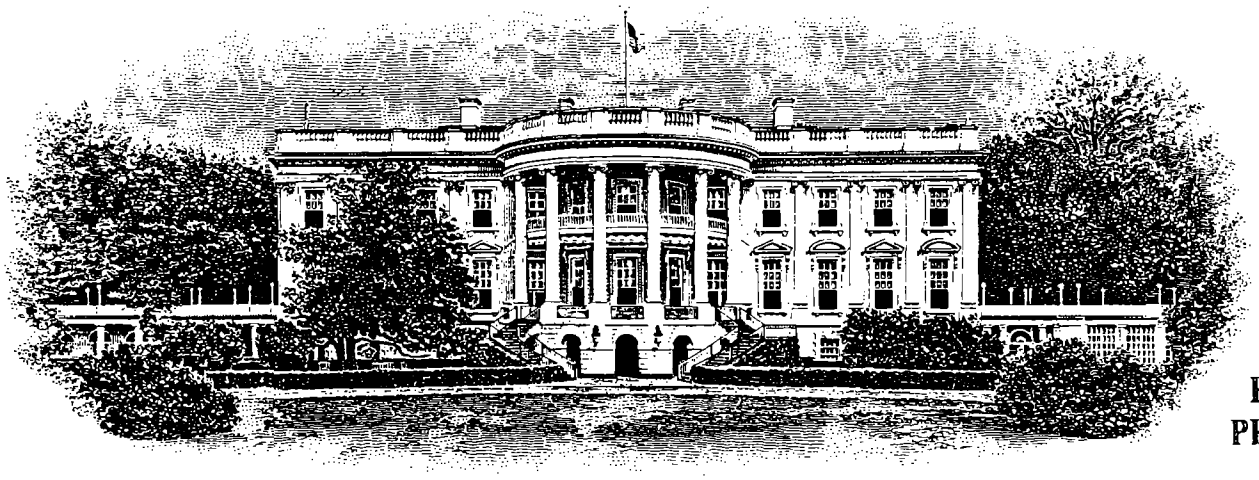
DEVORAH

ORGAN

DONATION

The White House



THE WHITE HOUSE

Office of the Vice President

For Immediate Release: **Contact: (202) 456-7035**
September 24, 1999

VICE PRESIDENT GORE LAUNCHES NEW EFFORTS TO INCREASE ORGAN DONATION NATIONWIDE

Washington, DC -- Today, in an event with families who have donated and received life saving organs, Vice President Gore unveiled a series of new Federal and public-private initiatives to increase the rate of organ donations nationwide.

These initiatives include: the enactment of the Organ Donor Leave Act; a new $13 million grant program to provide funds to community based organizations implementing strategies to increase organ donation; a series of new television ads and corporate partnerships designed to inform the public about the importance and process of organ donation; and new Federal efforts to educate health care providers nationwide about best practices in working with the families of potential donors.

This year, of the 65,000 patients on the national organ transplant waiting list, almost 5,000 will die while waiting for a donated organ. Less than one-third – about 20,000 – are likely to receive transplants. Most Americans say they support donation and would carry out their loved one's wishes if they knew them, but only about half of families asked give consent because they don't know what their family member would have wanted.

"The steps we are taking today will not only highlight the need for organ donation," said Vice President Gore. "It will make organ donation more possible, and will help more of America's families to share the gift of health and life."

Specifically, the Vice President announced:

The enactment of the Organ Donor Leave Act. Today, President Clinton will sign the Organ Donor Leave Act, which was sponsored by Congressman Elijah Cummings (D-MD) and Senator Daniel Akaka (D-HI), into law. Because the current seven-day limit on leave for Federal employees for organ donation is insufficient for recovery, this important legislation increases the amount of paid leave available in addition to sick or annual leave to Federal employees who donate organs for transplants. As the country's largest employer, this new law will help the Federal government set the example for the private sector as well as other public organizations. Under this new law, Federal employees serving as organ donors would receive up to 30 days of paid leave in addition to sick or annual leave.

The launch of a $13 million grant program to improve local organ donation efforts. Today, the Vice President released the first $5 million in grant funds to 18 grantees nationwide to improve the donation request process, increase outreach to minority communities, and implement school based and workplace donor education programs designed to educate families about the importance of organ donation. For instance, grantees will use internet based services to support donation; develop easy to access computer centers in public areas where they can

record their wishes on organ donation at the same time they renew their drivers' licenses; provide information on organ donation to teenagers in drivers education classes; and utilize parents of organ donors as counselors to other donor families.

New public service announcements to educate families about organ donation. Today, the Vice President released new television public service announcements, developed by the Coalition on Donation, in conjunction with Buena Vista Television and UNOS, to promote organ donation and encourage families to share their decisions on donation. These advertisements, which will be distributed to all major networks and cable stations, are expected to receive $10 million worth of donated air time for the advertisements. They include a toll-free number (1800 355 SHARE) that provides families with information on the importance of organ donation and helps them discuss this difficult subject with their loved ones.

A series of regional conferences to promote best practices in working with the families of potential donors. The Vice President announced that, beginning in early December, the Department of Health and Human Services (HHS) will hold four regional conferences to bring together health care providers and transplant professionals from hospitals and organ procurement organizations to share successful strategies for communicating with potential donor families. A new resource guide developed by HHS, *Roles and Training for the Donation Process*, will be used to educate conference attendees. This guide, developed in cooperation with hospitals and transplant professionals, will also be distributed to every hospital participating in the Medicare program by the end of the year.

AL GORE'S LONG STANDING COMMITMENT TO INCREASING ORGAN DONATION.

- Vice President Gore has a longstanding commitment to increasing organ donation nationwide. As a representative, together with Senator Orin Hatch, he cosponsored the National Organ Transplant Act of 1984, established a computerized network to match donated organs with the patients who need them, outlawed the buying and selling of organs, and called for a study of the ethical issues surrounding transplants.
- The Clinton-Gore Administration launched the National Organ and Tissue Donation Initiative in December 1997 to involve public and private partners to educate providers and consumers about the importance of organ donation.
- During 1998, HHS issued a new regulation requiring hospitals to notify organ procurement organizations (OPOs) of all deaths and imminent deaths in order to ensure that opportunities for donation are not overlooked. In 1998, organ donation increased 5.6 percent, resulting in approximately 600 additional organ transplants and up to 14,000 more tissue transplants – the first substantial increase since 1995. HHS continues to work with health care organizations, faith organizations, educational organizations, state partners, and donor and recipient groups to educate the public about the importance of organ donation.
- The Federal government is educating its employees about donation, in order to serve as a model for other employers. With assistance from the Office of Personnel Management, HHS has provided donation materials to over 100 Federal agencies for employees, including donation messages on pay stubs and full-page donation ads in the federal health plan catalog for the past two years.

Roundtable Discussion on Organ Donation

Old Executive Office Building, Room 450
Washington, DC
Friday, September 24, 1999 -- 11:15am - 12:00pm

Briefing prepared by Sarah Bianchi (202) 456-5585

EVENT

You are hosting a roundtable discussion on the issue of organ donation. You are having a discussion with four people who received a life saving organs, donated an organ, or have family members who donated an organ. (Some of the participants will also have family members on the stage).

This event is OPEN PRESS

LOGISTICS

Off-stage announcement of **the Vice President;**

The Vice President proceeds onto stage and takes seat, joining the organ donor/recipient families;

The Vice President makes brief remarks and opens the discussion with organ donor/recipient families;

The Vice President moderates the discussion with four organ donors and recipients and some of their family members;

The Vice President closes the discussion and departs.

YOUR ROLE AND CONTRIBUTION

This event provides you an opportunity to highlight your longstanding commitment to organ donation. You are announcing some new steps the Administration is taking to promote this issue, including (1) the enactment of the Organ Donor Leave Act; (2) a new $13 million grant program to provide funds to community based organizations implementing strategies to increase organ donation; (3) a series of new television ads and corporate partnerships designed to inform the public about the importance and process of organ donation; and (4) new Federal efforts to educate health care providers nationwide about best practices in working with the families of potential donors.

NEW ORGAN DONATION INITIATIVES

Background on organ donation. This year, of the 65,000 patients on the national organ transplant waiting list, almost 5,000 will die while waiting for a donated organ. Less than one-third – about 20,000 – are likely to receive transplants. Only 8 percent of the tissue needed for surgery is available. Most Americans say they support donation and would carry out their loved one's wishes if they knew them, but only about half of families asked give consent because they don't know what their family member would have wanted.

Specifically, the Vice President announced:

The enactment of the Organ Donor Leave Act. Today, President Clinton will sign the Organ Donor Leave Act, which was sponsored by Congressman Elijah Cummings (D-MD) and Senator Daniel Akaka (D-HI), into law. Because the current seven-day limit on leave for Federal employees for organ donation is insufficient for recovery, this important legislation quadruples the amount of paid leave available in addition to sick or annual leave to Federal employees who donate organs for transplants. As the country's largest employer, this new law will help the Federal government set the example for the private sector as well as other public organizations. Under this new law, Federal employees serving as organ and tissue donors would receive up to 30 days of paid leave in addition to sick or annual leave.

