

Policy Update

GAO Report Reveals Extent of Underfunding of Kidney Disease Research Relative to Health Burden Cost

The American Society of Nephrology (ASN) has repeatedly cautioned health care policy-makers that kidney diseases are at staggering levels and, for decades, there have been too few new therapies for treating patients. Now, the US Government Accountability Office (GAO) has conducted a study and published its findings in a new report released January 18, 2017, *National Institutes of Health: Kidney Disease Research Funding and Priority Setting*, that statistically validates these points. The report highlights the inadequacies of federally funded medical research for kidney diseases in the face of a staggering burden on patients and taxpayers.

GAO conducted the study at the request of members of Congress from both the House of Representatives and the Senate. Prior to that request in 2015, ASN had formally requested these members of Congress to call on GAO to conduct the study. GAO is a part of the federal legislative branch, and only members of Congress can direct the agency to undertake studies.

The study, a “performance audit,” was conducted from February 2016 to December 2016 and examined two primary factors affecting federally funded kidney disease research: 1) the level of NIH funding for biomedical research on kidney diseases, and for other leading diseases and conditions; and 2) how the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) sets priorities for kidney disease research.

GAO reported that the “NIH, within the Department of Health and Human Services, is the primary federal agency that conducts biomedical research on kidney disease, as well as various other diseases and conditions. NIH’s budget—\$30 billion in fiscal year 2015—mostly funds extramural research that sup-

ports research personnel working at universities, medical schools, and other institutions. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)—one of NIH’s 27 institutes and centers (IC)—has primary responsibility for kidney disease research.”

GAO began by identifying diseases and conditions with a high disease burden in the United States relative to other conditions based on data from the Centers for Disease Control and Prevention (CDC). Investigators analyzed CDC’s national survey data, and interviewed CDC officials to identify conditions that had high mortality, or were chronic conditions with high prevalence, or both. They then matched the diseases and conditions identified with fiscal year 2015 data—the most current available—from NIH’s Research, Condition, and Disease Categorization (RCDC) system, which categorizes NIH research projects (and associated funding) into categories.

One unique aspect of kidney diseases in terms of policy is that Medicare covers every American suffering from kidney failure—regardless of age—and guarantees them access to dialysis or kidney transplants through the End-Stage Renal Disease (ESRD) Program. Kidney failure is the only condition covered by Medicare for patients under 65 years of age. More than 20 million Americans have kidney diseases and more than 650,000 have kidney failure.

Despite this commitment to care for patients with kidney diseases, the report demonstrates a significant gap between investment in research and the disease burden. Annually, the federal government spends more on the Medicare ESRD program (nearly \$32 billion) than it invests in the entire National Institutes of Health (NIH) budget (\$30 billion). With just \$564 million dedicated to kidney disease research at NIH,

ASN analysis of the report reveals that the equivalent of 1.7% of the annual total cost of care for kidney failure is invested in research to improve therapies and discover cures.

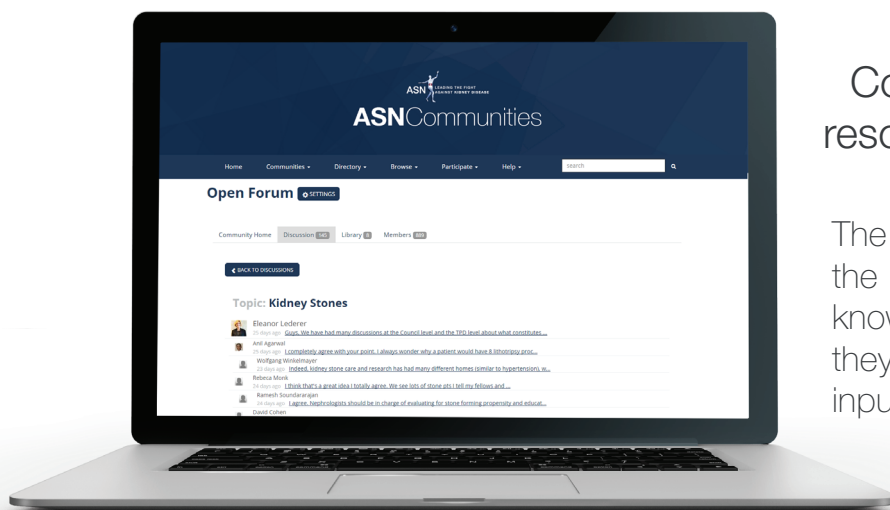
“Kidney diseases are devastating the lives of millions of Americans,” said ASN President Eleanor Lederer, MD, FASN. “Innovation has not kept pace with the magnitude of the diseases, and the current underinvestment in kidney research is detrimental to patients and taxpayers. Today’s GAO report highlights the extent of the gap between our investment in innovation to treat and cure kidney diseases and the outsized burden they place on every American.”

ASN announced at a White House Organ Summit last year its pledge of the first \$7 million to launch a prize competition incentivizing the development of novel technologies for renal replacement therapy to improve quality of life for patients with kidney diseases. The society has also pledged to work with Congress to ensure the United States’ investment in research to cure kidney diseases is adequate to meet the challenge it poses to patients and taxpayers.

“Despite the federal government’s commitment to care for patients with kidney failure, for decades we have seen too few new therapies for kidney patients,” said Crystal Gadegebeku, MD, Chair of the ASN Policy and Advocacy Committee. “This report strengthens ASN’s resolve to foster innovation that improves patients’ lives and extends the value to the Medicare program that has saved so many lives.” ●

Requesters of the GAO report were Congressional Kidney Caucus co-chair Rep. Tom Marino (R-PA), Rep. Barbara Comstock (R-VA), House Science Committee chair Rep. Lamar Smith (R-TX), Sen. Ben Cardin (D-MD), and Sen. Bill Nelson (D-FL).

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