

**Written Statement of**

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**United States House of Representatives  
Committee on Appropriations  
Subcommittee on Labor, Health and Human Services, Education and Related Agencies**

**Washington, D.C.  
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**On Behalf of the Transplant Roundtable  
A Coalition of the Following Organizations:**

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

Chairman Regula and Members of the Subcommittee:

The Transplant Roundtable requests that the subcommittee support full funding of the “Organ Donation and Recovery Improvement Act” (P.L. 108-216), which was signed into law by President Bush on April 5, 2004. This important legislation authorizes an additional \$23 million to the Division of Transplantation (“DoT”) within the Health Resources and Services Administration (“HRSA”) and \$2 million to the Agency for Healthcare Research and Quality (“AHRQ”). This represents a total appropriation to DoT of \$46 million in FY 2006 and an additional \$2 million to AHRQ.

### **Background**

Mr. Chairman, as you well know, one of the most pressing problems in the field of organ transplantation is the lack of available donor organs, which creates long waiting lists of candidates for organ transplants. The Bush Administration, led by Secretary of Health and Human Services Michael Leavitt, is providing strong leadership in this area and continuing the efforts of former Health and Human Services Secretary Tommy Thompson’s “Gift of Life” initiative.

Despite the progress made by the Administration and in Congress, the need for organs is greater than ever. Today, 88,061 individuals are on the waiting list for organ transplants<sup>1</sup>—yet only 2,271 transplants have been performed year-to-date.<sup>2</sup> Sadly, sixteen people die every day waiting for a donated organ—that is one death every 91 minutes. And the problem is getting worse, not better, as our population ages. Regrettably, despite a record number of transplants, the number of registrations on the waiting list has quadrupled in the past ten years widening the gap between those waiting for a transplant and the number of organs available.

### **Organ Donation and Recovery Improvement Act**

Thanks in part to your support, Congress and the President have recognized the need to authorize new initiatives aimed at increasing organ donation, improving recovery rates, and supporting scientific pursuit in transplantation. With unanimous consent in the Senate and with

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<sup>1</sup> As of April 12, 2005.

<sup>2</sup> As of April 8, 2005.

only two dissenting votes in the House, the Organ Donation and Recovery Improvement Act was signed into law by President Bush in 2004. The Transplant Roundtable would like to thank you for your support of the Organ Donation and Recovery Improvement Act and ask that you ***support full funding of this legislation.***

The law authorizes \$25 million in new funding for travel and subsistence expenses for living donors, organ donation education and awareness activities, grants for hospital organ coordinators, and other programs designed to increase organ donation rates and improve organ recovery rates. A summary of the new authorizations are as follows:

*\$5 million for the implementation of a new program providing the reimbursement of travel and subsistence expenses for living donors.* Transplant science has improved to the point where it is possible for healthy (living) donors to give one kidney or a portion of their liver to another in need. Living donation is a crucial means to providing a life-giving liver or kidney without utilizing scarce deceased donor organs. However, often the financial burdens for living donors outstrip the potential donors' ability to donate. Currently, insurers (including federal health programs) will pay for the medical procedures associated with living donation, but not the travel and living expenses of the donor, nor the expenses of a family member of the donor to support the donor's recovery. Removing this key financial disincentive to donate will undoubtedly increase the ability of living donors to make the full commitment to donate—and increase the supply of available organs.

This program could also offer substantial cost savings for the Medicare program. Essentially, for every new transplanted kidney from a living donor, Medicare would avoid direct dialysis costs of approximately \$55,000 per year for each patient transplanted since the waiting time for a deceased donor kidney is approximately 4 years longer than a living donor kidney. Therefore, for every new donor facilitated by this program, Medicare would save approximately \$220,000 over four years, minus the cost of immunosuppressive drugs.

*\$3 million to provide grants to hospital-based “organ coordinators” that can increase the rate of successful organ donations and transplants.* The Transplant Roundtable believes that greater progress can be made in organ donor coordination and we strongly support new funding in

this area to assist in implementing advanced coordination activities. The use of in-hospital coordinators, pursued collaboratively between hospitals and organ procurement organizations as outlined in the legislation, has been identified as a significant change agent by HHS within the national Organ Donation Breakthrough Collaborative. Similarly, this model has been adopted in Ontario and Quebec as these provinces adopt and apply creative approaches for meeting organ recovery and transplantation needs. In brief, increased organ recovery has been directly attributable to the inclusion of this approach.

*\$15 million in new funding for grants and demonstration projects to more effectively promote organ donation.* More often than not, simple awareness by patients and their families about the facts of organ donation can make the difference between life and death. Studies have shown that over 95% of families would consent to organ donation if they knew it was the wish of their loved one. Education and awareness can be a highly effective tool in saving the lives of patients needing transplants.