The launch of a $13 million grant program to improve local organ donation efforts. Today, the Vice President released the first $5 million in grant funds to 18 grantees nationwide to improve the donation request process, increase outreach to minority communities, and implement school based and workplace donor education programs designed to educate families about the importance of organ donation. For instance, grantees will use internet based services to support donation; develop easy to access computer centers in public areas where they can record their wishes on organ donation at the same time they renew their drivers' licenses; provide information on organ donation to teenagers in drivers education classes; and utilize parents of organ donors as counselors to other donor families.

New public service announcements to educate families about organ donation. Today, the Vice President released new television public service announcements to promote organ donation and encourage families to share their decisions on donation. These advertisements, which will be distributed to all major networks and cable stations, are expected to receive $10 million worth of donated air time for the advertisements. They include a toll-free number (1800 355 SHARE) that provides families with information on the importance of organ donation and helps them discuss this difficult subject with their loved ones.

A series of regional conferences to promote best practices in working with the families of potential donors. The Vice President announced that, beginning in early December, the Department of Health and Human Services (HHS) will hold four regional conferences to bring together health care providers and transplant professionals from hospitals and organ procurement organizations to share successful strategies for communicating with potential donor families. A new resource guide developed by HHS, *Roles and Training for the Donation Process*, will be

used to educate conference attendees. This guide, developed in cooperation with hospitals and transplant professionals, will also be distributed to every hospital participating in the Medicare program by the end of the year.

THE VICE PRESIDENT'S LONG STANDING COMMITMENT TO INCREASING ORGAN DONATION.

- The Vice President has a long record on increasing organ donation nationwide. As a representative, together with Senator Orin Hatch, he cosponsored the National Organ Transplant Act of 1984, established a computerized network to match donated organs with the patients who need them, outlawed the buying and selling of organs, and called for a study of the ethical issues surrounding transplants.

- The Clinton-Gore Administration launched the National Organ and Tissue Donation Initiative in December 1997 to involve public and private partners to educate providers and consumers about the importance of organ donation.

- During 1998, HHS issued a new regulation requiring hospitals to notify organ procurement organizations (OPOs) of all deaths and imminent deaths in order to ensure that opportunities for donation are not overlooked. In 1998, organ donation increased 5.6 percent, resulting in approximately 600 additional organ transplants and up to 14,000 more tissue transplants – the first substantial increase since 1995. HHS continues to work with health care organizations, faith organizations, educational organizations, state partners, and donor and recipient groups to educate the public about the importance of organ donation.

- The Federal government is educating its employees about donation, in order to serve as a model for other employers. With assistance from the Office of Personnel Management, HHS has provided donation materials to over 100 Federal agencies for employees, including donation messages on pay stubs and full-page donation ads in the federal health plan catalog for the past two years.

BACKGROUND ON EVENT PARTICIPANTS

Oscar Robertson (the Big O) is generally considered the greatest all-around player in basketball history and international ambassador for the game 24 years after retirement. He has been an all-time all-star at every level- high school, college, the Olympics and the National Basketball Association, which recently named him one of the greatest players of all time. During his pro career he served from 1963 to 1974 as President of the NBA Players Association and today is President of the Retired NBA Players Association.

Since his retirement, Mr. Robertson has been active as a broadcaster, author, clinician and entrepreneur. One of the nation's leading small business owners, he is founder and President of Cincinnati-based Orchem, Inc. and Orpack-stone Corporation.

One of Mr. Robertson's proudest achievements was his 1997 donation of a kidney to his daughter, Tia, who had suffered a kidney failure as a result of lupus. He has since become

active with the National Kidney Foundation, serving as an ambassador for organ donation and as Honorary Spokesperson for the 1998 U.S. Transplant Games, where Tia participated with fellow transplant athletes and won a gold medal in doubles tennis.

Tim Thompson a 42 year old telecommunications expert for United Postal Service, lost his wife Harriet, aged 32, to a brain aneurysm three years ago. Because of the recent death of a close relative, Tim and his wife had discussed organ donation and he knew that she wanted to be a donor. Because he was overwhelmed trying to cope with the reality of his wife's sudden death and the impact it would have on their two children, Anne-Hamilton (aged 11) and David (aged 7), he doesn't think that he would have remembered that Harriet wanted to be an organ donor. Even if he had remembered, Tim thinks that he would have had an extremely difficult time bringing it up with hospital staff. When a nurse asked him about the possibility of donation, he remembers feeling "pure relief" at the idea that someone was there to help him carry out his wife's wishes. Harriet's organs went to seven different people, all of whom are doing well. Tim, who now serves on the Kentucky Organ Donation Affiliates' Board of Directors, is working with UPS to develop a workplace donation education initiative. His project has been selected as one of the first HHS Model Programs to Increase Organ Donation, and will receive almost $140,000 of the $5 million in grant funds that the Vice President is releasing today.

Jose Torres received his donated liver in July of 1997. A few months before that, he developed debilitating pains in his abdomen. He thought that it was food poisoning, and his wife Maria rushed him to the hospital – where he ended up staying for almost a month. Jose was diagnosed with a rare liver disease, and he and his family learned that without a transplant, he had less than a year to live. Those months were stressful ones for the family; Jose was forced to leave his job as a homicide detective and stay at home. Maria was forced to work extra hours and worried about the family's financial future; their six children all spent more time at home to try and help as much as they could instead of playing sports after school and taking up extracurricular activities. Jose calls his transplant a "gift from God" – he and his family now appreciate every day they have together. He speaks whenever he can about the importance of organ donation.

Sarah Lee Beck and her husband Mark donated their three year old daughter Anna's heart valves, corneas, liver, and kidneys after she died of a brain aneurysm in February 1998. Sarah said that the decision to donate Anna's organs was not a difficult one; although the day her daughter died was the worst one of her life, there was never any question about what they would do. She and her husband Mark have both pledged to donate their organs, and she speaks with pride of the people Anna helped. Sarah is extremely thankful for the support and guidance her local transplant organization provided her when they made their decision. Sarah and Mark have two children, David (aged 6 months) and Lily (aged 3).

STATEMENT BY THE PRESIDENT

Today, I am pleased to sign into law H.R. 457, the Organ Donor Leave Act, which would enhance the Federal Government's leadership role in encouraging organ donations by making it easier for Federal employees to become donors.

Currently, more than 65,000 Americans are awaiting an organ transplant. Each year, almost 5,000 Americans died while waiting for an organ to become available. This amounts to an average of 13 citizens each day. Many of these deaths would have been prevented if there were a sufficient supply of donor organs. H.R. 457 is a valuable tool to help address the needs of Americans waiting for organs by encouraging donations by Federal employees.

In 1997, my Administration launched the National Organ and Tissue Donation Initiative, which included new efforts by the Federal Government to increase awareness among Federal employees of the need for organ and tissue donation. The Department of Health and Human Services, in partnership with the Office of Personnel Management, has implemented a Government-wide campaign to encourage Federal employees to consider organ donation, and country's largest employer, to set the example for the private sector as well as other public organizations.

H.R. 457 builds on the Administration's longstanding commitment to increasing organ donations nationwide. Under current law, a Federal employee may use up to 7 days of paid leave each year, other than sick leave or annual leave, to serve as a donor. Recent surveys of doctors and hospitals indicate that

the current seven-day limit is clearly insufficient for recovery from an organ donation surgery. This bill increases the amount of paid leave available to Federal employees who donate organs for transplants, providing up to 30 days of paid leave, in addition to annual and sick leave, for organ donation.

In addition to our current efforts, my Administration will go forward in the coming weeks with the framework for an organ allocation system that will serve patients better. Our approach, which has been validated by the Institute of Medicine, calls for new allocation policies to be designed by transplant professionals, not by the Government, and would ensure better and fairer treatment for patients. We need an organ allocation system that is as good as our transplant technology, and it is time for sound allocation policies to go into effect.

It gives me great pleasure to sign H.R. 457 into law. I welcome the opportunity to offer Federal employees the chance to participate in this life-saving effort.

