



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILEDATE September 20, 1999

TO: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):

Deborah Adler
DPC
(202) 456-5707

FROM: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):



U.S. Department of Health and Human Services
Office of the Secretary

LISA A. GILMORE, MSW, MBA
Special Assistant to the Deputy Secretary

H.H. Humphrey Bldg., Room 614G
200 Independence Avenue, S.W.
Washington, DC 20201

(202) 690-6133
Fax (202) 690-7755
lgilmore@os.dhhs.gov

RECIPIENT'S FAX NUMBER (202) 456-5557NUMBER OF PAGES TO SEND (INCLUDING COVER SHEET): 3

COMMENTS:

Re: organ donation event.

Lisa

Organ & Tissue

COALITION ON DONATION

Share your life. Share your decision.®

MEMORANDUM

To: Lisa A. Gilmore
Special Assistant to the Deputy Secretary

From: G. David Fleming
Executive Director

Subject: Organ Donation Event

Date: September 20, 1999

Larry Hadman
Nat Kidney
Foundation

Spurs player
liver

Please share the following updates with the White House. Please feel free to give me a call with any further questions.

1. The satellite feed to distribute the Promax PSAs has been scheduled for Friday, September 24. The requirement for including the PSA distribution in the event is that Buena Vista, Promax and UNOS are given credit for the effort and that they are working with the Coalition on Donation, a partner in the National Initiative, to distribute the PSAs.
2. There will not be a radio(audio) element of the PSAs.
3. Waiting for confirmation from Buena Vista as to network commitments and total expected donated media time.
4. The MBNA/Coalition on Donation Visa Card has been a great success with only limited exposure. There are currently 250+ cardholders. The true marketing of the card will start in conjunction with the Coalition Annual Meeting in October 1999.
5. The following should be invited to the event:

	<u>Phone</u>	<u>Fax</u>
Rick Britton, Arnold Communications	804-697-4366	804-697-4440
Fred Moore, Arnold Communications	804-697-4317	804-697-4440
David Murphy, Actna US Healthcare	215-775-5013	215-775-6742
Howard Nathan, Coalition on Donation	215-599-2065	215-963-0587
Sal Sardo, Buena Vista Television	818-560-5194	818-955-9471



**United States
Office of
Personnel
Management**

FAX TRANSMISSION

OFFICE OF CONGRESSIONAL RELATIONS

1900 E St., N.W., Room 5H30
Washington D.C. 20415
(202) 606-1300
Fax: (202) 606-1344

To:	Devorah Adler
Office:	DPC
Fax #:	456-5557
From:	Kim Weaver
Subject:	Organ Donor Event
Date:	September 21, 1999
Pages:	2 (including cover sheet)

COMMENTS:

Devorah,

Thank you for the information about Friday's event. Here's the information about the organizations/people OPM would suggest should be included. Please call if we can provide any assistance.

Congressman Elijah Cummings (staffer Tania Shand), Senator Daniel Akaka (staffer Nanci Langley), and Senator Bill Frist were instrumental in moving the organ donor leave bill (H.R. 457).

The North American Transplant Coordinators Organization and the American Nephrology Nurses Association (contact Eileen Meier at 202 408-7034) have been involved in a number of organ donor issues.

OPM staff who have worked on this bill include:

Henry Romero, Associate Director, Workforce Compensation and Performance Service (and 3 of his staff)

Steve Cohen, Associate Director, Office of Workforce Relations (and 3 of his staff)

Gay Gardener, Office of Legislative Analysis

Thanks,
Kim



United States
Office of
Personnel
Management

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COMMENTS:



UNITED STATES
OFFICE OF PERSONNEL MANAGEMENT
WASHINGTON, DC 20415-0001

OFFICE OF THE DIRECTOR

September 21, 1999

Devora Adler
Domestic Policy Council
The White House
Washington, D.C. 20502

Devora,

Per our conversation today, the following names are submitted for attendance at the official signing ceremony of H.R. 457, the "Organ Donor Leave Act."

- Janice R. Lachance, Director, OPM
- Congressional Sponsors:
 - Senator Frist
 - Senator Akaka
 - Representative Cummings

Should you have any questions please contact me at 606-2725.

