

Policy Update

Kidney Advocates Urge NIH Funding Boost, Living Donor Protections

By Zachary Kribs

Advocates from the American Society of Nephrology (ASN) and 21 other kidney and transplant health care organizations met with nearly 100 members of Congress or their staff during the third perennial Kidney Community Advocacy Day on September 19, 2017 (Table 1). A total of 75 advocates urged 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 that would eliminate barriers to living donation and increase access to transplants.

The Capitol Hill visits were part of an ongoing effort by ASN to bolster its legislative agenda. In March, advocates from ASN and the American Association of Kidney Patients met with members of Congress to advocate for increased research funding in the face of the administration's proposed budget cuts to the NIH, as well as to identify potential sponsors of the Living Donor Protection Act. Partly as a result of their efforts, Congress soundly rejected the administration's proposed NIH cuts, instead proposing an increase in funding in line with ASN's request, and has added nearly 30 co-sponsors to the Living Donor Protection Act. Kidney Community Advocacy Day expands on the progress made in previous efforts, with advocates calling on Congress to finalize the increase to the NIH budget and to pass the Living Donor Protection Act.

"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."

Funding for kidney research and elimination of barriers to living organ donation are highly important issues to the kidney care and transplant community. ASN rallied to support these two causes with the 21 other organizations on Kidney Community Advocacy Day to show unity in the kidney care and transplant community in the face of a challenging political climate and era of austerity for many federal budgets.

Report reveals disease burden, funding mismatch

In January, the U.S. Government Accountability Office released a report detailing that 17% of Americans (40 million) have kidney diseases and about 680,000 have kidney failure and rely on dialysis or a transplant to live. The GAO data show 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 urged 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 the agency currently receives.

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

Participants in Kidney Community Advocacy Day represented a diverse group of kidney care and transplant physicians and patients, and traveled from 22 different states to speak to Congress about the importance of kidney research and living donation. Roughly 60% of these individuals had experienced a previous Kidney Community Advocacy Day. The night before, advocates gathered for a group dinner and training session during which staff from the represented organizations provided guidance on effective Capitol Hill advocacy and answered questions about the current political climate and its effect on kidney and transplant issues.

During the day, advocates shared their own personal experiences with kidney diseases with their congressional delegations. They cited these personal stories, as well as the high prevalence and large human toll of kidney diseases, as reasons for their involvement in advocating for more research funding and better care. After the event, participants urged others to get involved in advocacy, and many pledged to participate in a future Kidney Community Advocacy Day. ●



Left to right: Hon. Karen Thurman (a former congressional representative from Florida representing the PKD Foundation), Edward Drake II (Georgia, American Association of Kidney Patients), and John Menendez (Florida, Alport Syndrome Foundation), meet with a staff member from the office of Sen. David Perdue (R-GA).

Table 1. Participants in Kidney Community Advocacy Day 2017

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 Dialyzers United
IgA Nephropathy Foundation of America
Lowe Syndrome Association
NATCO
National Kidney Foundation
National Renal Administrators Association
NephCure Kidney International
Polycystic Kidney Disease Foundation
Renal Pathology Society
Renal Physicians Association
Society for Transplant Social Workers
Transplant Recipients International Organization