HHS FACT SHEET

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

May 19, 1999

Contact: HRSA Press Office
(301) 443-3376

NATIONAL ORGAN AND TISSUE DONATION INITIATIVE

*Overview: In December 1997, Vice President Al Gore and HHS Secretary Donna E. Shalala launched the National **Organ** and Tissue Donation Initiative. In 1998, the first full year of the Initiative, **organ** donation increased 5.6 percent, the first substantial increase since 1995. Several actions by HHS and its partners in the National Initiative contributed to the year-one success:*

- *During 1998, HHS issued a new regulation to ensure that hospitals work collaboratively with **organ** procurement organizations in identifying potential donors and approaching families. Hospitals are now required to notify **organ** procurement organizations (OPOs) of all deaths and imminent deaths. This helps ensure that opportunities for donation are not overlooked.*
- *HHS conducted a national conference aimed at identifying most effective evaluation strategies for activities to increase donation and transplantation. HHS also funded research on why families consent, or refuse to consent, to the donation of organs of a loved one.*
- *Working with dozens of partner organizations in the private and volunteer sectors, HHS worked to increase awareness of the need for **organ** and tissue donation. Awareness efforts centered on informing individuals that once they make the decision in favor of **organ** donation, they need to share their decision with their families since families are usually asked to give consent.*
- *HHS is supporting a $5 million extramural support program for FY1999 to fund 15-20 projects up to three years that test strategies for increasing **organ** and tissue donation or that replicate successful donation programs.*

*Currently, about 62,000 patients nationwide await **organ** transplants, and some 12 die each day while waiting. Less than one-third - about 20,000 - receive transplants each year. While the number of cadaveric donors rose in 1998 to nearly 5,800, with about three organs recovered from each donor, it still falls far short of the substantial and growing need. Most Americans say they support donation and would carry out their loved one's wishes if they knew them, but only about half of families asked give consent. If families discuss and share their decision to donate, many more lives could be saved.*

Three Elements of the National Initiative

Building Partnerships and Increasing Family Discussion

Sharing life means sharing your decision. A new groundbreaking study funded by HHS' Agency for Health Care Policy and Research (AHCPR) and the latest Gallup survey on donation both confirm that nearly all Americans would consent to donation if they knew that their loved one had requested it. However, only half or fewer would consent if they were unaware of these wishes.

The AHCPR study, conducted by researchers at Case Western Reserve University and the University of Pittsburgh, examined families who had faced real-life decisions about donation and found that only 43 percent of them had ever discussed donation with their loved ones. Less than 25 percent knew if their loved ones carried donor cards. Families who were undecided when asked to donate were only half as likely to consent as those who were initially inclined to donate. Overall, less than half (47.5 percent) of

the families consented to donate, yet the overwhelming majority (95 percent) of the families indicated that knowledge of their loved one's wishes would have had substantial influence on their final decisions.

Partners respond by encouraging Americans to donate. Dozens of health care, business, minority, religious, educational and government organizations have joined this initiative to encourage all Americans to discuss and share their decision to donate with their families before the occasion to donate arises. They are reaching out to their employees, members, and the public to encourage donation, and thanks to HHS' partnership with the Coalition on Donation, they are using the same message as the national public awareness campaign developed by the Coalition and the Advertising Council, "Share your life. Share your decision."

Expanding Opportunities for Families to Donate

HHS' Health Care Financing Administration (HCFA) revised its Hospital Conditions of Participation for **Organ**, Tissue and Eye Donation (June 22, 1998, 63 Fed. Reg. 33856) effective August 21, 1998, to maximize opportunities to donate by requiring Medicaid- and Medicare-participating hospitals to notify OPOs of all deaths and imminent deaths so potential donors are identified and families are asked about donation. Hospitals now will refer 2.1 million hospital deaths annually to the nation's 62 OPOs or to a third party designated by the OPOs to handle the referrals. Hospitals also will work with the OPO to ensure that the family of every potential donor knows about its option to donate organs or tissues. Hospitals also will have agreements with at least one tissue bank and one eye bank to preserve and distribute tissues and eyes, as long as these agreements do not interfere with **organ** donation.

To ensure that individuals who approach families demonstrate discretion and sensitivity, hospitals must select an OPO representative or others who have completed a training course offered or approved by the OPO. Hospitals also must work with OPOs and the eye and tissue banks to educate hospital staff on donation issues and review death records to make sure potential donors were correctly identified.

To support these activities, HCFA and HHS' Health Resources and Services Administration (HRSA) will co-sponsor a June workshop to develop a resource guide to assist in educating and training hospital staff. In addition, they will co-host a conference in September to exchange information on successful strategies for increasing donation, including effective referral, consent, education and monitoring practices. Finally, the Joint Commission on Accreditation of Healthcare Organizations, which reviews the performance of most of the nation's hospitals, has incorporated the revised hospital conditions into its standards for accreditation.

HHS estimates that the revised hospital conditions can increase **organ** donation by 20 percent within the first two years. In addition to preliminary data indicating a 5.6 percent increase in **organ** donors in 1998, data collected from tissue banks by the Musculoskeletal Transplant Foundation suggests that tissue donation overall has increased about 52 percent since the new provisions took effect.

Finally, HCFA will continue to hold OPOs responsible for meeting performance standards. On a regular basis, OPOs are evaluated against their peers on five specific performance standards. HCFA will work with the Association of **Organ** Procurement Organizations (AOPO) toward stronger performance by OPOs.

In 1995, **organ** donation results for the nation's then 66 OPOs ranged from a high of 34.3 organs donated per million population to a low of 2.4 donors per million. (In 1996, two OPOs were terminated from Medicare and Medicaid participation because they did not meet current performance standards. In early 1997, two OPOs consolidated into one.)

Learning More About What Works to Improve Donation and Transplantation

HHS serves as a catalyst for the field by emphasizing and encouraging carefully designed and rigorous evaluation components and research projects to ascertain effective interventions for increasing donation. In fiscal year 1999, HRSA is providing up to $5 million for projects through a peer-reviewed, competitively awarded extramural support program. The goals of this program are to implement,

evaluate, and disseminate model interventions with the greatest potential for yielding a verifiable, demonstrable impact on donation and which are replicable, transferable and feasible in practice. The program will fund pilot and replication studies.

Other HHS agencies, especially the National Institutes of Health and AHCPR, are supporting research to improve donation and transplantation. At NIH, this research includes basic, pre-clinical, and clinical research on immune system functioning, graft acceptance and rejection, avoiding the need for re-transplantation, **organ** matching in diverse populations, methods to improve **organ** and tissue retrieval and preservation, and improving the quality of life for transplant patients. In addition, NIH's National Institute of Allergy and Infectious Diseases is supporting the development and evaluation of a statewide donor registry and education program by the Louisiana **Organ** Procurement Agency. The AHCPR study of donor and non-donor families is described above.

National Initiative Partners

Public Awareness Partners: HHS has teamed up with the **Coalition on Donation**, whose members include national and local organizations, to deliver a consistent, unified message on the importance of family discussion. With the **Advertising Council,** the Coalition on Donation has implemented a multi-year, national public awareness campaign.

Health Care Organizations: Health care organizations are uniquely positioned to educate their members, who in turn educate their patients, about the need for **organ** donation. The **American Medical Association**, the **American Academy of Family Physicians**, the **American Nurses Association**, the **American Association of Health Plans**, and the **National Medical Association** provide their members with **organ** donation educational materials. Other health organization partners include the **American Association of Neurological Surgeons** and the **Congress of Neurological Surgeons**.

Law Associations: Attorneys, especially those involved in estate planning, are in strategic positions to encourage and help Americans make end-of-life decisions, including donation decisions. The **American Bar Association**, through its Real Property, Probate and Trust Section, in partnership with HHS, will encourage attorneys to educate clients on **organ** donation.

Educational Organizations: Educators are key to teaching the nation's children and young adults about the need for donors. HRSA is partnering with the **American College Health Association**, the **University of Rhode Island** and **TransWeb University** (*http://www.transweb.org/journey*) to reach young people with the donation message.

Faith Organizations: Many Americans turn to religious leaders for guidance about **organ** and tissue donation and other end-of-life decisions. A number of faith and interfaith organizations are educating their members about the gift of life and helping HHS to promote the annual observance of **National Donor Sabbath**, a Friday-to-Sunday period two weekends before Thanksgiving. These organizations include: the **Congress of National Black Churches**, the **General Conference of the Seventh-day Adventist Church**, the **Interfaith Conference of Metropolitan Washington**, the **National Interfaith Coalition on Aging**, the **National Spiritual Assembly of the Baha'is**, the **Presbyterian Church USA**, the **Rabbinical Assembly**, the **Rabbinical Council of America**, the **Shepherd's Centers of America**, and the **Union of American Hebrew Congregations**.

Donor and Recipient Groups: The **National Kidney Foundation's National Donor Family Council** and HHS have teamed up to implement a new Web site at http://www.kidney.org/recips/donor to provide information and bereavement support for donor families. In addition, HRSA, the National Donor Family Council, and other national donor, recipient, and transplant organizations have joined together to host the sixth annual **National Donor Recognition Ceremony** on April 18, 1999 in Washington, D.C.

Business Organizations: The **U.S. Chamber of Commerce** and the **Washington Business Group on Health**, representing many large and small businesses, are helping members conduct employee education campaigns. **The Home Depot** also has made donation information materials available to its nationwide network of stores.

Media: Another HHS partner, the **James Redford Institute for Transplant Awareness**, is reaching out to national media organizations and schools, to promote public awareness. HHS worked with producers of the CBS special "Nicholas' Gift" to develop and air a 10-second post-program public service announcement featuring the Vice President and Mrs. Gore encouraging donation.