Sincerely,


Barry L. Price
Special Assistant to the Director

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILEDATE August 17, 1999

TO: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):

Deborah Adler

DPC

(202) 456-5707

FROM: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):

U.S. Department of Health and Human Services
Office of the SecretaryLISA A. GILMORE, MSW, MBA
Special Assistant to the Deputy SecretaryH.H. Humphrey Bldg., Room 614G
200 Independence Avenue, S.W.
Washington, DC 20201(202) 690-6133
Fax (202) 690-7755
lgilmore@os.dhhs.govRECIPIENT'S FAX NUMBER 202 456-5557NUMBER OF PAGES TO SEND (INCLUDING COVER SHEET): 5

COMMENTS:

HR 457 - Organ Donor Leave Act



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Office of the General Counsel
Legislation Division
Washington, D.C. 20201

July 23, 1999

URGENT

TO: ASL
ASPE
HRSA
NIH
ASMB
HCFA
IOS (Lisa Gilmore)
OPHS

FROM: Sondra Stigen Wallace *SSW/da*
Associate General Counsel

SUBJECT: Draft **STATEMENT OF ADMINISTRATION POLICY (SAP)** on HR
457 - Organ Donor Leave Act

The Office of Management and Budget has asked for the Department's views on the above-mentioned SAP.

In order that we may respond promptly to this request, please give your comments **AS SOON AS POSSIBLE** to RICHARD FRIEDMAN of this Division, who can be reached at 690-7773. **OMB HAS REQUESTED COMMENTS BY 4:00, TODAY. IF YOU INTEND TO RESPOND BY E-MAIL, PLEASE cc:GCL@OGC.LEG@OS.DC** (press F2 for Directory, type GCL).

Oral comments are generally acceptable. Extensive comments, however, should be in writing (either a mark-up or note).

If you have any questions concerning this referral, please call our Legislative Reference Service, 690-7750.

Attachments

cc:GC/H
OIG (St Cyr 5272Cohen)

JUL-23-1999 14:20 TO:52 - HHS

FROM:470 LINDSEY J

P. 3/5

DRAFT - NOT FOR RELEASEJuly**
~~June 11~~, 1999
(House)**H.R. 457 - Organ Donor Leave Act**
(Cummings (D) MD and 9 cosponsors)

The Administration supports H.R. 457, which would increase the amount of paid leave (separate from annual and sick leave) available to a Federal employee who serves as an organ donor from seven days a year to thirty days a year.

[Pay-As-You-Go Scoring]

H.R. 457 would not affect direct spending or receipts; therefore, it is not subject to the pay-as-you-go (PAYGO) requirement of the Omnibus Budget Reconciliation Act of 1990.]

JUL-26-1999 14:20 10182 - HRS

FROM: 473 LINDSEY J

P. 4/5

HR 457 RH

Union Calendar No. 97

106th CONGRESS

1st Session

H. R. 457

[Report No. 106-174]

To amend title 5, United States Code, to increase the amount of leave time available to a Federal employee in any year in connection with serving as an organ donor, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

February 2, 1999

Mr. CUMMINGS (for himself, Ms. NORTON, Ms. KILPATRICK, Mr. BENTSEN, Mrs. MORELLA, Mr. FORD, Ms. RIVERS, Mr. UNDERWOOD, Mr. FROST, and Mrs. JONES of Ohio) introduced the following bill; which was referred to the Committee on Government Reform

June 8, 1999

Additional sponsors: Mr. LUTHER, Mr. BARRETT of Wisconsin, Mr. CLYBURN, Mr. KENNEDY of Rhode Island, Mr. WYNN, Mr. HOYER, Ms. SLAUGHTER, Mr. KLECZKA, Mr. MOAKLEY, Mr. INSLEE, Mr. BAIRD, Mr. THOMPSON of Mississippi, Ms. BERKLEY, Ms. DELAURO, and Mr. WATT of North Carolina

June 8, 1999

Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

A BILL

To amend title 5, United States Code, to increase the amount of leave time available to a Federal employee in any year in connection with serving as an organ donor, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. INCREASED LEAVE TIME TO SERVE AS AN ORGAN DONOR.

(a) **SHORT TITLE.** This Act may be cited as the 'Organ Donor Leave Act'.