There are current projects within DoT that promote and encourage organ donation and awareness. An example of such a project is the HHS Breakthrough Collaborative that has demonstrably increased the number of transplanted organs. Last year, donations from deceased donors increased by 10.8% over 2003 levels. Donation also increased in the two years preceding 2003. This data correlates to an increase in funding for the DoT in FY 2001–FY 2003 from \$15 million to \$25 million and the high priority transplant programs received as a result of former Secretary of Health and Human Services Tommy Thompson’s “Gift of Life” initiative.

Though DoT has been level funded the past two fiscal years, the President’s FY 2006 proposed budget has DoT slated for a five percent cut (5%) in funding. Despite this proposed cut, the Bush Administration has established a new goal to double the number of deceased donations from 21,400 in 2003 to 42,800 in 2013. Additionally, the budget calls for doubling of the number of donations after brain death and donations after cardiac death and increasing organ yield from an average of three organs per donor to four per donor, all by 2013. Increased funding for organ donation projects yields results and without additional funding in FY 2006, the goals to double organ donation will not be achieved.

\$2 million for studies by the Agency for Healthcare Research and Quality into existing and new methods for organ recovery, preservation, and transportation. There is tremendous potential in the area of both health services and medical research to maximize existing donation practices. The Transplant Roundtable members are engaged in the development of many of these advances. Two examples are advances in live organ donation and methods to increase the successful transplantation of organs from “extended criteria” donors that are now being discarded.

Funding this authorization has the potential to improve scientific advancement in organ procurement and transplantation. In fact, some members of the Transplant Roundtable have already begun to implement this part of the Organ Donation Act by working directly with the AHRQ after securing report language in last year’s appropriations bill. This language stated that the Committee recognized that there “is presently no formal mechanism to scientifically evaluate the efficacy of many new medications, devices, surgical techniques, and technical innovations that are being developed to improve organ preservation and maximize organ usage. The Committee encourages AHRQ to study and develop scientific evidence in support of efforts to increase organ donation and improve the recovery, preservation, and transportation of organs.”

All of these programs are new and are in addition to the FY 2005 appropriation of \$24.4 million for HRSA’s Division of Transplantation. The DoT uses its current \$24.4 million appropriation to provide federal oversight of the nation’s organ procurement, allocation, and transplantation system, known as the Organ Procurement and Transplantation Network (“OPTN”). DoT also supports existing public education efforts to increase the rate of organ and tissue donation and manages a limited grant program to evaluate donation-enhancing activities. The Transplant Roundtable believes that these programs are of critical importance and strongly recommends that Congress support these existing initiatives and supplement them with the new authorizations under the Organ Donation and Recovery Improvement Act.

DoT also conducts public and professional education initiatives to improve awareness of organ and tissue transplantation in order to take the mystery out of organ donation, and thereby increase the rate of donation in the United States. DoT conducts a variety of activities such as

workshops, national conferences, exhibits, seminars, and special events to inform the public at large about the critical need for organ and tissue donors. Endeavors such as these must not be sacrificed since they are a crucial foundation to DoT's mission.

In addition to current and new authorizations, DoT is also authorized—but not explicitly funded under the new law—to establish and maintain mechanisms to evaluate the long-term effects associated with living donors. There are also several new studies mandated under the new law that are not expressly funded, such as studies on state donor registries, evaluations of living donation practices, and federal coordination of organ donation efforts.

An additional commitment of federal resources to address the nationwide shortage of donated organs is essential to both increase the success rate in organ transplantation and increase the number of organ donors available.

In order to accomplish this, Mr. Chairman, DoT will need new funding to fully implement the new activities under the Organ Donation and Recovery Improvement Act. The president's current FY 2006 budget proposal calls for a \$1.2 million cut of the FY 2005 level, for a total appropriation of \$23.2 million.

### **Conclusion**

The Transplant Roundtable strongly encourages the Subcommittee to increase the FY 2006 funding level for DoT to \$47 million. We also urge you to increase the appropriation for the Agency for Healthcare Research and Quality by \$2 million so that the agency can fund research into existing and new methods for organ recovery, preservation, and transportation as authorized under the Organ Donation and Recovery Improvement Act. ***This is the second year of a five year authorization and funding the Act is critical.*** The Act was not funded in FY2005 because it was enacted too late in the appropriations cycle. With the policy proposals contained in this new law and the programs currently funded by Congress through the DoT, we, as a nation, have it within our grasp to significantly reduce organ donor waiting lists within the next several years and, therefore, save the lives of thousands of Americans.