs

Advocates from the American Association of Kidney Patients and the American Society of Nephrology gathered in Washington, D.C., on March 28, 2018, for the 6th Annual Kidney Health Advocacy Day (KHAD) to meet with lawmakers, share their stories, and discuss the need for greater innovation for patients with kidney diseases.

The group of nearly 50 kidney patients and physicians met with more than 60 legislators and their staff. Highlighting the barriers to innovation in kidney care and the consequences of the lack of innovation, advocates urged Congress to support KidneyX, a new public-private partnership to accelerate innovation in the prevention, diagnosis, and treatment of kidney diseases.

“It is difficult to underestimate the exceptional venue that Kidney Health Advocacy Day provided to speak on behalf of researchers, clinicians, and most important, our patients,” said Alejandro Diez, MD, a transplant nephrologist at Ohio State University.

“Sharing narratives with legislative leaders on how our community fights against kidney disease, and particularly the promise of KidneyX, was a powerful experience. We all go into medicine out of a sense of altruism, hoping to become an agent of change,” Diez said. “The opportunity to participate in KHAD strengthened my love of nephrology and reaffirmed my commitment to advocate for my patients—the reason why I became a transplant nephrologist.”

In the United States, more than 40 million people are living with kidney disease, and more than 700,000 of those individuals have kidney failure and require either a kidney transplant or dialysis to live. Annually, Medicare pays nearly $34 billion to provide care for individuals with kidney failure, and dialysis, a therapy invented more than 50 years ago, remains the most common therapy for kidney failure despite poor outcomes for patients. Of all individuals beginning dialysis, 50% die within the first 5 years of treatment.

For Scott Burton, a lifelong kidney patient and founder of the Beerer Tomorrow Foundation, which works to raise awareness about kidney diseases, KHAD was “an educational and inspiring experience.”

“With kidney diseases continuing to grow in prevalence, I feel it’s crucial that research and innovation be at the top of the list of priorities,” Burton said. “Having lived this my entire life, I have observed the lack of advances in treatment options, so it’s my hope that KidneyX will be the catalyst to curb the growth of kidney disease, bringing about a positive outlook for future generations.”

Despite the immense burden kidney diseases place on patients and society, there has been a dearth of innovation compared to other areas of medicine, and our healthcare system has fostered a sense of complacency with existing therapies. KidneyX aims to accelerate breakthroughs in the development of new products including drugs, devices, biologics, and other therapies for people with kidney diseases.

With a recently signed Memorandum of Understanding between ASN and the U.S. Department of Health and Human Services (HHS), KidneyX has already begun to create a sense of urgency in the kidney community.

“This public-private partnership will stimulate new—and exciting research and development in the kidney space,” said Andrew Malone, MB, BCh, a professor of transplant nephrology at the University of Washington. KidneyX has made it “an exciting time to be a nephrologist, and I look forward to being in the position to offer better therapies for our patients.”

American Association of Kidney Patients advocate Toni Martin (right) and her daughter and caretaker Ashley Martin (center) join ASN advocate Alejandro Diez, MD, FASN (left) to describe the need for KidneyX and the accelerated development of treatments and therapies for people with kidney diseases during a meeting with the staff of Sen. Sherrod Brown (D-OH, not pictured).

On Capitol Hill, advocates noted that their call for support of KidneyX was well received, and that Congress shared their excitement for the accelerator. According to Mukta Baweja, MD, assistant professor at the Ichan School of Medicine at Mount Sinai, advocates at KHAD “grabbed the attention of our congressional leaders, galvanizing support for transforming our otherwise stagnant, inefficient, and costly—nearly $100 billion per year—approach to care.” She added, “It was fantastic to see the support our leaders have for our patients.”

After meeting with constituents during KHAD, Sen. Chuck Grassley (R-IA) wrote a letter to HHS Secretary Alex Azar voicing his support for accelerating breakthrough innovations for kidney patients, and applauding “the efforts of HHS to prioritize this initiative.”