Minority Organizations: The **National Minority Organ/Tissue Transplant Education Program** (MOTTEP), with the support of NIH's Office of Research on Minority Health and the National Institute of Diabetes and Digestive and Kidney Diseases, is the first national program to empower minority communities to promote minority donation and transplantation as well as good health habits. In turn, this effort should improve the chances for a well-matched **organ** amongst minorities waiting for transplants. Now in 15 sites across the country, MOTTEP's target populations include African Americans, Hispanic/Latinos, Native Americans, Asians, Pacific Islanders and Alaskan Natives. HHS is a national sponsor of **National Minority Donor Awareness Day 1999** (August 1) hosted by MOTTEP, **American's Blood Centers Foundation** and **The Marrow Foundation** in 22 cities nationwide.

State Organizations: HHS works with the **National Governors' Association**, the **National Conference of State Legislatures**, the **Council of State Governments** and the **Association of State and Territorial Health Officials** to encourage state efforts to increase donation. With the encouragement of the Department of Transportation's **National Highway Traffic Safety Administration**, the **National Association of State Emergency Medical Directors** passed a resolution for automated statewide donor registries linked to state motor vehicle departments.

Federal Partners: The federal government is educating its own about donation, hoping to serve as a model for other employers. For example, with assistance from the **Office of Personnel Management**, HHS has provided donation materials to federal agencies for employees, including donation messages on pay stubs and full-page donation ads in the federal health plan catalog for the past two years. The **Department of Defense**, which routinely asks patients in its health care system to consider donation, is making donation information materials available in its treatment facilities.

###

For more information on the National **Organ** and Tissue Donation Initiative, visit the U.S. Department of Health and Human Services' Web site at *http://www.organdonor.gov*, or contact: Health Resources and Services Administration, Division of Transplantation, 5600 Fishers Lane, Room 4-81, Rockville, MD 20857, 301-443-7577 (telephone), 301-594-6095 (fax)

###

Note: HHS fact sheets releases are available on the World Wide Web at: http://www.hhs.gov.

This page is maintained by the National Academies Office of News and Public Information

Craig Hicks
Internet editor

Jennifer Cooke
online producer

Contact us by e-mail
news@nas.edu

NEWS
THE NATIONAL ACADEMIES
National Academy of Sciences | National Academy of Engineering
Institute of Medicine | National Research Council

Date: July 20, 1999
Contacts: Cheryl Greenhouse, Media Relations Consultant
David Schneier, Media Relations Assistant
(202) 334-2138; e-mail <news@nas.edu>

FOR IMMEDIATE RELEASE

Organs Should Be Allocated Based on Medical Need Across Wider Geographic Areas

WASHINGTON -- Organs donated for transplantation should be made available across geographic areas made up of large numbers of people, to enhance the prospects that the organs will be allocated to patients with the most urgent medical needs, says a new report from the Institute of Medicine (IOM).

"The current system of organ procurement and allocation works reasonably well, but significant improvements in both its fairness and its effectiveness could be made," said committee chair Edward Penhoet, dean, School of Public Health, University of California, Berkeley. "The committee strongly believes that the federal government should provide oversight and review of the organ procurement and transplantation system with a focus on assuring that the system is equitable, is grounded on sound medical science, and always places the highest priority on the needs of the patients it serves."

In 1998 the U.S. Department of Health and Human Services (HHS) published a new regulation, setting the ground rules for organ procurement and allocation in the United States. Congress suspended implementation of the regulation, asking the IOM to study its possible ramifications on organ donation rates, equitable access to transplantation, and costs. The committee focused its attention primarily on issues relating to the policies and data concerning liver procurement and allocation, because those were at the center of the debate leading up to the committee's study.

Today, organ procurement organizations coordinate activities that relate to organ procurement and allocation within a defined area, covering populations ranging from about 1 million to 12 million people.

After a comprehensive assessment of the data for 68,000 patients on waiting lists for livers from 1995 to 1999, the committee found that organ procurement organizations serving larger populations are associated with improved access for patients most in need of a transplant and with lower mortality rates following transplantation. For that reason, livers should be allocated over an area large enough to serve at least 9 million people. This area should not be so geographically broad as to pose difficulties in transporting organs, which threatens the viability of the livers themselves. The allocation areas for other organs may differ depending on how long they can remain viable outside the body.

Supply and Demand

Nearly 21,000 Americans received a transplanted kidney, liver, heart, lung, or other organ in 1998. The number of transplants performed has risen in recent years, but demand continues to outrun supply. About 62,000 people presently are waiting for an organ, and 4,000 Americans died last year before they could get one.

The committee determined that one critical assumption in the ongoing transplantation debate is misleading. Geographic variability in the amount of time that patients must wait for a transplant was thought to be a good indicator of how well the system is performing. Based on a thorough review of waiting times for liver transplants, however, the committee found that those with the highest medical need actually wait for a comparable period of time at sites around the country.

However, the transplantation rates do vary for patients who are not as ill, depending on the size and location of the organ procurement organization that serves the transplant center at which the patient is registered. Moreover, patients who are less ill sometimes receive transplants before more severely ill patients who are served by a different organ procurement organization.

Low-income patients, regardless of their racial and ethnic backgrounds, are less likely than affluent white patients to be referred for evaluation because they often do not have access to health insurance and high-quality health services, the committee said. However, once patients are referred for an organ transplant, there appear to be no disparities in acceptance to a waiting list, or in access to transplantation.

Wider Geographic Areas

The committee's analysis addressed a number of concerns raised by the HHS regulation, including fears about reduced access to organs by low-income and minority patients, decreased donation rates, and increased costs associated with the new guidelines.

There is no evidence that the agency's proposed regulation would reduce access to organs for transplantation by minorities, people with low incomes, or people living in remote locations, the committee said. Some have feared that the regulation may result in closure of smaller transplant centers, but the evidence is inconclusive.

Distributing organs across a wider geographic area also is not likely to drive down organ donation rates, as some have speculated. The committee found little or no evidence that people or families would decline to donate, or that health professionals involved in organ procurement would be less diligent in their efforts, if they knew a donated organ would be used outside the donor's immediate geographic area.

Increasing the geographic area for organ distribution may result in a more expensive system, because of increased transportation costs and higher costs associated with transplants for sicker patients. The magnitude of cost increases will depend on how the regulation is implemented and how the practices of transplant centers change over time. The committee noted, however, that cost increases would be relatively minor compared to the total cost of transplantation and would likely be outweighed by the improved health benefits from the new allocation rules.

A More Active Federal Role

To improve the system, the federal government must play a more active role in the review and oversight of organ transplantation. Among other steps, HHS should establish better performance measures for determining how effectively the system is working. And it should create an independent, multidisciplinary scientific review board to provide guidance on how the organ procurement and transplantation system can

best serve the public interest.

A committee roster follows. The study was funded by the General Accounting Office and the Greenwall Foundation. The Institute of Medicine is a private, nonprofit organization that provides health policy advice under a congressional charter granted to the National Academy of Sciences.

Copies of **Organ Procurement and Transplantation: Assessing Current Policies and the Potential Impact of the DHHS Final Rule** are available from the National Academy Press at the mailing address in the letterhead; tel. (202) 334-3313 or 1-800-624-6242. The cost of the report is $34.95 (prepaid) plus shipping charges of $4.50 for the first copy and $.95 for each additional copy. Reporters may obtain a copy from the Office of News and Public Information at the letterhead address (*contacts listed above*).

INSTITUTE OF MEDICINE
Division of Health Sciences Policy

Committee on Organ Procurement and Transplantation Policy

Edward D. Penhoet, Ph.D. (chair)
Dean
School of Public Health
University of California
Berkeley

Naihua Duan, Ph.D. *
Statistics Group
RAND Corp.
Santa Monica, Calif.

Nancy Neveloff Dubler, LL.B.
Director, Division of Bioethics
Montefiore Medical Center, and
Professor of Bioethics
Albert Einstein College of Medicine
New York City

Charles K. Francis, M.D. [1]
President
Charles R. Drew University of Medicine and Science
Los Angeles

Robert D. Gibbons, Ph.D.
Professor of Biostatistics
Departments of Biostatistics and Psychiatry
University of Illinois
Chicago

Barbara Gill, R.N., M.N.
Clinical Nurse Specialist
Abilene Cardiothoracic and Vascular Surgery of Texas
Abilene

Eva Guinan, M.D.
Associate Professor of Pediatrics
Dana-Farber Cancer Institute
Harvard Medical School
Boston

Maureen Henderson, M.D., D.P.H. [1]
Professor Emeritus of Epidemiology and Medicine
University of Washington

Seattle

Suzanne T. Ildstad, M.D. [1]
Director
Institute for Cellular Therapeutics
University of Louisville
Louisville, Ky.

Patricia A. King, J.D. [1]
Carmack Waterhouse Professor of Law, Medicine, Ethics, and Public Policy
Georgetown University
Washington, D.C.

Manuel Martinez-Maldonado, M.D. [1]
Vice Provost for Research and Professor of Medicine
Oregon Health Sciences University
Portland

George E. McLain, M.D.
Assistant Chief of Anesthesiology
Martin Memorial Medical Center
Stuart, Fla.

