President Reaches for Middle Ground in His Budget Request

By Grant Olan

President Barack Obama released his budget request for fiscal year 2014 on April 10, 2013. In a departure from his grand and ambitious budget proposals of the past, the president made some significant concessions to meet congressional Republicans halfway.

Specifically, the president proposed to replace the $1.2 trillion sequester cuts to discretionary spending with $1.8 trillion in deficit reduction achieved through entitlement reform and nearly $1 trillion in new revenue that includes a new minimum tax of 30 percent on households earning more than $1 million after charitable giving, known as the “Buffett Rule.”

The president’s proposal includes a modest increase in the National Institutes of Health’s (NIH) funding, and small increases to programs for organ donation activities.

Of the $1.8 trillion in deficit reduction, $400 billion would be achieved through health care-related savings, such as cuts to Medicare providers’ graduate medical education payments, bad debt reimbursement reductions, and increases in Medicare drug rebates. The $400 billion also includes Medicare structural reforms and new measures to reduce Medicare and Medicaid fraud.

The President’s proposal contains some new initiatives, including:

- $100 billion for roads and railways
- $8 billion to help community colleges prepare students for existing jobs
- $1 billion to promote innovation in manufacturing
- $1.30 million to expand mental health treatment and prevention services

The president’s proposal also includes modest increases for existing programs and federal research agencies. For instance, included is $26 million for coordinating organ donation activities and for state grants to develop and improve donor registries, an increase of $2 million.

The budget would increase $471 million, or 1.5 percent over 2012, to $33.3 billion. Included in that funding is a new $100 million initiative called BRAIN, short for Brain Research through Advancing Innovative Neurotechnologies, to uncover new ways to prevent, treat, and cure neurological disorders. The overall NIH budget increase would also include new funding of $18 million for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) over 2012 for a total of $1.8 billion.

“The president should be commended for his proposed investments in NIH and other federal research agencies,” said John R. Sedor, MD, ASN Research Advocacy Committee Chair. “However, ASN is calling for Congress to provide $32 billion for NIH and $2 billion for NIDDK, the minimum amounts needed to avoid loss of promising research, like a groundbreaking discovery that helps explain racial/ethnic disparities that increase risks for kidney disease. African Americans are more than 4 times as likely as Caucasians to progress to advanced kidney failure. Now we know, thanks to recent NIDDK-funded research, that African Americans with two variants of the APOL1 gene face greater risk of kidney failure. This finding could lead to new interventions to improve the kidney health of African Americans.”

ASN has been working with the Ad Hoc Group of Medical Research, Coalition for Health Funding, and the kidney community to advocate for these NIH and NIDDK requests. The society is also supporting the Friends of AHRQ’s request for $433.7 million for the Agency for Healthcare Research and Quality, which is a 7 percent increase over 2012 and in line with the president’s request.

VA funding

While the president also requested a slight increase for medical and prosthetic research for veterans in 2014 of $586 million, ASN is supporting the Friends of VA Medical Care and Health Research’s (FOVA) more robust request of $611 million. This new funding would support new research into conditions veterans returning from Iraq and Afghanist an face, including polytrauma, multiple traumatic injuries such as a serious head injury in addition to a serious burn.

ASN is on the Executive Committee of FOVA, which is also requesting at least $50 million for up to five major Department of Veterans Affairs (VA) research facility construction projects and $175 million in nonrecurring maintenance and minor construction funding to address deficiencies identified in a VA congressionally requested report last year detailing an in-depth survey and analysis of the physical condition of all VA research facilities (www.aarc.org/vrep). For more information about the VA, FOVA, and FOVAs 2014 requests, see the March issue of *ASN Kidney News* (http://www.asn-online.org/publications/kidneynews/).

Despite the new initiatives and budget increases for federal research agencies the president proposed, taken together with his deficit reduction recommendations, annual federal budget deficits would dip from the current level of $937 billion to just $439 billion in 2023, or 1.7 percent of the gross domestic product. The nation’s debt would continue to grow, however, climbing from $16.8 trillion today to $25 trillion in 2023.

Of course, Congress controls the purse strings and Republican responses to the president’s budget request have been mixed. As lawmakers negotiate the 2014 budget, ASN will continue highlighting the importance of supporting innovative kidney disease research that will improve patient care, cut costs, and preserve the investigator pipeline.

ASN Joins Forces with Patient Advocates to Advance Kidney Health on Capitol Hill

By Grant Olan and Rachel Shaffer

Continuing an annual tradition, ASN leaders went to Capitol Hill for Kidney Health Advocacy Day on April 25, 2013. In a first for ASN, society leaders teamed up with patient advocates from the American Association of Kidney Patients (AAKP) and Dialysis Patient Citizens (DPC) for meetings with congressional offices in the House and Senate about issues of importance to ASN and the kidney care community. ASN, AAKP and DPC met with more than 40 congressional offices, and met personally with members of Congress in one of every four meetings. ASN, AAKP and DPC participants advocated for three key issues:

- Transplant legislation
- Medical research funding
- The Kidney Health Initiative (KHI)

Besides meeting with lawmakers from their own states, advocates also met with congressional leaders and members of Congress who sit on committees that have jurisdiction over the issues discussed, either from an “authorizing” perspective (meaning that the committee can tell a certain program or agency what it is allowed to or must do), or from an “appropriations” perspective (meaning that the committee is in charge of determining how much funding an agency or a program receives).