In the House of Representatives, a group of 17 bipartisan lawmakers led by Rep. Brian Babin (R-TX) and Congressional Kidney Caucus Co-Chairs Reps. Tom Marino (R-PA) and Susan DelBene (D-WA) called for Congress to match the $25 million raised by the private sector for KidneyX with equal public funding.

For many lawmakers, the matching public-private partnership created by KidneyX has been key to ensuring their support. At the heart of the partnership is the acknowledgment of shared responsibility between the public and private sector for providing breakthrough innovations to improve the lives of kidney patients.

“Improving care takes many actors: government, communities, health systems, and physicians,” said Sri Lekha Tummalapali, MD, MBA, a nephrology fellow at the University of California San Francisco Medical Center, further noting that the private sector sharing responsibility with public institutions can “improve access to care, funding for research, and align incentives … to ultimately create the change our patients need.”

Baweja, “The time for complacency with suboptimal standards of care is over. We must demand better for nephrology and for our patients.”

“All patients and nephrologists experience the problems that face kidney disease patients on a daily basis: poor access to care and transplantation, lack of therapies, and disparities in outcomes. Uniting the voices of patients and physicians on Kidney Health Advocacy Day to call for urgent change was a powerful experience. The personal stories of patients living through the disease matched the studies and statistics to create a narrative to Congress about the need for innovation. Representing the voices of constituents and participating in the democratic process shows that improving care takes many actors: government, communities, health systems, and physicians. Coming together with public institutions can improve access to care, funding for research, and align incentives through well-designed payment models to ultimately create the change our patients need.”

—Sri LekhaTummalapali, MD, MBA, nephrology fellow at the University of California San Francisco Medical Center
I had the great pleasure of representing ASN members and working with patients from AAKP to advocate for kidney research on Capitol Hill on March 28. We had very constructive meetings with members of Congress, all expressing support for the KidneyX project. This public-private partnership will stimulate new and exciting research and development in the kidney space. It is an exciting time to be a nephrologist and I look forward to being in the position to offer better therapies for our patients.

—Andrew Malone, MB, BCh, professor of transplant nephrology at the University of Washington

“ASN’s Kidney Health Advocacy Day was an educational and inspiring experience. With kidney disease continuing to grow in prevalence, I feel it is crucial that research and innovation be at the top of the list of priorities. Having lived this my entire life, I have observed the lack of advances in treatment options, so it is my hope that KidneyX will be the catalyst to curb the growth of kidney disease, bringing about a positive outlook for future generations. It was my pleasure to be a part of it and I look forward to becoming even more involved in the future.”

—Scott Burton, lifelong kidney patient and founder of the Forever is Tomorrow Foundation

“At KHAD 2018, we grabbed the attention of our congressional leaders, galvanizing support for transforming our otherwise stagnant, inefficient, and costly—nearly $100 billion per year—approach to care. It was fantastic to see the support our leaders have for our patients, but we still have a lot of work to do in order to implement optimal resolutions. We must not only advocate for cost-effective prevention and treatment strategies, but [also for] radical advancements that transcend transplantation and dialysis as our status quo. The time for complacency with suboptimal standards of care is over. We must demand better for nephrology and for our patients.”

—Mukta Baweja, MD, assistant professor at the Ichan School of Medicine at Mount Sinai

Help ASN Build the Future of Kidney Care

Submit your innovative teaching tool idea to the ASN Innovations in Kidney Education Contest. You could win a prize worth $5,000.

Today’s medical students and residents will create tomorrow’s cures. ASN wants to launch innovative tools that will inspire medical students and residents to think about nephrology in new ways. Topics can cover renal physiology, pathophysiology, and/or clinical management.

Innovative tools might include videos, smartboard talks, games, mobile apps, and/or other electronic instruments that create a dynamic learning environment and showcase the intricacies and challenges involved in studying the kidney.

You could win a prize worth $5,000 which includes complimentary registration to ASN Kidney Week 2018 in San Diego, CA.

Full contest guidelines and eligibility requirements are now available at www.asn-online.org/contest.

Contest entries are due by June 8, 2018.