(b) **IN GENERAL.** Subsection (b) of the first section 6327 of title 5, United States Code (relating to absence in connection with serving as a bone-marrow or organ donor) is amended to read as follows:

'(b) An employee may, in any calendar year, use--

'(1) not to exceed 7 days of leave under this section to serve as a bone-marrow donor; and

6/11/99 11:39 AM

202 401 5783: # 4 / 5

7-28-99 : 14:50 : DHHS/OGC/LEGISLATION-

SENT BY:

JUL-23-1999 14:20 TO:52 - HHS

FROM:470 LINDSEY J

P. 5/5

'(2) not to exceed 30 days of leave under this section to serve as an organ donor.'

(c) **TECHNICAL AMENDMENTS-** (1) The second section 6327 of title 5, United States Code (relating to absence in connection with funerals of fellow Federal law enforcement officers) is redesignated as section 6328.

(2) The table of sections at the beginning of chapter 63 of title 5, United States Code, is amended by adding after the item relating to section 6327 the following:

'6328. Absence in connection with funerals of fellow Federal law enforcement officers.'

Union Calendar No. 97

106th CONGRESS

1st Session

H. R. 457

[Report No. 106-174]

A BILL

To amend title 5, United States Code, to increase the amount of leave time available to a Federal employee in any year in connection with serving as an organ donor, and for other purposes.

June 8, 1999

Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

END



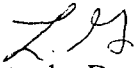
DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

SEP 15 1999

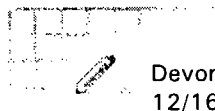
NOTE TO DEVORAH ADLER

From: Lisa A. Gilmore 
Special Assistant to the Deputy Secretary

Subject: Possible organ allocation hearing on September 22, 1999

This note is to inform you that we received information today that the Health and Environment Subcommittee of the Commerce Committee, chaired by Representative Bilirakis, is planning to hold a hearing on September 22 on the Bliley-Bilirakis bill to reauthorize the National Organ Transplant Act (NOTA). The draft bill contains a number of provisions that run counter to HHS' final OPTN rule. We don't have confirmation on the hearing or know what time of day it would be held. Depending on the final schedule, you may want to consider having an organ donation event either the day before or the day after the hearing. A number of members of the transplant community are likely to attend the hearing.

cc: Sarah Bianchi, Office of the Vice President
Elizabeth Summy, HHS Deputy Chief of Staff



Devorah R. Adler
12/16/98 10:58:46 AM

Record Type: Record

To: Devorah R. Adler/OPD/EOP

cc:

Subject: organs

final HCFA reg requiring hospitals to report all deaths to the organ procurement organizations; still getting data on increase in organs donations; huge increase \$10 million in 1999 funds -- new initiative with new money --- competitive program to increase organ donation and request different projects; report to Congress to be released on 12/21 that outlines for plan for organ procurement activities (but it's only 3 pages)

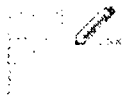
trying to get preliminary data to give a sense in increase (20% increase but that may be too high)

(national donor day (reauthorization of marrow act -- minority donors)

AHA new partner in national tissue organ initiative.

Write family
of give organ
donor

12/12/98 02:03:53 PM



Ann F. Lewis
12/12/98 02:03:53 PM

Record Type: Record

To: Elena Kagan/OPD/EOP, Christopher C. Jennings/OPD/EOP

cc:

Subject: Organ donations

The President expressed an interest in a radio address about organ donations --based on recommendation frm a friend. Its a good ida --is there a polcy or progress achievement we could use as a hook ? (No jokes about the OCngress, please)



NATIONAL DONOR DAY

December 2, 1998

Ms. Sue Greenberg
Office of the Vice President

Dear Ms. Greenberg,

I appreciated the opportunity of speaking with you on Monday, and per your direction, I want to clarify some issues surrounding National Donor Day and our request that the Vice President and/or Mrs. Gore serve as spokespersons.

National Donor Day is a partnership of America's leading health organizations concerned with life saving donation. The United Auto Workers and Saturn are the host of the event. The program was created last year by the United Auto Workers - Saturn Union Partnership Initiative, a program jointly administered by both union and management employees of Saturn. The central goal of the Union Partnership Initiative is to reach America's 17 million union members with the message that Saturn is union-made and American-made, and it is the result of a unique partnership between union and labor launched in Spring Hill, Tennessee, nine years ago. The Union Partnership Initiative works with numerous unions and labor councils on community action programs around America. For example, in Michigan, we raised funds for construction of Camp Fish Tales, one of only two summer camps in America for severely handicapped persons. We also work with both the National Education Association and the American Federation of Teachers on a Partnership Award program -- a program that recognizes school districts and their unions who work together in partnership (not as adversaries) in pursuit of quality in public education. Just two weeks ago we hosted 42 educators -- 1998 Partnership Award Winners -- for a three day visit to the Saturn Plant in Spring Hill and seminar discussions about partnership.

