



PRESS RELEASE

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AMERICAN SOCIETY OF NEPHROLOGY AND 19 KIDNEY COMMUNITY ORGANIZATIONS CALL ON CONGRESS TO PROTECT LIVING DONORS, FUND RESEARCH AND INNOVATION, AND REMOVE BARRIERS TO TELEHEALTH

Highlights

- Today, advocates of the American Society of Nephrology (ASN) and 19 other kidney health professional and patient organizations are meeting with their congressional delegations, calling on them to enact policies to improve kidney health
- Congress must pass the Living Donor Protection Act (H.R. 1255/S. 377) to remove barriers to living organ donation
- Congress must increase funding for kidney health across the federal government, including at NIDDK, KidneyX, and CDC
- Congress must increase access to telehealth by removing home and originating site restrictions

Washington, DC (September 22, 2021) – The prevalence of kidney diseases in the United States is at a record high. As such, members of 20 “kidney community” health care groups representing people with kidney diseases and the health professionals who serve them, including the American Society of Nephrology (ASN), will meet with their members of Congress to call for the passage of the Living Donor Protection Act (H.R. 1255/S. 377), increase funding for kidney research at the National Institute of Diabetes and Digestive and Kidney Diseases, kidney innovation at KidneyX, and disease surveillance at the Centers for Disease Control and prevention, and enable access to telehealth by removing legislative barriers such as the home and originating site restrictions as in the CONNECT for Health Act (H.R. 2903/S. 1512).

Kidney Diseases in the United States

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

Congress must support people with kidney diseases by removing barriers to therapies such as transplantation, funding research and innovation to better understand and treat kidney diseases, and enabling patient choice in care through the modernization of telehealth.

Saving Lives with Living Donor Transplants

Each day, 12 Americans die on the 100,000-person kidney transplant wait list. 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, the Living Donor Protection Act (H.R. 1255/S. 377) ensures insurance companies offering life, disability, and long-term care plans do not deny or limit coverage or raise premiums based on an individual's status as a living organ donor and clarifies that living organ donors can take Family and Medical Leave Act (FMLA) time to recover from donation surgery and maintain job security.

Funding Kidney Research, Innovation, and Surveillance

Kidney diseases are costly to the American public, yet despite recent strides, therapeutic options remain limited. Medicare alone spends more than \$130 billion annually managing kidney diseases, including \$50 billion to manage kidney failure, and more than one-half of Americans starting dialysis today will die within 5 years.

Congress must increase funding for kidney health across the federal government, including at least \$2.2 billion for kidney research at NIDDK, \$25 million for kidney innovation at KidneyX, and \$15 million public health intervention at the CDC, to continue to improve the care for people living with kidney diseases. In addition, as Congress considers its year-end spending legislation, Congress should avoid stopgap funding or government shutdowns which can threaten the momentum of kidney health research, innovation, and intervention and ultimately, the health of people with kidney diseases.

Enabling Access to Telehealth

Telehealth can improve the quality of kidney health care and reduce costs and can be especially useful in areas with workforce shortages or in rural or hard to reach care settings. During the COVID-19 public health emergency, the federal government waived many restrictions for accessing telehealth – including home and originating site restrictions - and telehealth utilization among Medicare beneficiaries jumped from .1% to 43.5% of all primary care visits.

Congress should remove outdated home and originating site restrictions to increase access to important telehealth care, as proposed in the CONNECT for Health Act (H.R. 2903/S. 1512) sponsored by US Reps Mike Thompson, D-CA, and David Schweikert, R-AZ in the House, and Sens. Brian Schatz, D-HI, and Roger Wicker, R-MS in the Senate.

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 21,000 members representing 131 countries. For more information, please visit www.asn-online.org or contact the society at 202-640-4660.

2021 Kidney Community Advocacy Day Partner Organizations:

Alport Syndrome Foundation
American Association of Kidney Patients
American Kidney Fund
American Nephrology Nurses Association
American Society of Diagnostic and Interventional Nephrology
American Society of Nephrology
American Society of Pediatric Nephrology
American Society of Transplant Surgeons
American Society of Transplantation
Home Dialyzers United

IGA Nephropathy Foundation of America
National Kidney Foundation
NephCure Kidney International
Oxalosis and Hyperoxaluria Foundation
Polycystic Kidney Disease Foundation
Rare Kidney Disease Foundation
Renal Pathology Society
Renal Physicians Association
Society for Transplant Social Workers
Veterans Transplant Association

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