

Policy Update

ASN Goes to NIH and PCORI

By Grant Olan

On September 19, 2014, ASN Secretary-Treasurer and Research Advocacy Committee Chair John R. Sedor, MD, FASN, joined other members of the committee and several of the society's advisory groups to visit the National Institutes of Health (NIH) and Patient-Centered Outcomes Research Institute (PCORI) for "Kidney Research Advocacy Day."

ASN began annual visits to NIH in 2012 to raise the profile of kidney disease, promote more kidney-related research, and encourage more cross-institute collaboration. This year, Kidney Research Advocacy Day participants met with leaders of the National Heart Lung and Blood Institute (NHLBI), National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), National Institute of Biomedical Imaging and Bioengineering (NIBIB), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and National Institute on Aging (NIA). The NIAMS and PCORI meetings were the first one-on-one meetings ASN has had with their leaders.

An internal ASN study of kidney research revealed that less than 1 percent of what the federal government spends on the cost of care for patients with kidney disease is invested in kidney research (approximately \$80 billion in Medicare expenditures vs. \$650 million for kidney research). The cost of just the Medicare End Stage Renal Disease (ESRD) program is nearly \$35 billion, which is more than the entire budget for NIH (less than \$30 billion in 2014).

Moreover, in 2013 NIH spent less per patient on kidney research vs. heart disease, cancer, and HIV/AIDS (\$30 on kidney research per patient compared to \$61, \$534, and \$2,898, respectively).

U.S. Congressional Kidney Caucus Co-Chair Rep. Tom Marino (R-PA) recently requested a review of federal investments in kidney research from the Government Accountability Office (GAO), a bipartisan agency that is highly regarded by Congress. Obtaining a congressional request for a GAO report on this topic is the cornerstone of ASN's aggressive new Research Advocacy Strategic Plan to bolster support for more federal kidney research funding.

"I believe the GAO report is a crucial first step in understanding the current kidney research landscape, and anticipate it will confirm that kidney research is underfunded," Dr. Sedor said.

"I believe the report will pay dividends for research funding down the line," ASN President Jonathan Himmelarb, MD, FASN added. "Once complete, ASN looks forward to sharing the results with the entire kidney community."

PCORI and each of the NIH institutes were receptive to ASN's concerns and expressed interest in working with the society to advance kidney-related research. Below are some takeaways from the Kidney Research Advocacy Day meetings.

National Heart Lung and Blood Institute (NHLBI)

ASN met with Lawrence J. Fine, MD, Branch Chief, Clinical Applications and Prevention Branch, NHLBI, and other senior staff at the institute. NHLBI supports collaboration with NIDDK and kidney-related initiatives, such as an Ischemia-Chronic Kidney Disease ancillary study. Most heart trials exclude patients with

advanced kidney disease despite the fact that heart disease is the leading cause of death for that population. ASN encouraged the institute to also measure albuminuria as well as collect and archive urine samples (for use by the research community) in the study and as many other studies as possible.

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

ASN met with NIAMS Deputy Director Robert H. Carter, MD, and other senior staff. NIAMS supports lupus nephritis research. A new NIH initiative called Accelerating Medicines Partnership (AMP) will explore possible biological pathways for treating lupus nephritis. AMP is a public-private partnership between NIH, industry, and nonprofit groups to increase the number of new diagnostics and therapies for patients and reduce the time and cost of developing them.

National Institute of Biomedical Imaging and Bioengineering (NIBIB)

ASN met with NIBIB Acting Deputy Director William J. Heetderks, MD, PhD, and other senior staff. NIBIB supports an initiative called the Quantum Grants Program. The goal is to make a "profound (quantum) impact on the prevention, diagnosis, or treatment of a major disease or national public health problem through the development and implementation of biomedical technologies within 10 years." The program is funding a project to develop an implantable bioartificial kidney.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

ASN met with NIDDK Director Griffin P. Rodgers, MD, Deputy Director Gregory G. Germino, MD, Kidney Urologic and Hematologic Diseases Division Director Robert A. Star, MD, and other senior staff. In addition to the issues outlined above, ASN and NIDDK discussed expanding NIH's loan repayment to include adult bench research, a possible 2015 NIDDK health disparities initiative and other institute research funding priorities, and the Kidney Research National Dialogue.

National Institute on Aging (NIA)

ASN met with NIA Deputy Director Marie A. Bernard, MD, and other senior staff. NIA has supported kidney-related initiatives on acute kidney injury, organ donation, and renal function in older Americans. NIA has also supported initiatives to advance research on multiple chronic conditions such as the request for applications on "Behavioral Interventions to Address Multiple Chronic Health Conditions in Primary Care." ASN encouraged the institute to also consider initiatives in other



areas where there has been little study, such as best management practices for older Americans nearing ESRD and kidney-mineral bone disorders.

Patient-Centered Outcomes Research Institute (PCORI)

ASN met with PCORI Chief Science Officer Bryan Luce, PhD, and other senior staff. PCORI is a new institute with a relatively small research grant portfolio and has provided more than \$16 million in grants for kidney-related projects to date. PCORI recently announced a joint collaboration with NHLBI on a comparative effectiveness research initiative to study how to reduce disparities in treating hypertension. The initiative is only the second PCORI-NIH collaboration. The first was for a study on falls among the elderly with NIH. ASN encouraged PCORI and NHLBI to consider kidney disease phenotypes given the significant association between the two. ●

Kidney Research Advocacy Day Participants

Frank C. Brosius, III, MD, University of Michigan Hospital
 Josef Coresh, MD, PhD, FASN, Welch Center for Prevention, Epidemiology & Clinical Research
 Deidra C. Crews, MD, FASN, Johns Hopkins University School of Medicine
 William Fissell, MD, Vanderbilt University
 Edgar A. Jaimes, MD, Memorial Sloan-Kettering Cancer Center
 Jordan A. Kreidberg, MD, PhD, Children's Hospital Boston
 Jeffrey H. Miner, PhD, Washington University Renal Division
 John R. Sedor, MD, FASN, MetroHealth Medical Center
 Mark L. Unruh, MD, University of New Mexico
 Tushar J. Vachharajani, MD, FASN, W.G. (Bill) Hefner VA Medical Center