“ASN was thrilled to partner with AAKP and DPC to advance these important issues on Capitol Hill,” said ASN President Bruce A. Molitoris, MD, FASN. “A collaborative effort to present both patient and physician perspectives strengthens our advocacy case for what we are asking Congress to do for those affected by and at risk for kidney disease.”

DPC President Eric Edwards commented, “Giving... Continued on page 18
“I have personally cared for patients who have lost their transplant because they could not afford the drugs they needed and were devastated to lose their gift of life,” said ASN Transplant Advisory Group chair Michelle Josephson, MD. “It was gratifying to advocate for legislation that would prevent other patients from going through that hardship.”

By making sure all patients got the drugs they need to keep their kidneys healthy, the Immuno bill would provide a cost-effective solution that will not only improve the lives of countless kidney transplant patients, but also use limited federal resources more effectively. AAKP, ASN, and DCP are committed to continuing to press for passage of this bill beyond Kidney Health Advocacy Day and in collaboration with the larger transplant and kidney communities.

Urging Congress to sustain medical research funding

In meetings with House and Senate appropriators and other lawmakers, ASN leaders and AAKP and DCP patient advocates discussed the significant prevalence of kidney disease and the expense of treating it—and highlighted the imperative of supporting the National Institutes of Health (NIH), including the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and the Department of Veterans Affairs (VA) research budgets. Advocates also highlighted the significant racial and ethnic disparities in kidney disease, and encouraged more research to elucidate and eliminate them.

More than 20 million children, adults, and veterans have kidney disease, the eighth leading cause of death in the United States today. The nearly 600,000 individuals who have end stage renal disease (ESRD) Program. Although patients who receive a kidney transplant must take the immunosuppressive drugs every day for the rest of their lives to prevent organ rejection, Medicare only provides the drugs for 36 months. After that time, many patients who are no longer eligible for Medicare have difficulty obtaining coverage or purchasing the drugs themselves. Patients who can’t take their drugs lose their kidneys and wind up back on dialysis, which costs Medicare more than the immunosuppressive drugs otherwise would and reduces many patients’ quality of life.

“Some patients don’t even apply to be wait-listed on the transplant list as they know they can’t afford the drugs and continue on dialysis indefinitely,” DPC member and patient advocate Michael Dickerson pointed out in congressional meetings. Dickerson, a college student who plans a career in nephrology, was diagnosed with CKD at an early age and after two kidney transplants is now back on dialysis.

Advancing the Kidney Health Initiative (KHI)

In addition to advocating for the Immuno Bill and HOPE Act, and trumpeting the value of investing in medical research, some ASN leaders—and AAKP President and Kidney Health Initiative Board of Directors member Sam M. Pederson—highlighted the Kidney Health Initiative. Focusing on members of Congress who sit on committees with jurisdiction over the FDA, advocates explained the goals, structure, and progress of the public-private partnership between ASN and FDA that aims to bring the kidney community together to improve patient safety and foster innovation in nephrology.

“It’s important that Congress know what FDA and the kidney community are doing to try to advance the therapies available to people with kidney disease,” commented Mr. Pederson, a kidney transplant recipient and previous CAPD patient.

ASN is grateful to the society’s leaders and the AAKP and DCP patient advocates for helping make Kidney Health Advocacy Day a success. The society will continue to engage Congress in the months to come as the budget process plays out and other legislation important to society members and the patients ASN serves moves forward.

Making the case for transplant legislation

Advocating for the passage of two transplant-related bills is a top ASN public policy priority for 2013. ASN leaders and patient advocates discussed the Comprehensive Immunosuppressive Drug Coverage Act and the HIV Organ Policy Equity (HOPE) Act in meetings and encouraged members of Congress to support these common-sense pieces of legislation.

The Comprehensive Immunosuppressive Drug Coverage Act (or “Immuno Bill”) would guarantee lifetime immunosuppressive drug coverage to the thousands of Americans who receive kidney transplants through the Medicare End Stage Renal Disease (ESRD) Program. Although patients who receive a kidney transplant must take the immunosuppressive drugs every day for the rest of their lives to prevent organ rejection, Medicare only provides the drugs for 36 months. After that time, many patients who are no longer eligible for Medicare have difficulty obtaining coverage or purchasing the drugs themselves. Patients who can’t take their drugs lose their kidneys and wind up back on dialysis, which costs Medicare more than the immunosuppressive drugs otherwise would and reduces many patients’ quality of life.

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