David Meltzer, M.D., Ph.D.
Assistant Professor
Section of General Internal Medicine, Department of Economics, and Harris School of Public Policy Studies
University of Chicago

Joseph E. Murray, M.D. [1,2]
Professor of Surgery, Emeritus
Harvard Medical School
Boston

Dorothy Nelkin [1]
University Professor
Department of Sociology and School of Law
New York University
New York City

Mitchell W. Spellman, M.D., Ph.D. [1]
Director of Academic Alliances and International Exchange Programs
Harvard Medical International
Harvard Medical School
Boston

STAFF

Andrew Pope, Ph.D.
Study Director

* Committee member until May 6, 1999
[1] Member, Institute of Medicine
[2] Member, National Academy of Sciences

Date: Thursday, March 26, 1998
FOR IMMEDIATE RELEASE
Contact: HRSA Press Office (301) 443-3376

HHS RULE CALLS FOR ORGAN ALLOCATION BASED ON MEDICAL CRITERIA, NOT GEOGRAPHY

Calls on Private Transplant Network to Develop Policies

HHS Secretary Donna E. Shalala today announced a new regulation to improve the nation's **organ** transplantation system, to assure that allocation of scarce organs will be based on common medical criteria, not accidents of geography.

The new rule calls on the **Organ** Procurement and Transplantation Network, the private sector system created by the National **Organ** Transplant Act of 1984, to develop revised **organ** allocation policies that will reduce the current geographic disparities in the amount of time patients wait for an **organ**. The rule also calls on the OPTN to develop uniform criteria for determining a patient's medical status and eligibility for placement on a waiting list. The criteria will be aimed at assuring that patients with greatest medical need will receive scarce organs based on medical judgment and common medical criteria, no matter where they live or in what transplant center they are awaiting treatment.

"Patients who need an **organ** transplant should not have to gamble that an **organ** will become available in their local area, nor should they have to travel to transplant centers far from home simply to improve their chances of getting an **organ**," Secretary Shalala said. "Instead, patients everywhere in the country should have an equal chance to receive an **organ**, based on their medical condition and the judgment of their physicians."

"HHS does not want to choose which patients receive scarce organs. Those choices must be made by transplant professionals," she said. "But this regulation will help assure that organs are allocated on the basis of medical need, and that availability of organs will not be impeded by arbitrary geographic lines."

In addition to today's action, the Clinton Administration last year launched a new National **Organ** and Tissue Donation Initiative with public and private sector partners, aimed at increasing **organ** donation by 20 percent within two years.

"The real answer to the problem of scarce organs is to increase the number of **organ** donations," Secretary Shalala said. "Our national initiative is a serious new effort to bring about more **organ** donation."

Under the regulation announced today, performance goals would be established to guide the OPTN as it modifies existing **organ** allocation policies. Under the current policies, matching organs are usually made available to all listed patients in a local **organ** procurement area before they are made available to other patients outside the area. This means less ill patients in the local procurement may receive a transplant while patients with more urgent medical need in another area continue to wait.

Under today's regulation, three new sets of criteria for **organ** allocation would be developed by the OPTN. Development of the criteria would include public input and comment and final HHS approval. Secretary Shalala emphasized that the regulation looks to transplant professionals in the OPTN to develop the revised policies. "We are not substituting our judgment for the judgment of medical professionals," she said. "We are asking them to make the system fairer, and we are setting clear performance goals to guide their work." The criteria to be developed by the OPTN are:

- Criteria aimed at allocating organs first to those in the highest medical urgency status, with

reduced reliance on geographical factors. This should reduce disparities in waiting times for patients at different transplant centers in different areas of the country. Today, there is a wide variation in waiting times, with patients in some areas waiting five times longer or more for an **organ** than in other areas. The new criteria would provide for wider sharing to assure organs were made available to patients with greatest medical need.

- Criteria to be followed in deciding when to place patients on the waiting list for an **organ**. Today, each transplant center establishes its own criteria, with the result that patients listed at one center may not be as ill as patients not yet listed at another center with more stringent medical listing criteria. Under the regulation, the OPTN would develop medically objective criteria to be used by all transplant centers.

- Criteria for determining the status of patients who are listed. Medically objective, uniform criteria would help ensure a "level playing field" in selecting among patients and determining which have the greatest medical need. The OPTN is already developing uniform criteria of this kind.

The final rule includes a new 60-day comment period, and becomes effective 90 days after publication in the Federal Register. The OPTN would have another 60 days to propose new criteria for livers, and a year for development of criteria for other organs.

"Together, these new uniform criteria will add up to a fairer and more understandable system, which will serve both patients and the transplant system better," Shalala said.

Other provisions of today's regulation include enhanced access to center-specific data about transplant centers, measuring outcomes and helping patients and physicians to choose among transplant centers; a broad definition of the composition of the OPTN membership and board of directors; the process for HHS review of OPTN policies before they become mandatory for OPTN members; and approval authority over the fees charged for registration on the OPTN waiting list (currently $357, usually paid by an insurer, most often Medicare or Medicaid.)

In 1996, some 20,000 Americans - about 55 each day - gained a new lease of a better life through transplantation. However, more than 55,000 people are on the transplant waiting list nationwide, and some 4,000 people - 10 every day - die in the U.S. while awaiting a donated **organ**.

The OPTN includes transplant centers and **organ** procurement organizations, as well as other public, medical and professional organizations

The final rule is available on the World Wide Web at *http://www.hrsa.dhhs.gov/bhrd/dot/dotmain.htm.*

###

Note: HHS press releases are available on the World Wide Web at: http://www.hhs.gov.

Paul Thornell@OVP 09/23/99 06:47:56 PM

Record Type: Record

To: Sarah A. Bianchi/OVP@OVP, Satish Narayanan/OVP@OVP, Barbara D. Woolley/WHO/EOP@EOP, Devorah R. Adler/OPD/EOP@EOP

cc: David R Thomas/OVP@OVP, William T. Glunz/OVP@OVP

Subject: Congressionals for Organ Donor event

Rep. Elijah Cummings (MD) D
Rep. Donna Christensen (VI) D
Rep. Tom Barrett (WI) D
Rep. Patrick Kennedy (RI) D

Lisa Gilmore <lgilmore@os.dhhs.gov>
09/23/99 05:45:22 PM

Please respond to lgilmore@os.dhhs.gov

Record Type: Record

To: Devorah R. Adler/OPD/EOP, sarah a. bianchi@ovp

cc: Barbara D. Woolley/WHO/EOP, Campbell Gardett <cgardett@os.dhhs.gov>
Subject: Recommended Acknowledgments for VP's organ remarks

Sarah and Devorah -- Here are the recommended acknowledgements (also in attached file). The first one is a must have b/c it was a condition of announcing the PSAs. I'll be here tonight and can quickly review the VP's remarks in no time flat. Thanks. - Lisa

RECOMMENDED ACKNOWLEDGMENTS FOR VICE PRESIDENT'S REMARKS
IN ORDER OF PRIORITY

THE SPONSORS OF THE PSAs MUST BE ACKNOWLEDGED BECAUSE IT WAS A CONDITION FOR MAKING THE PSAs A PART OF THE ANNOUNCEMENT

1. Five New PSAs: As a partner in the National Initiative, the Coalition on Donation in conjunction with Buena Vista Television and UNOS are distributing five PSAs via satellite today to media outlets nationwide to increase awareness of the need for organ donation. We encourage networks to take advantage of this opportunity.

OTHER KEY ACKNOWLEDGMENTS

2. New Grantees: we've confirmed that at least 15 individuals who will be receiving the new grants will be in attendance - we recommend asking them to stand up

3. Rear Admiral Kenneth Moritsugu, Deputy Surgeon General at the Department of Health and Human Services (attendance confirmed, will be in uniform in front row). [Note: Deputy Surgeon General Moritsugu lost his wife, Donna Lee Jones Moritsugu, in an automobile accident in 1992, and his daughter, Vikki Lianne, in a separate automobile accident in 1996. Both of them were organ and tissue donors.]

4. Congressional representatives: Acknowledge especially the chief sponsors of the Organ Donor Leave Bill: Representative Elijah E. Cummings (D-MD) and Senator Daniel Akaka (D-HI). In addition, acknowledge the role of the Office of Personnel Management in working with HHS and Congress on this bill. OPM staff will be in atttendance.

