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ASN and Advocates from 21 Other Health Care Organizations are on Capitol Hill Urging Congress to Support Kidney Disease Research and the Living Donor Protection Act

Washington, DC (September 19, 2017) – Advocates from the American Society of Nephrology (ASN) and the 21 other health care organizations listed below are meeting with their representatives and senators today. They will urge <u>Congress</u> to continue its historic support of research funding for the National Institutes of Health (NIH) and to cosponsor and pass the Living Donor Protection Act (H.R. 1270), no-cost legislation to eliminate barriers to living donation and increase access to transplants.

"The prevalence of kidney diseases in the U.S. is at a record high – I would even say rampant," said Crystal A. Gadegbeku, MD, chair of the ASN Policy and Advocacy Committee. "With a tremendous need for more innovation in kidney therapies coupled with a national organ shortage, we need Congress to move both to provide kidney-specific research funding, similar to the Special Diabetes Program, which has led to a Food and Drug Administration-approved artificial pancreas – and to take steps to eliminate barriers to donation by enacting the Living Donor Protection Act. This year's Government Accountability Office (GAO) report about the prevalence of kidney diseases in America and the underfunded state of kidney research should be both a wake-up call and a rallying cry for members of Congress and all Americans."

In January, the GAO released a report detailing that 17% of Americans (40 million) have kidney diseases and about 680,000 have kidney failure and whom rely on dialysis or a transplant to live. The GAO data shows that Medicare spends nearly \$33 billion on kidney failure, while the investment in federally funded kidney research is the equivalent of just about 1% of that amount. The *United States Renal Data System (USRDS)* data places total Medicare spending for all kidney diseases at \$103 billion. In order to bring better value to Medicare and improve patient outcomes, patient and physician advocates are urging Congress to support an additional \$150 million per year over 10 years to establish a Special

Statutory Funding Program for Kidney Research at The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), supplementing regularly appropriated funds they currently receive.

Advocates are also asking Congress to pass the Living Donor Protection Act, H.R. 1270, to remove barriers to living organ donation to address the nation's organ shortage crisis. There are over 100,000 Americans on the kidney transplant wait list. While every 14 minutes a patient is added to that list, 13 Americans die every day waiting for a kidney transplant. Besides increasing quality of life, transplants also save Medicare expenditures compared to dialysis: Medicare about \$30,000 per transplant patient versus nearly \$90,000 per hemodialysis patient annually on average.

GAO also highlighted that the government's unique role in the care of patients with kidney failure. In 1972, Congress made a commitment to treat all Americans with kidney failure through the Medicare End Stage Renal Disease (ESRD) Program—the only Medicare program that provides coverage for patients with a specific health condition regardless of age.

## About the American Society of Nephrology

Since 1966, the American Society of Nephrology (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 nearly 17,000 members representing 112 countries. For more information, please visit <a href="www.asn-online.org">www.asn-online.org</a> or contact us at 202-640-4660.

## 2017 year's Kidney Community Advocacy Day participants:

Alport Syndrome Foundation
American Association of Kidney Patients
American Kidney Fund
American Nephrologists of Indian Origin
American Nephrology Nurses Association
American Society of Nephrology
American Society of Pediatric Nephrology
American Society of Transplantation
American Society of Transplant Surgeons
Children's Organ Transplant Association

Home Dialyzors United
IGA Nephropathy Foundation of America
Lowe Syndrome Association
NATCO
National Kidney Foundation
National Renal Administrators Association
NephCure Kidney International
Polycycstic Kidney Disease Foundation
Renal Pathology Society
Renal Physicians Association
Society for Transplant Social Workers
Transplant Recipients International Organization