

Policy Update

Bringing HOPE to a Divided Congress

HOPE Act Would Lift Ban on Transplanting HIV+ Organs in HIV+ Patients

By Mark Lukaszewski

Legislation to end a 1980s-era federal ban on the transplantation of organs from deceased HIV+ donors to patients with HIV is moving forward in Congress. At a time when reaching across the aisle is rare, the overwhelming bipartisan support for the HIV Organ Policy Equity Act (HOPE Act) and its rapid advancement in the House and Senate underscore the importance of this legislation.

Research indicates that lifting this medically outdated ban could add up to 600 organs per year for HIV-infected transplant candidates. That means patients with HIV could get faster access to a new supply of HIV+ organs. This would not only help individuals with HIV, but would reduce the organ shortage for the more than 95,000 Americans currently on a transplant waitlist—with or without HIV—who are in the same organ pool.

Momentum in the Senate and House

In a political environment where very little legislation is being passed, the HOPE Act has quickly advanced

since its introduction on February 14, 2013, by Sen. Tom Coburn (R-OK) and Sen. Barbara Boxer (D-CA) in the Senate, and by Rep. Lois Capps (D-CA) and Rep. Andy Harris (R-GA) in the House. Less than 5 months later, the bill had passed the Senate with one amendment by unanimous consent on June 17, 2013. Building off this momentum, the House of Representatives Energy & Commerce Committee slated the HOPE Act for markup—the final hurdle before reaching the House floor for a vote—on July 17, 2013, where it was again unanimously approved with no objections.

ASN has made the HOPE Act a policy priority, and in doing so, ASN staff has met with nearly one in three of the members of the House of Representatives offices who ultimately cosponsored the HOPE Act. ASN has been working with an extremely diverse group of advocacy organizations, ranging from the HIV and LGBT communities to medical and transplant societies. This broad support is not limited to the public sector. Because of the tremendous bipartisan support, it is possible that the House version of the HOPE Act will be

passed under suspension of the rules—a procedure used to quickly pass noncontroversial bills. Since the HOPE Act has already passed the Senate, and looks to be able to pass the House of Representatives, the next step would be the President's desk, making the Hope Act one of only a handful of bills to be signed into law in the 113th Congress.

Benefits for patients, physicians, and taxpayers

The HOPE Act is a scientifically sound, no-cost bill, which could increase access to transplantation, potentially saving lives and millions of dollars by eliminating the need for dialysis, which can cost upwards of \$80,000 annually per patient. Most important, passage of this bill could make a significant difference for patients and their families who are waiting for the gift of life.

ASN will remain in close contact with the staff of the bill's sponsors and will provide consistent updates to ASN members as further developments occur. ●

A Preview of This Fall's Congressional Budget Showdown

By Grant Olan

These days, it seems that Congress lurches from one fiscal crisis to the next with another one set for this fall. The clock for passing a budget for Fiscal Year 2014, which begins on October 1, is quickly running out. If Congress fails to pass a budget or appropriations funding government services beyond that date, non-essential federal offices will be closed and non-essential employees furloughed. While the impact on health care would be minimal—Medicare and other mandatory federal programs would still operate—public health and medical research programs would be in jeopardy.

Congress faces a number of challenges. For one, the House of Representatives and Senate are unable to agree on funding levels for each of the 13 appropriation bills. The Senate budget levels are above funding caps established by the 2011 Budget Control Act passed by Congress to cut the federal deficit. The House and Senate have not had a conference to reconcile their funding levels for each of the appropriation bills. Complicating matters, the United States will again hit the “debt ceiling” this fall, the legal limit of how much debt the government can assume. Some Republicans say they will refuse to raise the debt ceiling unless there are more federal budget cuts.

If Congress does manage to pass a budget that raises funding levels beyond the existing caps, lawmakers must also amend the 2011 Budget Control Act. Otherwise there will be an across-the-board cut, known as “sequestration,” to bring federal discretionary spending program budgets in line with the caps, including budgets for the Agency for Healthcare Research and Quality (AHRQ) and National Institutes of Health (NIH).” The FDA and NIH have already sustained significant cuts. NIH's budget in 2013 was \$29.1 billion compared to \$30.6 billion in 2012. The

budget for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the largest source of federal funding for kidney research, was cut \$99 million in 2013 (Table 1).

“These cuts will mean fewer and smaller research projects aimed at finding treatments and cures for kidney disease, and lost jobs,” said John R. Sedor, MD, ASN Research Advocacy Committee chair. “ASN remains committed to protecting NIH, NIDDK, and the rest of the medical re-

search enterprise from more cuts under sequestration and has teamed up with NDD United, a national coalition of 3200 organizations, to fight back.”

“We are facing a time where prominent scientists in the field of nephrology are unsure how and if they will be able to maintain their laboratories over the next several years,” added ASN Research Advocacy Committee Member Jordan A. Kreidberg, MD, PhD. “The field was already in crisis before the sequester, now it is in uncharted territory.” ●

How have NIH budget cuts affected your research?

ASN recently launched a survey to collect feedback from its members on how cuts might affect (or have affected) them to share with Congress. The society is also looking for volunteers to provide tours of their labs and/or institutions for members of Congress and their congressional staff so they can learn about the benefits of research. To complete the survey and volunteer, go to <http://www.surveymonkey.com/s/XYBFX6Q>.

Table 1. Impact of sequestration on federal research budgets

*Dollars in Millions	FY13 Budget (operating under FY12)	After Sequestration (VA exempt)	Difference
AHRQ	\$369	\$350	\$19
CDC	\$5,657	\$5,368	\$289
FDA	\$2,506	\$2,378	\$128
NIH	\$30,632	\$29,070	\$1,562
NIDDK	\$1,947	\$1,848	\$99
VA Research	\$581	\$581	\$0