5. Donor family members and transplant recipients in the audience. In

Bill Summary & Status for the 106th Congress

Item 1 of 3716

PREVIOUS BILL | NEXT BILL
PREVIOUS BILL:COSPONSORS | NEXT BILL:COSPONSORS
NEW SEARCH | HOME | HELP | ABOUT COSPONSORS

S.1334
SPONSOR: Sen Akaka, Daniel K. (introduced 07/01/99) D-HI

COSPONSORS(11):

NC-D Sen Edwards, John - 07/01/99
D-MI Sen Levin, Carl - 07/01/99
D-MD Sen Sarbanes, Paul S. - 07/01/99
R-MS Sen Cochran, Thad - 07/20/99
D-CT Sen Lieberman, Joseph I. - 07/29/99
R-OH Sen DeWine, Michael - 08/05/99
Sen Frist, Bill - 07/01/99 R-TN
Sen Stevens, Ted - 07/01/99 R-AK
Sen Durbin, Richard J. - 07/01/99 D-IL
Sen Collins, Susan M. - 07/22/99 R-ME
Sen Santorum, Rick - 08/03/99 R-PA

Passed by voice vote / Unanimous Consent

6/12

Bill Summary & Status for the 106th Congress

Item 2 of 3716

PREVIOUS BILL | NEXT BILL
PREVIOUS BILL:COSPONSORS | NEXT BILL:COSPONSORS
NEW SEARCH | HOME | HELP | ABOUT COSPONSORS

H.R.457
SPONSOR: Rep Cummings, Elijah E. (introduced 02/02/99)

COSPONSORS(24):

Rep Norton, Eleanor Holmes - 02/02/99	Rep Kilpatrick, Carolyn C. - 02/02/99
Rep Bentsen, Ken - 02/02/99	Rep Morella, Constance A. - 02/02/99
Rep Ford, Harold Jr. - 02/02/99	Rep Rivers, Lynn N. - 02/02/99
Rep Underwood, Robert A. - 02/02/99	Rep Frost, Martin - 02/02/99
Rep Jones, Stephanie Tubbs - 02/02/99	Rep Luther, Bill - 03/02/99
Rep Barrett, Thomas M. - 03/02/99	Rep Clyburn, James E. - 03/02/99
Rep Kennedy, Patrick J. - 03/02/99	Rep Wynn, Albert Russell - 03/02/99
Rep Hoyer, Steny H. - 03/02/99	Rep Slaughter, Louise McIntosh - 03/02/99
Rep Kleczka, Gerald D. - 03/02/99	Rep Moakley, John Joseph - 03/02/99
Rep Inslee, Jay - 03/02/99	Rep Baird, Brian - 05/04/99
Rep Thompson, Bennie G. - 05/04/99	Rep Berkley, Shelley - 05/12/99
Rep DeLauro, Rosa L. - 05/12/99	Rep Watt, Melvin L. - 05/12/99

2/25

HRSA GRANTS: MODEL PROGRAMS TO INCREASE ORGAN DONATIONS

Applicant: Education Development Center & New England Organ Bank, Boston, MA

Project: Increasing Organ Donation by Enhancing End-of-Life Care: A Family-Centered, Quality Improvement Program

Empirical research has established that families are more likely to consent to organ donation if they are satisfied with the care that their loved ones received at the end of life. The New England Organ Bank and the Education Development Center of Boston will collaborate with hospitals in Massachusetts, Rhode Island, and New Hampshire to enhance end-of-life care and improve the donation request process. The study aims to increase health professionals' comfort and skill discussing death and dying and to build a hospital's capacity to support families through the end-of-life period.

Total Funding: $937,892

****

Applicant: The National Kidney Foundation, New York, NY

Project: Take Time to Talk: A Family Discussion Guide

The National Kidney Foundation will study the feasibility of incorporating a donation education program into funeral pre-planning activities. The goal of this program is to provide individuals the opportunity to conduct family discussions about donation at the time they are making other end-of-life arrangements. If successful, this program could introduce an untapped source for donation education.

Total Funding: $439,413

****

Applicant: The South-Eastern Organ Procurement Foundation, Richmond, VA and the University of Rhode Island, Providence, RI

Project: **Stage-Based Curriculum Training for Procurement Coordinators to Increase Family Consent for Organ and Tissue Donation**

The aim of this project is to improve family donation consent rates by training procurement coordinators to match their donation requests to reflect the family's readiness to donate. This project, involving staff from 16 of the Nation's 61 organ procurement organizations, represents the first multi-center study of requester training program effectiveness.

Total Funding: $1,212,883

****

Applicant: The California Transplant Donor Network, San Francisco, CA

Project: Proposal to Increase Organ Donation Consent Rates Involving Targeted Minority Populations

The California Transplant Donor Network has achieved notable success in capturing Hispanic community support for organ donation. This grant award will facilitate the development of cultural diversity and request training programs to garner donation support among African Americans and Asians in Northern California.

Total Funding: $1,374,620

****

Applicant: The Regional Organ Bank of Illinois, Chicago, IL

Project: Impact of Educational Interventions Regarding Organ Donation on Declaration of Intention to Donate and on Family Discussion in the African American Community

This project seeks to increase the number of African-Americans who are willing to join the state organ donor registry and talk to their families about their decision by assessing the effectiveness of two separate strategies to encourage registry participation and by conducting and evaluating an ethnically sensitive media campaign.

Total Funding: $366,584

****

Applicant: Kentucky Organ Donor Affiliates, Louisville, KY

Project: Increasing Commitment to Organ and Tissue Donation Through a Work-Site Intervention

Kentucky Organ Donor Affiliates proposes to collaborate with United Parcel Service (UPS) to study the effect of a work-place donor education program. This program could potentially serve as a model for corporate education programs throughout the country.

Total Funding: $137,349

****

Applicant: The Johns Hopkins School of Medicine and Johns Hopkins University, Baltimore, MD

Project: Interdisciplinary Experiential Training for End-of-Life Care and Organ Donation

This project will implement and evaluate a family-centered program focusing on end-of-life decision making and organ donation discussions with the goal of increasing the frequency of donation consent. The proposed program will utilize a multi-disciplinary approach involving such health care professionals as physicians, nurses, hospital clergy, and organ procurement coordinators who play consistent, important, and inter-dependent roles in caring for patients and families when organ donation is possible.

Total Funding: $929,044

****

Applicant: Emory University and LifeLink of Georgia, Atlanta, GA

Project: The Renaissance State-Wide Initiative to Increase Organ Donation in the State of Georgia

The purpose of this project is to replicate a successful donation-enhancing program launched at Emory University Hospital in Atlanta known as the "Renaissance Project." This end-of-life care model will be expanded to four additional Georgia hospitals with the goal of enhancing family support practices and increasing the number of organ donors at each institution.

Total Funding: $606,716

****

Applicant: LifeGift Organ Donation Center, Houston, Texas

Project: Project to Increase Organ Recovery From Level 1 Trauma Centers

This project proposes to replicate a successful pilot program which significantly increased organ donation by placing "in house procurement coordinators" in two Level 1 Trauma Centers. This proposal will disseminate the concept to hospitals demonstrating significant untapped donor potential in Detroit, Chicago, Seattle, and Houston.

Total Funding: $606,270

****

Applicant: Golden State Donor Services, Sacramento, CA

Project: Increasing Donation in the Hispanic Community Through Mass Media

This project aims to reverse the declining rate of donation consent among Hispanic families in the Sacramento area by implementing and evaluating an ethnically sensitive media campaign. This undertaking is especially critical in California due to the disproportionate rate at which Hispanics are placed on the transplant waiting list due to end-stage organ failure.

Total Funding: $444,510

****

Applicant: Oklahoma Organ Sharing Network

Project: Project Team Life

This proposal seeks to increase commitment to donate by implementing a curriculum designed to introduce organ and tissue donation and transplantation to elementary and secondary school students. This project could potentially serve as a collaborative working model for donor education programs and public school systems.

Total Funding: $770,644

****

Applicant: LifeGift Organ Donation Center, Houston, TX

Project: African-American Community Outreach Project

This program aims to increase family donation discussions and minority community support by implementing and evaluating an intensive education and training program targeting African American religious and spiritual leaders in Harris County, TX. The project will prepare clergy to develop and implement effective donation education and support programs for each of their congregations.

Total Funding: $595,342

****

Applicant: The Center for Donation and Transplant, Albany, NY

Project: Testing and Replication of a Model Volunteer Program

This project proposes to increase donation consent rates by evaluating and replicating a volunteer program teaching mothers of organ donors to counsel potential donor families about the option of donation. This program represents the first formalized program assessing the effectiveness of a former donor family member's role in the donation decision process.

Total Funding: $783,882

****

Applicant: Louisiana Organ Procurement Agency, Metairie, LA

Project: The Kiosk Learning Center: A Community Outreach Approach to Increase Donor Consent Rates, Public Access, and Overall Awareness

This project will attempt to improve driver's license renewal efficiency and enhance donor education and registry access by placing ATM-like kiosks in public venues. This program will promote a convenient one-stop system as a means to enhance public commitment to donation.

Total Funding: $1,049,759

****

Applicant: Upstate New York Transplant Services, Buffalo, NY

Project: Decision for Life: An Intervention to Increase Organ Donation in the African American Community

This program seeks to increase the number of African Americans in the Buffalo urban community who have signed donor cards and discussed donation with their families. It aims to achieve this goal by increasing medical student and resident awareness of the importance of approaching families in a culturally sensitive manner and by training African American community educators to implement public education programs.

