

Testimony
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Organ Donation: Utilizing Public Policy and Technology to Strengthen Organ Donor Programs

Statement of

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Good afternoon Mr. Chairman, Members of the Subcommittee. Thank you for the opportunity to meet with you today on behalf of the Health Resources and Services Administration (HRSA) to discuss the roles and responsibilities of the Division of Transplantation in strengthening our nation's organ donor programs and awareness activities. I appreciate your continuing support of the organ donation and transplantation programs.

Background

The need for organ transplants continues to grow and this demand continues to outpace the supply of transplantable organs. Nineteen people in this country will die every day because a life-saving organ does not become available to them.

During the past decade, the number of deceased donors increased between 2-3 percent annually while the annual growth rate in the number of individuals waiting for an organ transplant increased by approximately 8 percent. Even with the recent unprecedented 10.8 percent increase in the number of deceased donors in 2004, followed by a 6.2 percent increase in 2005, there were still about 97,000 individuals waiting for an organ transplant at the end of 2006.

HRSA is responsible for administering a number of organ donation and transplantation programs. The National Organ Transplant Act (NOTA) (P.L. 98-507), as amended, authorized the creation and operation of: (1) the Organ Procurement and Transplantation Network (OPTN), operated under contract with HRSA, which facilitates the matching of donor organs with individuals waiting for an organ transplant; (2) the operation of the Scientific Registry of Transplant Recipients (SRTR), which facilitates

the ongoing evaluation of the scientific and clinical status of organ transplantation; and (3) grants and contracts to conduct projects designed to increase the number of organ donors.

Additional program authorities were provided by the Organ Donation and Recovery Improvement Act (ODRIA) (P.L. 108-216), which amended NOTA, to help increase the number of organ donors and number of organs made available for transplantation. The key additional authorities under ODRIA include: (1) grants to States to support organ donation awareness programs; (2) grants and contracts to support public education and outreach activities designed to increase the number of organ donors, including living donors; (3) grants to qualified organ procurement organizations and hospitals to establish programs to increase the rate of organ donation; (4) the expansion of grant making authority to include public institutions; (5) the development and dissemination of educational materials to inform health care professionals and other appropriate professionals about organ, tissue and eye donation; (6) financial assistance to living donors to help defray travel and other incidental non-medical expenses; and (7) mechanisms to evaluate the long-term effects of living organ donation.

Current Activities

In 2006, a total of 28,923 organ transplant operations were performed nationwide, up from 28,112 the year before. From the 2006 operations, 31,184 organs were transplanted; of that number, 24,461 organs came from deceased donors (78.4 percent), and 6,723 transplanted organs were from living donors (21.6 percent).

At HRSA, one of the ways we are keeping donation efforts on a fast track is through our highly successful Organ Donation Breakthrough Collaborative. The Collaborative brings together donation professionals and hospital leaders to identify and share best practices to maximize organ donation rates in their facilities. Some of the Collaborative outcomes include: Hospital-Organ Procurement Organization (OPO) teambuilding, increased donors after cardiac death, and increased conversion rates and donors in non-Collaborative hospitals. The goal is to raise donation rates to 75 percent of eligible organ donors. The results are most impressive: since 2003, the number of hospitals that have achieved the 75 percent goal has increased from 55 to 301.

To complement the Organ Donation Breakthrough Collaborative, the Organ Transplantation Breakthrough Collaborative was initiated in October 2005. This Collaborative is designed to make more organs available for transplantation by increasing the average number of organs retrieved from each donor. The goal of this Collaborative is to increase the number of organs transplanted from deceased donors by 22.6 percent.

This year, HHS joined with private companies and organizations across America in encouraging their employees to "Give Five-Save Lives." The "Give Five-Save Lives" challenge asked employees to support donation by taking five minutes out of their workday to enroll in a State organ donor registry or sign a donor card.

"Give Five-Save Lives" grew out of our Workplace Partnership for Life program, which today includes more than 11,000 workplace partners committed to addressing the shortage of transplantable organs. Through this Workplace Initiative, more than 400,000 individuals signified their intent to be organ donors in State registries over the 2006 holiday season from Thanksgiving to the New Year.

In February, HRSA announced the results of a 2005 Gallup Organization survey which indicates that Americans continue to strongly support the donation of organs and tissues for transplantation. More important, the survey also found that 52.3 percent of Americans have taken personal actions to become organ donors since a similar 1993 survey on donation.

Donor families want things to proceed the best way possible to have some good come out of tragedy. Consistent with our efforts to increase organ donation, there are strong safeguards in place to ensure that life-saving care of the critically ill patient comes first. There is a strict prohibition against the transplant team participating in the care of the patient who is a potential donor. There is also a thorough consent process which includes time for the family to think about and discuss the decision, and donation can only proceed with a signed consent. Three IOM reports have supported the value of donation after cardiac death, when appropriate.