With regard to National Donor Day, UAW - Saturn has served as a catalyst to create an ecumenical effort among organizations who share a common message of donation but who, prior to 1998, had never worked together. In addition to last year's organizations (American Red Cross, American Association of Blood Banks, Coalition on Donation, National Marrow Donor Program, National Minority Organ and Tissue Education Program, Transplants Recipients International Organization and the U.S. Department of Health and Human Services), in 1999 we are pleased to welcome the National Kidney Foundation, American Association of Blood Banks, Rotary International District 6760 (Tennessee) and The Marrow Foundation. Donor Day is their event, we are the host.

Is National Donor Day a commercial event? After last year's effort we surveyed nearly 400 participating Saturn retailers and they said (true to its design) it did *not* sell cars, nor did it drive in "qualified prospects" over and beyond a usual Saturday's attendance. Saturn retailers did rate it as the best *community event* ever done by Saturn, and over ninety percent of the retailers wanted to do it again in 1999 -- the other ten percent are more than willing to join the effort with changes, most logistical in nature. Most sites had blood collection by a local blood bank and in many instances, vehicles were removed from the showroom to accommodate blood collection. Approximately 8,000 units of blood were drawn! Attesting to the non-commercial nature of the event, nearly all exposure was due to public relations coverage by print and radio media. There was no national or regional advertising budget. In some communities the results were very strong. Saturn of San Antonio raised 107 units of blood in only five hours -- Saturn of Staten Island 72 units. The blood banks tell us that these (and many other retailer results) are phenomenal! Almost all were achieved by working with community groups, and gaining non-paid media coverage. Over sixty percent of all locations had in attendance one or more transplant recipients. National Donor Day is envisioned as a "celebration of life" by those saved by donation.

In requesting the Vice President and Mrs. Gore's participation as spokespersons for National Donor Day 1999, we saw it as a logical extension of last year's event where at the Vice President's volition, National Donor Day leadership was invited to the West Wing of the White House for a photo opportunity. The Vice President's support parallels that of Tennessee Senator Frist (a transplant surgeon) who spoke at our press event, Deputy Surgeon General Kenneth Moritsugu (a donor spouse and parent) who spoke both at our press event and at the Saturn national meeting (by video), and the Bill and Beverly Young Fund of The Marrow Foundation which is providing a minimum of \$25,000 to offset the cost of marrow typing in next February's National Donor Day. Congressman Young and his wife are parents of an adult marrow transplant recipient.

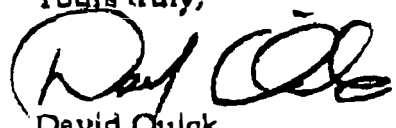
National Donor Day has also received community service awards at the annual meetings of America's Blood Centers, Transplant Recipients International Organization and the American Association of Blood Banks. Its relevance is heightened by the recent Marrow Reauthorization Act of 1998.

It has been suggested by our partners that we propose to the Vice President and Mrs. Gore different, progressive levels of involvement:

- Level One:
 - Message on Vice Presidential Letterhead for distribution at 400 National Day Events
 - Quote for Donor Day national press release
 - Photo op at the White House for 1999 event (February 11)
- Level Two:
 - Radio PSA by the Vice President and/or Mrs. Gore
 - Attend press conference (February 11 in Washington DC)
- Level Three
 - Available for a limited number of press interviews
 - Attendance at an actual Donor Day event (February 13)
 - Other TBD

Thank you for the opportunity to elaborate upon our September 21, 1998, request to you. We are amply aware of the Vice President's and Mrs. Gore's commitment to donation and hope that they can respond in a timely and positive manner to our request.