Total Funding: $810,330

****

Applicant: Donor Network of Arizona, Phoenix, AZ

Project: Comprehensive Approach to Raising Organ and Tissue Donation Consent in the Hispanic Population

This project proposes to increase donation consent rates among Hispanic families through a comprehensive approach to increase donor awareness and family discussions. Implementation will include community, media, and requester outreach.

Total Funding: $880,937

****

Applicant: Minority Organ and Tissue Transplant Education Program (MOTTEP) Howard University, Washington, D.C.

Project: "Say YES!" to Organ and Tissue Donation; Implementation and Evaluation of a Promising Youth Intervention

This project seeks to increase the number of youth registering to become donors when obtaining a driver's license by encouraging family discussions and promoting an informed donation decision. This program will enhance existing school-age driver curriculum with materials that will measurably increase family discussion on organ and tissue donations, raise positive consent rates, and increase youth awareness of organ donation needs.

Total Funding: $464,163

****

Applicant: The Transplantation Society of Michigan and TransWeb

Project: Measuring the Effectiveness of a Multimedia Internet-Based Approach to Increasing Donor Registry Participation

This project aims to expand a previously existing transplant education Internet site by creating a new path focusing on the donor family's view of organ donation. The project's intent is to encourage participants to join the donor registry and will provide specially-designed electronic greeting cards to notify family members of the registrant's desire to donate.

Total Funding: $895,699

****

SPEAKERS AT ORGAN DONATION EVENT

Tim Thompson, a 42 year old telecommunications expert for United Postal Service, lost his wife Harriet, aged 32, to a brain aneurysm three years ago. Because of the recent death of a close relative, Tim and his wife had discussed organ donation and he knew that she wanted to be a donor. Because he was overwhelmed trying to cope with the reality of his wife's sudden death and the impact it would have on their two children, Anne-Hamilton (aged 11) and David (aged 7), he doesn't think that he would have remembered that Harriet wanted to be an organ donor. Even if he had remembered, Tim thinks that he would have had an extremely difficult time bringing it up with hospital staff. When a nurse asked him about the possibility of donation, he remembers feeling "pure relief" at the idea that someone was there to help him carry out his wife's wishes. Harriet's organs went to seven different people, all of whom are doing well. Tim, who now serves on the Kentucky Organ Donation Affiliates' Board of Directors, is working with UPS to develop a workplace donation education initiative. His project has been selected as one of the first HHS Model Programs to Increase Organ Donation, and will receive almost $140,000 of the $5 million in grant funds that the Vice President is releasing today.

Oscar Robertson (the Big O) is generally considered the greatest all-around player in basketball history and international ambassador for the game 24 years after retirement. He has been an all-time all-star at every level- high school, college, the Olympics and the National Basketball Association, which recently named him one of the greatest players of all time. One of Mr. Robertson's proudest achievements was his 1997 donation of a kidney to his daughter, Tia, who had suffered a kidney failure as a result of lupus. He has since become active with the National Kidney Foundation, serving as an ambassador for organ donation and as Honorary Spokesperson for the 1998 U.S. Transplant Games, where Tia participated with fellow transplant athletes and won a gold medal in doubles tennis.

Jose Torres received his donated liver in July of 1997. A few months before that, he developed debilitating pains in his abdomen. He thought that it was food poisoning, and his wife Maria rushed him to the hospital – where he ended up staying for almost a month. Jose was diagnosed with a rare liver disease, and he and his family learned that without a transplant, he had less than a year to live. Those months were stressful ones for the family; Jose was forced to leave his job as a homicide detective and stay at home. Maria was forced to work extra hours and worried about the family's financial future; their six children all spent more time at home to try and help as much as they could instead of playing sports after school and taking up extracurricular activities. Jose calls his transplant a "gift from God" – he and his family now appreciate every day they have together. He speaks whenever he can about the importance of organ donation.

Sarah Lee Beck and her husband Mark donated their three year old daughter Anna's heart valves, corneas, liver, and kidneys after she died of a brain aneurysm in February 1998. Sarah said that the decision to donate Anna's organs was not a difficult one; although the day her daughter died was the worst one of her life, there was never any question about what they would do. She and her husband Mark have both pledged to donate their organs, and she speaks with pride of the people Anna helped. Sarah is extremely thankful for the support and guidance her local transplant organization provided her when they made their decision. Sarah and Mark have two children, David (aged 6 months) and Lily (aged 3).

SCRIPT FOR VICE-PRESIDENTIAL EVENT ON ORGAN DONATION

TIM THOMPSON

- My wife Harriet donated her organs three years ago. You don't usually think much about organ donation when you're in your early 30s, but Harriet and I had actually discussed it before she died, because a cousin of ours died of cancer.

- When Harriet died suddenly, I was really glad I knew what her wishes were. She was a pediatric nurse who spent her whole life helping people, and it was just natural that she would want to help others even after she was gone.

- But even more important was the fact that the hospital staff asked me if I knew what Harriet's views on donation were. I was so overwhelmed by her death and the impact that would have on our two children, I wouldn't have thought to ask about it. When the nurse wanted to talk to me about donation, I was so relieved that there was someone to help me carry out her wishes.

- Now, I work to educate others about the importance of organ donation, and to help them talk about this difficult subject with their loved ones. Because Harriet helped me realize how important this issue is to millions of families across America, I represent organ donor families on the Board of Directors of Kentucky Organ Donor Affiliates. Mr. Vice President, I work every day to represent the interests of donor families. The millions of dollars that you are releasing to communities all over the country will help me and people just like me continue this very important work. Thank you for longstanding commitment to this issue.

OSCAR ROBINSON

- When my daughter Tia developed lupus three years ago, she went into kidney failure pretty quickly. We were terrified – she was only in her late twenties when she got sick, and you just don't anticipate having to deal with that kind of debilitating illness in a young woman. It was heartbreaking to see my daughter so sick and so frightened, and it was killing us not to be able to do anything about it. That's the worst with your kids – that they sometimes have problems that you can't fix.

- The doctors told us that in order to live a normal life, she would need a new kidney. My whole family got tested, but I was the only one who was a match. There was never any question about what I would do. This was my baby girl we were talking about – and there's nothing I wouldn't do for her. There was really no other choice for me.

- Thanks to the transplant (which has worked well for the past two years), I now have weeks, and months, and years more to spend with my daughter. And, Mr. Vice President, because of your efforts, there are thousands of families around the country who now have more time with their children and your loved ones, and I want to thank you for that.

SARAH BECK

- When our daughter Anna died, it was the worst day of my life. One second we were watching the Olympics; then we were watching her struggle for her life in a hospital bed. It was horrifying. There is no way to describe the impact of the death of a child.

- Once we realized there was nothing we could do for her, we never had any questions about whether we should donate Anna's organs. My husband and I have made that decision for ourselves, and it seemed like the right decision for her as well.

- Anna donated her kidneys, liver, heart valves, and corneas. Thanks to my little girl, six people have been able to see better and live longer lives. Every time my husband and I look at our two children – my daughter is three and my little boy is 6 months old – we think of Anna and remember her. And I know that there are six people out there, who – when their parents look at them – think of my little girl as well and thank her for the days and months and years that they have to spend with their children. And I'm so grateful for that.

- Mr. Vice President, I know that you are a father, and I learned recently that you became a grandfather. You can understand the pain of losing a child. And so – when I can – I work to help other families in danger of losing their children by talking about the importance of this issue to everyone I can.

JOSE TORRES

- When I first got sick, I didn't think too much of it – I thought that it was something I ate, and that it would go away. I ended up spending almost a month in the hospital. The doctors told me I needed a new liver – and that if I didn't get one, I would die within the next 12 months.

- They sent me home to rest and wait. Those were the hardest months of my life – to sit and wait while the time I had left to spend with my wife and my children was slipping away. Before I got sick, I was a homicide detective. I protected people. Now, I sat by and watched my wife grow thinner and lose sleep – she spent three days at my bedside without sleeping. I watched my kids grow quieter. I worried about who would take care of my family if something happened to me. I worried that my children were missing out on being kids because they were worried about me. You don't expect to worry about these things in your thirties. You don't expect to have six kids and then just leave them.

- When we got the call that a liver was available, it was one of the happiest days of our lives. I've had my new liver for 3 years and 2 months now, and we're doing just fine. Each day, I thank God for being able to play sports with my kids, spend time with my wife, and work at a job that I love.

- Mr. Vice President, without your efforts and the good work that goes on all around the country on this issue, I wouldn't be here today. It's not often that you get to speak in front of a crowd like this, and I want to take this opportunity to thank you for your leadership.

