

March 9, 2005

The Honorable Kay Granger
House of Representatives
Washington, DC 20515

Re: Support Full Funding of \$25 million for the “Organ Donation and Recovery Improvement Act of 2004” in the FY 2006 Labor, HHS and Education Appropriations Legislation

Dear Congresswoman Granger:

The 10 undersigned organizations of the Transplant Roundtable request that you support full funding of \$25 million in the FY 2006 Labor, Health and Human Services, and Education appropriations bill for the “Organ Donation and Recovery Improvement Act of 2004” (P.L. 108-216), which was enacted on April 5, 2004. Despite authorizations for FY 2005 for programs enacted under the bill, there was no new funding appropriated in the FY 2005 omnibus appropriations bill.

This important legislation will assist the federal government, states, and other entities improve efforts to promote organ donation, reduce the waiting list, and improve the practice of organ recovery so that more Americans receive life-giving organs. With more than 87,000 Americans currently awaiting organ transplantation and 6,000 expected to die in 2005, FY 2006 is a critical year for funding this new law.

The Organ Donation and Recovery Improvement Act of 2004 authorized \$25 million in FY 2005 and “such sums as necessary” for FY 2006 through FY 2009. However, the bill was not funded in FY 2005 due, in part, to its enactment late in the appropriations cycle. As a result, FY 2006, the second year of the five-year authorization, is a critical year to achieve funding.

We are requesting an initial appropriation of \$25 million to immediately begin implementation of the critical programs authorized under the law. This would represent a total appropriation of \$47 million (\$24 million current appropriation plus \$23 million) for the Health Resources and Services Administration’s Division of Transplantation and an additional \$2 million for the Agency for Healthcare Research and Quality to carry out the new authorizations.

Full funding of this legislation would include the following:

- \$5 million in new federal funding for the reimbursement of travel and subsistence expenses for living donors—healthy donors who give one kidney or a portion of their liver—who would otherwise be unable to donate.
- \$15 million in new funding for grants and demonstration projects to more effectively promote organ donation. These funds should be in addition to currently authorized and appropriated funds.

- \$3 million to provide grants to hospital based “organ coordinators” that can increase the rate of successful organ donations and transplants.
- \$2 million for studies by the Agency for Healthcare Research and Quality (AHRQ) into existing and new methods for organ recovery, preservation, and transportation.

The need for full funding this year is more critical than ever. The President’s FY 2006 budget proposes a cut of almost five percent in funding for the federal program primarily responsible for the implementation of the new authorizations, the Health Resources and Services Administration’s Division of Transplantation (DoT). This cut is in spite of a special focus in the HHS budget on implementation of the organ donation law. Additionally, the Office of Management and Budget, through the Program Assessment Rating Tool program, has set the goal of doubling the number of transplanted organs by 2013. However, it is simply not possible for DoT to implement these new authorizations without additional funding, let alone a cut in funding.

Last year, deceased donations increased by 10.8% over 2003 levels, a major improvement. To continue this trend, Congress must build on this success by appropriating new funding for the Organ Donation and Recovery Improvement Act programs. In addition to improved numbers of deceased donors, funding the travel and subsistence expenses for low-income living donors who would otherwise be unable to donate could mean substantial savings for the Medicare program.

Because of the shortage of donated organs from deceased donors, the current median waiting time from being placed on the waiting list (at the stage of a patient’s disease where kidney dialysis becomes necessary to sustain life) to transplantation now exceeds four years. By its own estimate, Medicare would avoid direct dialysis costs exceeding \$55,000 per patient per year for each patient transplanted. Therefore, for every new donor facilitated by this program, Medicare would save a minimum of \$220,000 over four years. Four-year savings to Medicare (from patients transplanted in FY 2006 alone) would exceed \$110 million. A similar four-year savings would accrue on a continuing basis for each subsequent year.

Assuming an average expenditure of \$5,000 per new donor on travel and subsistence expenses, and a new donor population of 1000 donors per year, the cost to the Federal government under this program would approach \$5 million per year. This amount would be recouped to the federal government many times over if savings to the Medicare program are considered.

We share the opinion, along with many in Congress and the Administration, that enactment of the Organ Donation and Recovery Improvement Act of 2004 was a very positive step toward meeting the needs of people awaiting available organs. But only with adequate appropriations will this bipartisan law allow the federal government, states, and other public and private entities to expand their current organ donation efforts and create new, effective organ donation programs.

Therefore, the Transplant Roundtable requests that you express to the Chairman and Ranking Member of the House Appropriations Subcommittee on Labor, HHS, and Education your support for full funding of \$25 million for the Organ Donation and Recovery Improvement Act in FY 2006.

Thank you in advance for your consideration of this request. If you have any questions or need any more information, please do not hesitate to contact Peter Thomas (American Society of Transplant Surgeons) at (202) 466-6550.

Sincerely,

American Association for the Study of Liver Diseases
American Association of Kidney Patients
American Liver Foundation
American Society of Pediatric Nephrology
American Society of Transplantation
American Society of Transplant Surgeons
Association of Organ Procurement Organizations
National Kidney Foundation
North American Transplant Coordinators Organization
United Network for Organ Sharing