

## Policy Update

### Kidney Community Advocacy Day 2015: 16 Organizations Unite to Demand Action from Congress

By Mark Lukaszewski

On Thursday, September 10, 2015, the American Society of Nephrology (ASN) convened Kidney Community Advocacy Day 2015. An unprecedented group of more than 100 representatives of 16 kidney patient and health professional organizations banded together to demand Congress support legislation that would increase kidney research funding and remove barriers for people considering living kidney donation (Table 1). Altogether, advocates met with over 120 congressional offices.

Now in ASN's third year of hosting the event, members of the kidney community united on Capitol Hill to underscore the need for this vital legislation by emphasizing the scope of the public health burden to Congress, including that more than 20 million Americans have kidney diseases, nearly 650,000 of these with end stage renal disease (ESRD).

#### Increasing kidney research funding

Organizations called on Congress to strengthen kidney research funding, critical for the development of new treatments and cures for the millions of Americans suffering with kidney diseases. More investments in kidney research and innovation are needed to reduce the significant burden of kidney diseases on both patients and Medicare. Currently, NIH invests less in kidney research than other major diseases both in terms of absolute numbers and per patient.

Yet, as of 2013, federal investments in kidney re-

search were less than 1 percent of Medicare costs for patients with kidney disease. Advocates emphasized they didn't want Congress to take money away from other medical research. Instead they conveyed the fact that since 1972 the federal government has paid nearly all the costs of care for ESRD patients on dialysis (\$80 billion annually), yet a commensurate investment to slow or cure kidney diseases hasn't occurred. Last year, 1 percent of Medicare patients accounted for nearly 8 percent of Medicare expenditures. Yet the government hasn't committed the necessary capital for research funding to develop the most cost-efficient therapies to reduce the burden of kidney diseases on patients and Medicare.

"The kidney community has come together to ensure patient voices are heard in Congress," said ASN Past President Jonathan Himmelfarb, MD, FASN. "We're committed to providing better care and treatments for patients with kidney disease. Congress can do that by bolstering kidney research investments and enacting legislation that promotes organ donations."

#### Removing barriers to living donation

Kidney Community Advocacy Day representatives also emphasized the importance of transplantation in context of the forthcoming Living Donor Act (LDA) (Table 2). Each congressional office learned that every 14 minutes a patient is added to the kidney waitlist and 12 Americans die each day waiting for a transplant. Advocates noted that transplantation is cost-effective for Medicare, with annual costs of \$32,922 per transplant

patient vs. \$87,845 per hemodialysis patient.

"Kidney transplants are the best treatment option for most patients with kidney failure, yet there aren't enough donated kidneys for everyone who needs them," said ASN Secretary-Treasurer and Public Policy Board Chair John R. Sedor, MD, FASN. "More than 100,000 people are on the waiting list for a kidney transplant," Dr. Sedor added. "Congress can help them by enacting commonsense legislation that promotes organ donations by ensuring insurance coverage and job security for donors."

The LDA would help to increase the number of kidney transplants by eliminating barriers to donation. The legislation would prohibit insurers from denying or limiting coverage or from charging higher premiums to living organ donors; ensure living organ donors can use "time off" protected by the Family and Medical Leave Act (FLMA) to recover from donation surgery and maintain job security; and require that the Department of Health and Human Services (HHS) update its education programs to include and explain the new changes for donors.

This unified advocacy day built tremendous momentum on Capitol Hill and showed members of Congress that while organizations may have different goals they are able to unify to promote change. ASN will continue to work with other members of the community in order to advance shared goals, and will keep *ASN Kidney News* readers updated. To learn more about ASN policy, please visit <https://www.asn-online.org/policy/>.

**Table 1**  
**Kidney Community Advocacy Day 2015 participating organizations**

- Alport Syndrome Foundation
- American Association of Kidney Patients
- American Kidney Fund
- American Nephrology Nurses Association
- 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
- National Renal Administrators Association
- NephCure Kidney International
- Oxalosis and Hyperoxaluria Foundation
- Polycystic Kidney Disease Foundation
- Society for Transplant Social Workers

**Table 2**  
**Key benefits of the Living Donor Act**

- Ensure living organ donors have access to life, disability, and long-term care insurance:
  - Banning this discriminatory behavior would eliminate an unnecessary hurdle for living donors. Currently, 11 percent of living organ donors experience difficulty securing or paying for insurance after their procedures.
- Allow living organ donors Family and Medical Leave Act "time off" to recover:
  - Without this guarantee, many people who want to be living donors simply cannot afford the risk of unemployment. Kidney donor hospitalization averages 3 to 7 days and donors typically do not return to work sooner than 4 weeks postdonation.
- Educate and encourage more Americans to consider living donation via a HHS campaign:
  - Making more people aware of the benefits of living kidney donation to those in kidney failure and the new ways this law protects donor rights would help boost transplant rates overall.
  - Raising awareness is imperative: the number of kidney transplants performed in the US is equal to less than 1 percent of the number of patients on dialysis annually.