Yours truly,



David Quick
Team Leader
UAW - Saturn Union Partnership Initiative
800 738-1817

P.S. *"Dear Saturn, My life had only about four hours to run when I received the gift of life nearly a year ago. I know that your program will help others..."*
Visitor to www.saturn.com

HHS NEWS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

FOR IMMEDIATE RELEASE
Wednesday, June 17, 1998

Contact: HCFA Press Office
(202) 690-6145

HHS ANNOUNCES NEW HOSPITAL RULES TO INCREASE ORGAN DONATION

HHS Secretary Donna E. Shalala today announced new regulations aimed at saving lives by substantially increasing organ donation in the United States.

Under the final rule, U.S. hospitals will be required to notify an organ procurement organization (OPO) of all deaths that occur in the hospital. The new requirement will ensure that OPOs have the opportunity to determine the suitability of every potential organ donor, thus increasing the opportunities to contact families and request organ donation. HHS estimates that the new provisions can increase donation by 20 percent over the next two years.

"Organ donation saves lives. But in too many cases today, we are missing opportunities to save people simply because families are never contacted and donation is never even considered as an option," Secretary Shalala said.

"I want our organ procurement organizations to do a better job of making more organs available to save more lives," she said. "The first step is to assure that OPOs are informed of all deaths in hospitals. Then they can determine in each case whether there is the potential for organ donation and, using appropriate discretion and sensitivity, approach the subject of donation with the families."

The regulation, affecting all 5,200 short-stay hospitals in the country, becomes a condition for participation in the Medicare program. The new final rule is the latest step in the National Organ and Tissue Donation Initiative, launched by Vice President Gore last December.

An estimated 12,000 to 15,000 deaths each year could result in organ donation. However, in 1997 only 5,475 deaths resulted in donation. One 1996 study indicated that, out of all deaths that could result in donation, families agreed to donation in 32 percent of cases, and families denied consent in 37 percent of cases. But in 27 percent of cases, representing some 3,000 to 4,000 deaths, either potential donors were not identified or no request was made to the family. (Another 5 percent ultimately proved medically unsuitable.)

At the same time, the number of Americans who die each year waiting for an organ transplant is about 4,000.

- More -

"In the absence of the requirement we are making today, we have been missing thousands of opportunities for donation each year," Secretary Shalala said. "With better identification of potential donors, we can substantially reduce the number of deaths among those awaiting a transplant."

Under the rule, hospitals will refer 2.1 million hospital deaths annually to the nation's 63 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 will also 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.

"By requiring hospitals to report all deaths and imminent deaths to OPOs, we hope to increase the supply of organs and thus reduce the number of people on waiting lists for organ transplants," said Nancy-Ann DeParle, administrator of the Health Care Financing Administration, the HHS agency that oversees Medicare. OPOs in states that have passed similar laws have seen an increase of up to 40 percent in organ donation.

Consent for organ donation is requested even in cases where the individual has signed an organ donor card. The card provides an indication of the individual's wish, but consent by survivors is still needed. "That's why it's so important to not only sign the organ donor card, but also to tell your family your wishes," Secretary Shalala said.

In working directly with families, hospitals and OPOs must demonstrate discretion and sensitivity with respect to the circumstances, views and beliefs of the families of potential donors. To this end, 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 identified correctly.

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

December 18, 1998



Lisa Gilmore
Special Assistant to the Deputy Secretary
Department of Health and Human Services
200 Independence, SW — Room 606G
Washington, DC 20201

Dear Lisa:

The nation's hospitals strongly support the goal of increasing organ donations. Organ donation is an issue that requires great sensitivity and is extremely personal, so it's very important that efforts to encourage donation recognize the sensitive nature of this issue.

That's why the American Hospital Association supports the Health Care Financing Administration's decision to give hospitals a year to work with their organ procurement organizations (OPO) on systems and policies that can help them comply with newly issued organ procurement rules designed to increase donations. The new rules, part of the standards hospitals must meet to participate in the Medicare program, are designed to identify more potential organ donors, and require hospitals to report all deaths and imminent deaths to OPOs.

To help our members make a smooth transition to these new rules, the AHA is working with our state hospital associations to disseminate guidelines on these new requirements. I've attached a copy of the guidelines for your information. I've also enclosed some information, prepared with HCFA's help, to aid our members in deciphering the new requirements; our members can access this important information on AHA's Web site (www.aha.org).

Hope this is helpful. If you need anything further, please call me at (202) 626-2339.

