



# PRESS RELEASE

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## AMERICAN SOCIETY OF NEPHROLOGY AND AMERICAN ASSOCIATION OF KIDNEY PATIENTS SEEK CONGRESSIONAL SUPPORT FOR KIDNEY RESEARCH AND INNOVATION

### *RENEW REQUEST FOR LIVING ORGAN DONOR PROTECTIONS*

#### Highlights

- Today advocates of the American Society of Nephrology (ASN) and American Association of Kidney Patients (AAKP) will meet with their Congressional delegations to ask for new policies to improve kidney health for 37 million Americans living with kidney diseases
- Congress will be asked to increase funding for kidney health research at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
- Congress will be asked to accelerate innovation by increasing investment in KidneyX
- Congress will be asked to protect insured and uninsured living organ donors, legislation such as the Living Donor Protection Act (H.R. 1255/S. 377) seeks to remove barriers to living organ donation

**Washington, D.C. (March 23, 2023)** – The prevalence of kidney diseases in the United States is at a record high. Today, more than 50 advocates from ASN and AAKP including patients, caregivers, living kidney donors, and kidney health professionals, are scheduled to conduct 90 virtual meetings with Congressional leaders and staff over the course of just 8 hours. Advocates will call for increased investment in kidney research at NIDDK, kidney innovation through KidneyX, and to protect insured and uninsured living organ donors to increase the availability of kidney transplantation.

“Kidney health professionals witness the courage of people living with kidney diseases every day, especially during the COVID-19 pandemic, when they experienced unique challenges and were among the highest risk for death. People with kidney diseases matter...and they deserve better. ASN is proud to partner with AAKP to call on Congress to improve the lives of people with kidney diseases by increasing funding for kidney health research at NIDDK, supporting kidney health innovation through KidneyX, and protecting living organ donors who provide so many with the gift of life,” stated Susan E. Quaggin, MD, FASN, ASN President

“AAKP is very proud of our long partnership with ASN the tremendous bipartisan and bicameral relationships we have worked together to establish across the Congress. COVID-19 has exacerbated the strain on kidney patients and their allied professionals, and we are asking

Congress to act today to support greater research, innovation, and organ donor protections so the nation is better prepared to manage the increased prevalence of kidney disease as well as COVID-19's impact on kidney health," stated Richard Knight, AAKP President and a fifteen-year kidney transplant patient.

### **Kidney Diseases in the United States**

More than 37,000,000 Americans are living with kidney diseases, including more than 800,000 with kidney failure, a life-threatening condition for which there is no cure. Kidney diseases disproportionately impact Black, LatinX or Hispanic, Asian, and Indigenous Americans, are costly to the public, and are associated with the highest risk of severe outcomes from COVID-19.

During Kidney Health Advocacy Day, Congress will be asked to support people with kidney diseases by removing barriers to therapies such as transplantation, funding research to better understand and prevent kidney diseases, and increasing investment in accelerating innovation and access to innovation for people living with kidney diseases.

### **Supporting Kidney Research at NIDDK**

Congress will be asked to increase funding for kidney health across the federal government, including an increase of at least \$632 million for kidney research at NIDDK to keep pace with medical inflation, study COVID-19, and continue to improve the care for people living with kidney diseases.

Kidney diseases are costly to the American public. Medicare alone spends more than \$125 billion annually to manage kidney diseases, including \$50 billion to manage kidney failure. This burden may grow because of the COVID-19 pandemic; 30 percent of people hospitalized with COVID-19 develop kidney damage, even in people without a history of kidney diseases.

More research is needed to improve the care of people with kidney diseases. However, the U.S. government invests less than one percent of this cost in kidney disease research and has not provided NIDDK with any dedicated funding to study the impact of COVID-19 on people with kidney diseases.

### **Accelerating Innovation at KidneyX**

Congress will be asked to increase its investment in accelerating innovation by providing \$25 million for kidney innovation at KidneyX. In addition, Congress should ensure that regulatory and payment systems enable patient access to innovation and retain the attention of the private sector.

Therapeutic options for people with kidney diseases remain limited. Dialysis is the most common therapy for kidney failure, yet more than one-half of Americans starting dialysis today will die within five years.

KidneyX is a public-private partnership to accelerate innovation in the prevention, diagnosis, and treatment of kidney diseases. Established in 2018, KidneyX has supported 67 innovators across five prize competitions in 22 states. Currently, KidneyX is running the Artificial Kidney Prize Phase 2, which seeks to promote the integration and advancement of prototype bioartificial kidneys.

## **Saving Lives with Living Donor Transplants**

Congress will be asked to protect insured and uninsured living organ donors. Legislation such as the Living Donor Protection Act (H.R. 1255/S. 377), sponsored by U.S. Reps. Jerry Nadler (D-NY) and Jaime Herrera Beutler (R-WA), and with Sens. Kirsten Gillibrand (D-NY) and Tom Cotton (R-AR), seeks to ensure living donors can access life, disability, and long-term care insurance and to codify a 2018 U.S. Department of Labor decision that living organ donors are protected under the Family and Medical Leave Act (FMLA) and can take time to recover from donation surgery and maintain job security.

Each day, 12 Americans die on the 100,000-person kidney transplant waitlist. Congress must take action to protect living organ donors to encourage living donation of kidneys. Currently, one in four living organ donors experience difficulty in securing or paying for life, disability, and long-term care insurance, and these barriers lead to inequity. White Americans are twice as likely to receive a kidney transplant from a living donor than Black Americans.

## **About the American Society of Nephrology**

*Since 1966, ASN has been leading the fight to prevent, treat, and cure kidney diseases throughout the world by educating health professionals and scientists, advancing research and innovation, communicating new knowledge, and advocating for the highest quality care for patients. ASN has more than 20,000 members representing 132 countries. For more information, visit [www.asn-online.org](http://www.asn-online.org) and follow us on [Facebook](#), [Twitter](#), [LinkedIn](#), and [Instagram](#).*

## **About the American Association of Kidney Patients**

*Since 1969, AAKP has been the largest patient organization in the U.S. driving policies to increase kidney patient consumer care choice and access treatment innovation. AAKP established the largest U.S. kidney voter registration program, KidneyVoters™, in 2018 and the Decade of the Kidney™ global innovation initiative in 2019. Follow AAKP on social media at [@kidneypatient](#) on Facebook, [@kidneypatients](#) on Twitter, [@kidneypatients](#) on Instagram, and visit [www.aakp.org](http://www.aakp.org) for more information.*

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