Last month, HRSA announced grant winners under the State Donor Registry Support Program. The grants help States without a registry to develop one, and help those States with a registry to make enhancements to keep pace with technology and new information. The aim of the program is to help ensure that all U.S. residents have an opportunity to indicate and store their donation wishes where they can be reliably retrieved at their time of death.

HRSA currently operates two demonstration grant programs designed to increase knowledge about practices that are effective in increasing the number of organs available for transplantation. The Social and Behavioral Interventions to Increase Organ and Tissue Donation grant program funds projects to implement and evaluate social and

behavioral studies to increase family consent to donation and/or individual intent to donate. The Clinical Interventions to Increase Organ Procurement grant program focuses on clinical activities that begin after consent is determined or given at time of death and extend until transplantation. Improving these clinical activities influence whether a particular donor actually progresses to become a donor and the number and quality of organs that may be procured for transplantation.

HRSA also awarded a cooperative agreement to the Regents of the University of Michigan with a subcontract to the American Society of Transplant Surgeons to provide support for reimbursement of travel and subsistence expenses incurred toward living organ donation with priority given to those potential donors without the financial means to pay these expenses.

Three hundred twenty-three hospitals have recently won the Department's Medal of Honor for substantially raising the organ donation rates of eligible donors from their facilities. The ceremony to congratulate these hospitals will be held this October in Tennessee.

Despite these advances, HRSA is humbled by the fact that people are still dying because of the lack of available organs. In our vigilance, HRSA sustains support for other organ donation programs. The OPTN, which HRSA manages, continues to improve the efficiency of the organ transplantation system by improving organ allocation policies and monitoring policy compliance by transplant programs and OPOs. Grants were awarded to OPOs and hospitals to establish program coordinating organ donation activities. In our outreach efforts, HRSA maintains support for public and professional education programs.

HRSA is pleased that, in response to a Departmental request, the Department of Justice's Office of the Legal Counsel (OLC) issued an opinion on March 28, 2007 concerning the proper interpretation of the criminal prohibition on organ transfers for "valuable consideration" in section 301 of NOTA. The OLC concluded that paired exchanges and living donor/deceased donor exchanges do not involve "valuable consideration" under section 301 and are therefore not prohibited under this statute. The published opinion is binding on U.S. Attorneys' offices (which have the primary role in enforcing Federal criminal laws, such as section 301). Because of this opinion, concerns about the legality of paired exchanges or of living donor/deceased donor exchanges have been resolved, enabling the OPTN contractor to operate a nationwide paired exchange system. We believe that this will result in hundreds of additional lives saved each year.

Working together, we are making great strides, but we still have a long way to go.

Future Activities

HRSA is always looking for new and better ways to increase the number of organ donors and donor awareness. Some major activities underway include:

Breakthrough Collaboratives

Both the Organ Donation Breakthrough Collaborative and the Organ

Transplantation Breakthrough Collaborative are designed to rapidly spread best practices
of organ procurement organizations and donor hospitals to increase the number of
deceased donors and to increase the number of organs made available for transplantation
from each deceased donor. We will continue these efforts.

Our most recent initiative is the Transplant Growth and Management

Collaborative. The goal of this collaborative is to save or enhance thousands of lives a
year by maximizing the number of organs transplanted from each and every donor and
building the necessary capacity within the Nation's transplant programs to transplant
35,000 organs annually. Elements of the Initiative include: a best practices study

(December 2006 – February 2007), expert panel meeting (May 2007) and a Transplant
Center Growth and Management Collaborative (to be launched in October 2007).

Organ Procurement and Transplantation Network (OPTN)

The OPTN is working to revise the national kidney/kidney-pancreas allocation policy to optimize net lifetime survival benefit of kidney/kidney-pancreas transplantation. Additionally, the OPTN is working to improve the information technology and operations infrastructure of the OPTN to allow more rapid and efficient placement of deceased donor organs.

Scientific Registry of Transplant Recipients (SRTR)

The SRTR conducts analyses of information for all organ donors and transplant recipients to be used for public and professional information and policy making purposes.

Organ Donation Support

The program will continue to test new approaches to increase the number of donors as well as the number and quality of donor organs for transplantation. We are looking for approaches that yield results.

Public and Professional Education Programs

The programs will continue to promote organ and tissue donation through a variety of initiatives targeted to the general public and to medical and other professionals who are influential in the organ donation process. We must continue to get the word out.

Conclusion

While nearly 29,000 individuals received life-saving transplants in 2006, the need to increase the number of successful transplants remains critical. There are close to 97,000 patients on the national waiting list to receive an organ, and 19 will die every day because a life-saving organ does not become available to them.

Working together, we can change these numbers. HRSA is proud of its leadership role in this most worthwhile effort. There are clear signs we are moving in the right direction, but we must do everything we can to keep the momentum going.

Thank you for giving me the opportunity to come here today to discuss the organ donation and transplantation, and for your dedication and interest in these vital programs. I would be happy to answer any questions you have.