Sincerely,

Alicia Mitchell
Assistant Director, Media Relations



Washington, DC Center for Government and Public Affairs
Chicago, Illinois Center for Health Care Leadership

Liberty Place, Suite 700
325 Seventh Street, N.W.
Washington, DC 20004-2802
(202) 638-1100



THE HOSPITAL & HEALTHSYSTEM ASSOCIATION OF PENNSYLVANIA

Dear State Hospital Association Executive:

Organ transplants save countless lives, and hospitals and health systems are vital to making certain they do. Our field is about to be challenged to do even more in this important area. The Health Care Financing Administration (HCFA) published the Medicare and Medicaid conditions of participation for hospitals pertaining to organ procurement, effective August 21, 1998. The new provision requires hospitals to notify organ and tissue banks of each death or imminent death in the hospital.

Heeding the concerns of the AHA and the Association of Organ Procurement Organizations, HCFA is delaying the enforcement of its rule for one year. In general, the AHA believes hospitals and organ procurement organizations need additional time to establish a smooth and collaborative notification process to comply with the law. In an effort to assist all of our members in meeting the new challenges, we want you to know about the very successful work under way in Pennsylvania.

Pennsylvania, recognizing the disparity between organ and tissue supply and demand, was the first state to enact a law requiring the routine referral of all deaths and impending deaths to the regional organ procurement organization. The 1994 law, after which the federal law is modeled, resulted in a 40 percent increase in organ donations in the first three years its enactment.

Because Pennsylvania has had time and experience in developing effective processes to comply with the routine referral law, the AHA is sending you a copy of the third edition of The Hospital & Healthsystem Association of Pennsylvania manual, *Guidelines for Hospitals on Organ and Tissue Donation*, for your use in developing guidelines for your membership. We are also including much of the information in the guidelines on a diskette to help you make the appropriate modifications for your state.

The "Process Model" for organ and tissue donation on page one guides the user step-by-step through the donation process from the hospital's perspective. Each numbered box in the process model also has a corresponding "Points to Remember" page with important information for hospital staff. According to Pennsylvania providers, donation will be neither an administrative nor a financial burden for hospitals if an effective system is developed and procurement organization staffs are used appropriately.

While HCFA's enforcement delay has given hospitals and health systems a little breathing room, we must continue to work with local organ procurement organizations to ensure a smooth and timely implementation. We hope the enclosed guidelines will "jump start" the process for you and your members. If you have questions on the enclosed materials, contact Cheri Kroboth Rinehart, vice president, integrated delivery systems, The Hospital & Healthsystem Association of Pennsylvania at (717) 561-5325 or by e-mail at crinehart@hap2000.org.

As Pennsylvania mentions in the introduction to its guidelines, "participation by all hospitals in the donation process can go a long way toward reducing the gap between supply and demand. Each hospital may not be able to participate equally, but each hospital's participation is equally important: One individual who donates all of the organs and tissues he can possibly donate can help up to 150 people." One of our great strengths is the union between the national and state associations. This is a perfect way to demonstrate that cooperation to our members, and show we are working together to better serve them.

Sincerely,



Dick Davidson
President
American Hospital Association

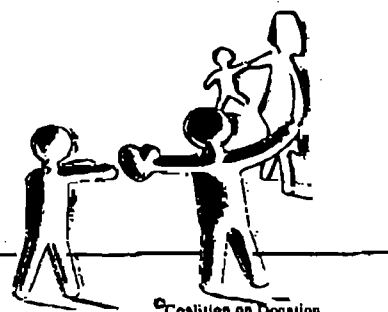


Carolyn Scanlan
President/CEO
The Hospital and Health Systems
Association of Pennsylvania

National Organ and Tissue Donation Initiative



U.S. Department of Health and Human Services



June 17, 1998

National Initiative Fact Sheet

Overview: While medical advances now enable more than 20,000 Americans per year to receive organ transplants that save or enhance their lives, not enough organs are available to help everyone in need. As a result, about 4,000 people die in the U.S. each year -- about ten every day -- while waiting for a donated kidney, liver, heart, lung, or other organ. Today, more than 55,000 people are on the national organ transplant waiting list.

In recent years, progress has been made in creating awareness of the need for organ and tissue donation. Most Americans indicate they support organ donation. Nonetheless, only about 50 percent of families asked to donate a loved one's organs agree to do so. Moreover, thousands of opportunities to donate are missed each year, either because families do not know what their loved ones wanted, or because potential donors are not identified for organ procurement organizations and their families are never asked.

