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## ASN and AAKP Advocates are on Capitol Hill Urging Congress to Support Kidney Disease Research and the Living Donor Protection Act

Washington, DC (March 29, 2017) – Advocates from the American Society of Nephrology (ASN) and the American Association of Kidney Patients (AAKP) are meeting with Representatives, Senators, and their respective staffs today to urge Congress 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," said Crystal A. Gadegbeku, MD, chair of the ASN Policy and Advocacy Committee. "We need Congress to provide kidney-specific research funding, similar to the Type I Diabetes Program, which has led to a Food and Drug Administration approved artificial pancreas. The recent 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."

Paul T. Conway, president of the American Association of Kidney Patients and a thirty-six year kidney patient stated, "kidney patients share the same aspirations as every other American including a good job, the ability to help provide for their family and to own a home. Yet, for the millions of Americans suffering from kidney disease, and for the more than a half a million currently on dialysis, their ability realize their dreams is dependent upon research-driven innovations and greater access to kidney transplants. As scientific and patient advocacy organizations, ASN and AAKP are united in their efforts to advance patient health outcomes and respectfully request the U.S. Congress to support increased kidney disease research and to pass the Living Donor Protection Act."

In January, the GAO released a report detailing that 17% of Americans (40 million) have kidney diseases and about 680,000 have kidney failure – most of

whom rely on dialysis 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, ASN and AAKP 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 for both groups 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. 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 www.asn-online.org or contact us at 202-640-4660.