LAST	FIRST	ORGANIZATION
Admire	Allen	Banyon Communications
Aiken-O'Neill	Patricia	Eye Bank Association of America
Applegate	William	American Society of Transplantation
Arden	Jonathan	Washington Regional Transplant Consortium
Beck	Sarah Lee	
Beigay	Teresa	Division of Transplantation
Benjamin	Milton	First Family Pledge Campaign
Beyersdorf	Tom	Transplantation Society of Michigan
Borowiecki	Marion	Transplant Resource Center of Maryland
Bottenfield	Helen	LifeNet
Brigham	Lori	Washington Regional Transplant Consortium
Brock-Smith	Cynthia	Office of Personnel Management
Brown	LaTonya	Office of Personnel Management
Butler-Hamlett	Brenda	American Society of Minority Health Transplant Professionals
Carver	Joseph	Aetna U.S. HealthCare
Cellucci	Margaret	Transplant Resource Center of Maryland
Chen	D.W.	Division of Transplantation
Chianchiano	Gandolfo	National Kidney Foundation
Chisholm-King	Janet	Office of Personnel Management
Cochran	Lawrence	Tennessee Donor Services
Cook	Mike	Arnold Communications
Cowherd	Robin	LifeNet
Crosier	Vicki	NKF National Donor Family Council
Dalrymple	Lindsey	Office of Grants Management
Dennis	Gary	National Medical Association
DeStefano	David	Washington Regional Transplant Consortium
Driver	Lynn (Mr.)	Indiana Organ Procurement Organization
Eiche	Jon	The Living Bank International
Fenandez-Bueno	Carlos	Washington Regional Transplant Consortium
Fiske	Charlie	National Transplant Action Committee
Fleming	David	Coalition on Donation
Ganikos	Mary	Division of Transplantation
Givens	Veronica	Office of Personnel Management

Goetz	Diane	National Kidney Foundation				
Gordon	Mary	National Minority Organ Tissue Transplant Education Program				
Graham	Walter	United Network for Organ Sharing				
Gurne	Patricia	Washington Regional Transplant Consortium				
Hairston	Dorothy	New York Organ Donor Network				
Hall	Mike	American Liver Foundation				
Hartnett	Elizabeth Ann	Office of Grants Management				
Hauffman	Sally	Transplant Resource Center of Maryland				
Hawkins	Donald	LifeNet				
Haywood	Alyson	American Liver Foundation				
Hicke	Thomas	Office of Personnel Management				
Hostetter	Lynne	Transplant Resource Center of Maryland				
Jacobbi	Louise	Louisiana Organ Procurement Agency				
Jacobs	Amy	Transplant Recipients International Organization				
Jellings	Denise	Transplant Recipients International Organization				
Jennings	Thoman					
Jones	Eleanor	University of Michigan/TransWeb				
Kamat	Miguel	Division of Transplantation				
Kappel	Jenna	Association of Organ Procurement Organizations				
Kendrick	Martie	Patient Access to Transplantation				
Knisely	Evan	Patient Access to Transplantation				
Kory	Lisa	Transplant Recipients International Organization				
Kroemer	Kurt	American Red Cross Tissue Services				
Lawson	Rebecca	LifeNet				
Lee	Laura	National Institutes for Health				
Leino	Victor	American College Health Association				
Lewis	Linda	American Association of Motor Vehicle Administrators				
Lewis	Diane	Oklahoma Donor Coalition				
Lewis	David	LifeBanc				
Luskin	Rich	New England Organ Bank				
Mande	Jerry					
Marx	Jeffrey	Wendy Marx Foundation				
May	Randy	American Red Cross Tissue Services				
McBride	Ginny	Division of Transplantation				
McCluskey	Charles	University of Florida				

McDaniel	Clint	Mississippi Organ Recovery Agency				
McGaw	Lin	United Network for Organ Sharing				
McGuigan	James	The Gift of Life Foundation				
McGuigan	Karren	Gift of Life Foundation				
Meier	Kathryn	URI Cancer Prevention Research Center				
Merion	Robert	University of Michigan/TransWeb				
Miles	Patrice	National Minority Organ Tissue Transplant Education Program				
Miller	Jenny	Kentucky Organ Donor Affiliates				
Miller	Joshua	University of Miami School of Medicine				
Minogue	William	Washington Regional Transplant Consortium				
Montgomery	Jan					
Morgan	Rudy	Organ and Tissue Acquisition Center				
Mowe	Jeanne	American Association of Tissue Banks				
Muldoon	Sylvie	Washington Regional Transplant Consortium				
Murphy	David	Aetna U.S. HealthCare				
Nelson	Anice	Office of Personnel Management				
Nelson	Jon	Office of Special Programs				
Neylan	John	American Society of Transplantation				
Nicely	Bruce	North American Transplant Coordinators Organization				
Nielson	Marcie	AFL-CIO				
Noble	Joshua	Religious Action Center				
Obot	Nseudo	Transplant Recipients International Organization				
O'Connor	Kevin	New England Organ Bank				
O'Donnell	Joseph	Transplant Resource Center of Maryland				
O'Flynn	Paul	Kentucky Organ Donor Affiliates				
Osborn	Lisa	LifeNet				
Osborn	Blake	LifeNet				
Osborne	Eugene	California Transplant Donor Network				
Pagan	Melinda					
Park	Marilyn	AFL-CIO				
Parsons	Donald	Kaiser Permanente				
Patrick	Charles	Alabama Organ Center				
Paykin	Catherine	National Kidney Foundation				
Perl	Rebecca					
Perrini	Joann Catherine	Office of Personnel Management				

Peterson-Meier	Eileen	American Nephrology Nurses Association				
Pickard	Eileen May	Asian Pacific American Institute for				
Price	Barrye	Office of Personnel Management				
Reardon	Clare	Wisconsin Donor Network				
Rees	Jeffrey	University of Vermont				
Reggio	Gail Jacqueline	Eye Bank Association of America				
Rios	Elena	National Hispanic Medical Association				
Robbins	Mark	URI Cancer Prevention Research Center				
Roberts	Brenda Lee	Office of Personnel Management				
Robertson	Oscar					
Robinson	Sullivan	Congress of National Black Churches				
Rodriques	Carmen					
Rodriques	Moises					
Romero	Henry	Office of Personnel Management				
Ronquillo	Anthony	Texas Organ Sharing Alliance				
Sanchez	Javier	Hispanic Serving Health Professions Schools				
Sardo	Sal	Buena Vista Television				
Sardo	Michael	Buena Vista Television				
Saunders	Warren	New York Organ Donor Network				
Schaeffer	Margaret	LifeNet				
Schantz-Trum	Mary Jo	Washington Regional Transplant Consortium				
Seely	Michael	Association of Organ Procurement Organizations				
Shoaf	Mary Loretta	American Association of Neurological Surgeons				
Simon	Mark	Upstate New York Transplant Services				
Simpkins	Barbara	The Links, Inc				
Sparkman	Kevin	Gift of Life Donor Program				
Speas	Cindy	Washington Regional Transplant Consortium				
St. Martin	Laura	Division of Transplantation				
Staubi	Paul	Wendy Marx Foundation				
Stevens	Keith Paul	LifeBanc				
Strieby	June	Office of Personnel Management				
Taft	Frank	Center for Donation and Transplant				
Thompson	Tim	Kentucky Organ Donor Affiliates				
Torres	Jose					
Torres	Maria					

Turner	Robert	Oklahoma Organ Sharing Network				
Van Amringe	Margaret	Joint Commission on Accreditation of Healthcare Organizations				
Vangor	Paul					
Vincent	Angela	National Medical Association				
Weaver	Kim	Office of Personnel Management				
Webb	Toni	Washington Regional Transplant Consortium				
Weber	Sarah Kathryn	The Marrow Foundation				
Weir	Bruce	Transplant Recipients International Organization				
Whiteman	Marlene	First Family Pledge Campaign				
Wilcom	Glenna	Office of Grants Management				
Williams	Michael	Johns Hopkins University				
Winstead	Donald	Office of Personnel Management				
Woodrow	Michael	Wendy Marx Foundation				

Q: Tim Thompson, tell us about your experiences with organ donation?

Tim's wife Harriet died of a brain aneurysm three years ago, at age 32. He was glad that a nurse asked him about the possibility of organ donation because he was so overwhelmed by the death of his wife that he would not have brought it up himself. He is now an donation activist and is one of our new grantees.

Suggested Follow Up Question

Q: Tim, I understand you're receiving an award today. Tell us a little bit about your program.

Q: Oscar Robertson or "the Big O" is one of the greatest basketball players of all time – but he is proudest of another accomplishment. Oscar, tell us about your experience with organ donation.

Oscar's daughter Tia was diagnosed with kidney failure as a result of lupus in 1997. Oscar successfully donated his kidney to her so that she could live a normal life.

Suggested Follow Up Question

Q: How has your experience changed your life?

Q: Sarah Beck, you are part of a donor family. Can you tell us about your experience?

Sarah's three year old daughter Anna died of a brain aneurysm in 1998. The family donated her Anna's heart valves, corneas, liver, and kidneys to six different people.

Q: Jose Torres you have so many family members here today. Tell us about your experience with organ donation?

Jose received a liver transplant in July of 1997. The months before he received a transplant were extremely stressful for him and his family. His wife Maria, and children Carmen, Melinda, and Moses are present.

Suggested Follow Up Question

Q: How has this experience affected your family?