The Clinton Administration's new National Organ and Tissue Donation Initiative will build on more than a decade of experience gained from government, private and volunteer efforts. Focusing on known barriers to donation, it will take action to achieve substantial increases in donation and transplantation, by:

- Creating a broad national partnership of public, private and volunteer organizations to encourage Americans to agree to organ and tissue donation. The partnership will emphasize the need to share personal decisions on organ donation with one's family.
- Working with health care providers, consumers and physicians to ensure that deaths are reported to organ procurement organizations whenever there is a potential for donation.
- Learning more about what works to bring about donation, through research and evaluation, including an HHS conference on best practices next spring.

HHS estimates that the number of organ donors nationwide could increase by 20 percent within two years. These increases would substantially reduce the number of deaths among those waiting for organ transplants.

- 2 -

A New National Initiative for Donation

PROBLEM – The Barriers to Donation: The major barrier to donation today is low rates of family consent to donation, at the time the family is asked. At present, when families are asked to agree to donation, only about half give consent. Too often, it's because the family does not know the individual's wish. The latest national Gallup study indicates that nearly all Americans would consent to donation if they knew that their loved one had requested it – but only half as many would consent if they did not know. Unfortunately, only about half of Americans who want to donate have told their families.

In addition, some families are unnecessarily denied the opportunity to donate when deaths that could result in organ donation are not identified and reported to organ procurement organizations (OPOs).

GOAL #1 – Increase Consent to Donation: To increase families' willingness to consent to donation, the National Initiative will bring together public and private sector partners to encourage all Americans to make a personal decision about donation and to share that decision with their families. Working together, we can reach millions more Americans with consistent, credible, tested messages that work.

GOAL #2 – Ensure that Families are Asked: The new initiative aims at increasing identification of deaths that could result in donation, and ensuring referral to organ procurement organizations (OPOs). HHS has revised its conditions of participation for all 5,200 short-stay hospitals in the United States so that hospitals and OPOs will work collaboratively to identify potential donors and approach families. Under a final rule to be published in June 1998 in the *Federal Register*, U.S. hospitals will be required to notify an OPO of all deaths in the hospital. The new requirement will assure that OPOs have the opportunity to determine the suitability of every potential organ donor, thus increasing the opportunities to contact families and request organ donation. HHS estimates that the new provisions can increase donation by 20 percent over the next two years.

HHS worked with hospitals, OPOs, tissue banks, physicians, patient groups and others to develop the final rule. This rule was suggested by approaches that have been successful in other areas. For example, studies in southeastern Pennsylvania have found substantial increases since a 1994 law took effect.

GOAL #3 – Focus Research and Increase Knowledge: Another challenge is to learn more about what works, both to increase donation and to improve transplantation outcomes. A systematic approach is needed for planning and evaluation projects.

Three Elements of the National Initiative

Building Partnerships and Increasing Family Discussion

The essential role of families in consenting to donation is a key message of the initiative. Even when a donor card, driver's license, will, or living will is available to indicate the donor's wishes, next-of-kin will be asked to provide consent before donation can occur. 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. Materials developed for partners of the initiative feature the Coalition's message, "Organ and Tissue Donation: Share your life. Share your decision.SM "

National advertising and public awareness campaigns help to communicate consistent messages about organ and tissue donation, but individuals and families also need to learn about the importance of donation from people and organizations they trust. HHS is building strong partnerships with health care, community, educational, religious, minority, professional, and other organizations to ensure that Americans are given the opportunity to choose donation. To support these efforts, HHS has launched a new Web site at <http://www.organdonor.gov> to provide up-to-date information on organ and tissue donation and transplantation, helpful materials, upcoming events, and links to related resources on the Internet.

