

## Policy Update

### Kidney Community Unites to Raise Awareness on Capitol Hill

By Kevin F. Erickson, MD, and Mallika L. Mendu, MD, MBA

On May 1, 2014, kidney patient and health professional advocates gathered in Washington, DC, for Kidney Community Advocacy Day. Since 2010, ASN has organized an annual congressional advocacy day to raise awareness about kidney disease and promote issues important to the kidney community.

Building on the momentum from the first-ever Summit of U.S. Kidney Organizations at the society's annual scientific meeting in 2013, more than 100 advocates from 14 organizations met with 133 congressional offices, including 19 members of Congress—triple the number of participants and double the number of meetings from ASN's congressional advocacy day in 2013.

All the advocates were divided into state teams and met with members of their congressional delegation to promote increased funding for kidney research and the Comprehensive Immunosuppressive Drug Coverage Act of 2013.

#### Kidney research funding

More than 20 million Americans have kidney disease, which can have a significant effect on patients' health and quality of life. When patients' kidneys stop working, they need a kidney transplant or dialysis.

Dialysis continues to be associated with high morbidity, mortality, and costs. Since the federal government pays for most of dialysis care, it has a significant incentive to fund research to prevent kidney disease progression and improve the health of patients on dialysis.

Yet kidney disease remains underfunded relative to other diseases; total federal investments in kidney research equal less than 1 percent of the federal cost for providing kidney disease care. Kidney Community Advocacy Day participants asked for an additional \$150 million per year for 10 years above current funding levels to help address this disparity. More research will lead to better ways to diagnose, prevent, and treat kidney diseases of all kinds, improving the health of millions of Americans as well as reducing total federal expenses.

#### Comprehensive Immunosuppressive Drug Coverage Act of 2013

All patients with kidney failure receive Medicare coverage. For most patients with kidney failure, transplants

are the optimal therapy. Medicare pays for kidney transplants, but only provides 36 months of immunosuppressive drug coverage for patients who do not qualify for Medicare because of age.

After 36 months, patients must find a way to pay for the expensive immunosuppressive drugs, and many patients have difficulty affording these medications. Because immunosuppressive medications are necessary to preserve the function of transplanted kidneys, some patients lose their transplanted kidney when they encounter difficulties in affording these medications and are forced to reduce or discontinue the prescribed treatment driven by economic necessity.

This is a tragedy for patients, their loved ones, and kidney donors who have provided a precious gift. In addition, patients return to dialysis when their transplants fail at an annual cost to Medicare of \$90,000 compared to the less than \$5000 annual cost to Medicare for the immunosuppressive drugs.

The Comprehensive Immunosuppressive Drug Coverage Act of 2013 would extend Medicare coverage for immunosuppressive drugs over a recipient's lifetime—protecting Medicare's investment in the transplant and ensuring that no patients will lose their kidney. As of press time, 16 senators and 116 representatives have signed onto the bill as co-sponsors.

#### Innovations in Kidney Research Congressional Briefing

In conjunction with Kidney Community Advocacy Day, ASN co-sponsored a standing-room only congressional briefing: "New Hope for Patients: Discussion of the latest cutting-edge breakthroughs in artificial kidney research." Congressional Kidney Caucus Co-chairs Rep. Tom Marino (R-PA) and Rep. Jim McDermott (D-WA) served as honorary sponsors and spoke about their strong support for the kidney community and additional research funding to develop cures.

The following advocates, experts, and scientists also spoke at the briefing: William Fissell, Jonathan Himmelfarb, Shuvo Roy, Murray Sheldon, Robert Star, and Melanie Stewart.

"Currently kidney disease is the 8th leading cause of death in the U.S., affecting over 20 million Americans,

and costing the federal government over \$79 billion annually, including \$34 billion for treatment of end stage renal disease. But it doesn't have to be this way," Dr. Himmelfarb said. "There are innovators, inventors, and scientists working now on transformative technologies that have the potential to make a fundamental difference for people living with kidney disease. Investing in research that spawns and supports innovation is the hope for the future."

Summing up the day, ASN President Sharon Moe, MD, FASN, said: "It was a successful day by all accounts. More groups participated than ever before, more congressional offices were visited, and our new advocacy message was well received. I have been visiting offices for the past five years. It is clear that the kidney community is being heard and the voice of the American Society of Nephrology is well-respected."

ASN is grateful to all who participated in Kidney Community Advocacy Day and will continue its efforts to engage Congress on these important legislative issues affecting patients with kidney disease.

*Kevin F. Erickson, MD, and Mallika L. Mendu, MD, MBA, are ASN Public Policy Board Interns*

#### Kidney Community Advocacy Day Participants

Alport Syndrome Foundation  
American Association of Kidney Patients  
American Kidney Fund  
American Nephrology Nurses' Association  
American Society of Nephrology  
American Society of Pediatric Nephrology  
Dialysis Patient Citizens  
Home Dialyzors United  
IGA Nephropathy Foundation of America  
National Kidney Foundation  
NephCure Foundation  
PKD Foundation  
Renal Physicians Association  
Renal Support Network



ASN Public Policy Board Member Wolfgang Winkelmayr, MD, ScD, FASN, and Public Policy Board Intern Mallika L. Mendu, MD, MBA



(right to left) Rep. Larry Bucshon, MD, (R-IN) with ASN President Sharon Moe, MD, FASN, and ASN Executive Director Tod Ibrahim



ASN Councilor Mark Okusa, MD, FASN, (second from right) meeting with Rep. Robert Hurt's (R-VA) office



ASN Public Policy Board Member Raymond Hakim, MD, PhD, (third from right) and Policy Board Intern Kevin Erickson, MD (right)



ASN Acute Kidney Injury Advisory Group Chair Sarah Faubel, MD, (second from right) meeting with Rep. Joe Pitts's (R-PA) office