

Policy Update

By David L. White, Rachel Nell Meyer, and Zachary Kribs

A “tumultuous” 2017 in Washington

The first four months of 2017 have been nothing short of tumultuous in the Washington world of health care policy. As a result, the American Society of Nephrology (ASN) Policy and Advocacy Committee (PAAC) members are engaged on numerous policy fronts from efforts to repeal the Affordable Care Act (ACA) to the executive order on immigration and its travel ban to President Donald J. Trump’s budget proposal to cut funding for the National Institutes of Health (NIH) by nearly 20%.

It would be easy to view the current Washington environment as chaotic and feckless, but there has been a great deal more accomplished and moving forward than meets the eye. While ASN and the American Association of Kidney Patients (AAKP) hosted their fifth consecutive Kidney Health Advocacy Day (KHAD) 2017 on March 29, this year was anything but “business as usual.” The ASN PAAC also met for a day-long session on March 28 before KHAD. The following are highlights of what ASN took to Capitol Hill and is currently working on.

Fighting for NIH Research Funding

ASN refused to roll over on massive proposed NIH cuts and delivered that message to over 50 congressional offices during KHAD 2017 and is continuing to do so nearly daily—often with peer societies.

The battle for fiscal year (FY) 2018 was set in early March when the White House released an outline of its forthcoming budget request. The budget proposal contained a heavy-handed \$54 billion worth of cuts to non-defense programs to pay for a similar increase in military and security spending.

In the proposed budget, the Department of Health and Human Services (HHS) received the largest cut, a whopping \$15.1 billion, or 17.9% of its budget when compared to the previous year. HHS is also home to the National Institutes of Health (NIH), which would receive a proportionately large cut of \$5.8 billion, nearly 20% less when compared to the previous year. Applied equally across the NIH, this cut would mean a \$332.8 million reduction in the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) budget. Further complicating matters, the Trump Administration unexpectedly requested new spending cuts for all non-defense spending in FY 2017 on March 21.

ASN’s response to these proposed cuts in total was unequivocal in rejecting them and making a strong case for increased research funding. ASN President Eleanor Lederer, MD, FASN, “condemned” the proposed NIH cuts in a public statement issued by ASN on March 17.

Instead, ASN is asking for:

- Special Kidney Program for NIDDK: \$150 million per year for 10 years (new funding)
- \$2.165 billion for NIDDK (in FY 2018)
- \$2 billion increase for NIH (over FY 2017)

Many congressional offices have expressed openness to the idea of raising NIH funds despite President Trump’s budget proposals. More to come.

Protecting and Encouraging Living Organ Donation

ASN and American Association of Kidney Patients members know the value of kidney transplantation and are fighting to protect the rights of living donors and hopefully make the pathway to living donation easier. When both groups joined together for KHAD 2017, they delivered a strong endorsement for the Living Donor Protection Act (H.R. 1270), while asking for cosponsors and passage of this critical legislation. The ASN PAAC has made enacting the Living Donor Protection Act a top legislative priority for ASN in the 115th Congress.

Rep. Jaime Herrera Beutler (R-WA) and Rep. Jerry Nadler

(D-NY) introduced the legislation with the goals of protecting the rights of living donors and ensuring Americans are educated about living donation. The current organ shortage and wait-times to transplantation are growing, as evidenced by the more than 100,000 Americans currently on the wait list. Every 14 minutes a patient is added to the kidney wait list, and 13 Americans die each day waiting for a kidney.

The Living Donor Protection Act of 2017 offers three solutions to alleviate some of the barriers to transplantation faced by patients, their families, and potential living donors:

- Protects donors by ensuring they are not denied or given limited coverage or higher premiums by life, disability, or long term care plans.
- Secures jobs by allowing living donors to take time off work to recover from donation surgery without losing their jobs.
- Educates Americans about living donation by requiring that the HHS Secretary update informational materials regarding new protections for living donors.

The bill is already gaining cosponsors from both sides of the aisle in the House of Representatives. ASN, AAKP, and other kidney and transplant advocacy groups are collaborating to identify a lead Democrat and a lead Republican to introduce the bill in the Senate. Several Senate offices with whom ASN and AAKP met indicated their interest in cosponsoring the legislation when it was introduced.

“ASN commends Congresswoman Herrera-Beutler and Congressman Nadler for their leadership in introducing the Living Donor Act of 2017,” said ASN President Eleanor Lederer, MD, FASN. “More than 40 million Americans have kidney disease, and transplantation is the optimal therapy for those whose kidneys fail. ASN is proud to endorse this important legislation, which will help eliminate barriers and increase access to transplantation.”

CHRONIC Care Efforts Have Bright Prospects

After two years of ASN, the Alliance for Home Dialysis, and other stakeholders working with the Senate Finance Committee and the Finance Committee Chronic Care Working Group, the leadership of both the Finance Committee and the Working Group have introduced the Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act (S. 870), a bipartisan bill to strengthen and improve health outcomes for Medicare beneficiaries living with chronic conditions.

ASN strongly supports the legislation’s proposal to designate the dialysis facility as an originating site for telehealth services for home dialysis patients. Home dialysis—in the form of peritoneal dialysis (PD) or home hemodialysis (HHD)—is an important treatment option that, for some patients, offers significant clinical and quality of life advantages. By expanding home dialysis patients’ flexibility to use telehealth technology to interface with their nephrologists, this bill may help increase access to this important treatment option for patients with kidney failure.

As highlighted by a January 2017 Government Accountability Office (GAO) report, nearly 40 million Americans—roughly 17% of the US adult population—live with kidney diseases. Of these individuals, over 680,000 live with kidney failure, a life-threatening condition that must be managed by dialysis or a kidney transplant. Patients with kidney failure are among the most complex and most expensive patients in medicine, costing Medicare over \$103 billion annually.

“The policies outlined in the CHRONIC Care Act of 2017 that permit the utilization of new and innovative technologies like telehealth, and the elimination of barriers to coordination of care, will provide for improved outcomes of individuals managing kidney diseases, and will also reduce the burden of kidney diseases on the economy,” wrote ASN President Eleanor Lederer, MD, FASN, in a letter to Senate sponsors. ●

ASN Policy and Advocacy Committee Interns in Their Own Words

I had the great opportunity to attend my first ASN public policy committee meeting this month in Washington, DC. The meeting started with a briefing about the current state of health care in the US, as well as a discussion about many hot topics affecting people with kidney disease and the physicians who treat them. The topics discussed felt vital and relevant to what I read about in the news and what I experience in my daily practice. I then had the great opportunity to participate in my first Hill Day. It was exciting to be a part of Team Clambakes and Crabcakes, an homage to our home states of Massachusetts and Maryland. As part of the team, I had the opportunity to learn the art of advocacy from the extremely skilled and eloquent Deidra Crews, MD, Dan Weiner, MD, Mallika Mendu, MD, and David White, our dialysis and transplant veteran. I found my time in Washington to be extremely interesting and exciting. It has definitely inspired me to further pursue my interests in public policy.

This experience highlighted to me the importance of physician involvement in legislation. In the same way that we educate our students, residents, and fellows, it is critical to take that next step to educate our senators and representatives so that patient care and innovation do not suffer.

Lauren Stern, MD, Assistant Professor, Boston University School of Medicine, and ASN Policy and Advocacy Committee intern

As an intern on ASN’s Policy and Advocacy Committee (PAAC) for the year 2017, I participated in Kidney Health Advocacy Day (KHAD) on March 29, 2017. My 1-day experience on Capitol Hill during KHAD was, so to say, equivalent to spending 2 years at a graduate public policy training program—from learning best practices of policy stakeholder engagement during the advocacy training session prior to heading to Capitol Hill, to working alongside seasoned policy experts from the ASN Policy and Advocacy Committee and the American Association of Kidney Patients to present our policy requests to congressional staffers, to sharing our experiences with the kidney community on social media. While these experiences will, no doubt, further my long-term desire to voice the importance of kidney disease to policy makers, sharing our KHAD experiences on social media was probably the most gratifying, at least from the immediate vantage point. Using hashtags pertaining to our key legislative items such as #KidneyAdvocates (general), #YouOnlyNeed1 (Living Donor Protection Act), and #FundKidneyCures (Kidney Research Funding) to tweet about KHAD events and to share our photos, we were able to mobilize the nephrology community to join the urgent fight. I look forward to participating in upcoming ASN advocacy events!

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