Partners with HHS in the National Organ and Tissue Donation Initiative are:

- **Health Care Community:** The **American Medical Association** and the **American Academy of Family Physicians** are partnering with HHS to encourage physicians to make donation materials available in their offices and to discuss donation with patients. Already, one state medical society (the Texas Medical Association) is taking on organ donation as one of its major issues. Physicians in Texas will be encouraged to offer educational materials in their offices and to express support for organ donation to patients who ask. The **American Red Cross** will, through its nationwide community network, expand upon its current public awareness and education activities to increase organ and tissue donation. The **American Nurses Association** will educate its members and provide materials. The **American Association of Health Plans** will encourage plans to provide members with educational materials. The **National Medical Association** will help educate minority medical professionals, especially through HHS' MOTTEP program (see below.) The **American Association of Neurological Surgeons** and the **Congress of Neurological Surgeons** are also partners in the initiative.
- **Law Associations:** The **American Bar Association** is partnering with HHS to encourage attorneys to discuss donation with their clients during estate planning. The ABA's Real Property, Probate, and Trust Section will distribute materials, stimulate continuing legal education programs, and encourage state and local bar associations to adopt resolutions similar to the ABA's 1992 resolution that urges attorneys to get involved in donor education efforts.

- **Educational Organizations:** The Center for Study of the Freshman Experience and Students in Transition is teaming up with HHS to provide donor information to new college and university students in orientation packets and programs. In addition, HHS' Health Resources and Services Administration (HRSA) is funding a demonstration project with the American College Health Association, a national organization with more than 900 member institutions, to implement and test the effectiveness of college campus campaigns to increase donation. The project is modeled after a successful HRSA-sponsored pilot project at the University of Rhode Island. Finally, under a HRSA grant, TransWeb University has developed a new interactive electronic program to educate school-age children about organ donation and transplantation available at the Web site <http://www.transweb.org/journey>.
- **Religious Organizations:** The Congress of National Black Churches, representing 65,000 congregations, is partnering with HHS in a national project to educate its members about organ, tissue, and bone marrow donation. The Union of American Hebrew Congregations, with support from HRSA, developed a program guide on organ donation and transplantation which it distributed to its 850 member congregations. In addition, the Presbyterian Church USA, the General Conference of the Seventh-Day Adventist Church, the Interfaith Conference of Metropolitan Washington, and other faith organizations were asked by HHS to urge congregations across the nation to consider donation during the second annual National Donor Sabbath, November 14-16. To promote local participation, HRSA has provided copies of its new *National Donor Sabbath Resource Kit* to these organizations and to a network of non-profit and voluntary organizations in every state. A third National Donor Sabbath is planned for November, 1998.
- **Donor and Recipient Groups:** The National Kidney Foundation's Donor Family Council and HHS have teamed up to create a new Web site at <http://www.kidney.org/donor> to provide information and bereavement support for donor families. In addition, HRSA, the Donor Family Council, and other national donor, recipient, and transplant organizations are sponsoring the fifth annual donor recognition ceremony in August 1998 at the National Kidney Foundation's Transplant Games in Columbus, Ohio.
- **Business Organizations:** The U.S. Chamber of Commerce and the Washington Business Group on Health, representing many large and small businesses and organizations, will help their members conduct employee organ and tissue donation education campaigns. The Home Depot will also conduct educational activities for employees.
- **State Organizations:** HHS is working 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 disseminate information about model programs and legislation and to encourage state activities to increase donation.
- **Media:** The James Redford Institute for Transplant Awareness will reach out to national media organizations, especially using its films to build public awareness of the need for organ donation.

In addition, with assistance from the **Office of Personnel Management**, HHS is collaborating with other federal agencies to encourage federal employees to become donors, to share their decision with family members, and to serve as a model for the nation. For example, the **Department of Defense**, which has taken a progressive approach by routinely asking patients in its health care system to consider donation, is stepping up its efforts to encourage donation by making materials available in its treatment facilities and by improving the education of its providers on effective communication with patients and their families. In addition, the Office of Personnel Management included a full-page ad on donation in this year's *Guide to Federal Employees Health Benefits Plans* which was distributed to all federal employees. HHS is providing brochures, posters, and other materials to Federal agencies to share with their employees.

Expanding Opportunities for Families to Donate

HHS' Health Care Financing Administration (HCFA) has revised its conditions of participation for Medicare hospitals to ensure that they report all potential donors to their OPOs. Under the rule, hospitals will refer 2.1 million hospital deaths annually to the nation's 63 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 will also 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.

In working directly with families, hospitals and OPOs must demonstrate discretion and sensitivity with respect to the circumstances, views and beliefs of the families of potential donors. To this end, 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 identified correctly.

HCFA will also 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) and the American Congress of Organ Recovery and Donation (ACORD) 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

This initiative will be successful if it leads to significant increases in donation and transplantation, with fewer deaths among patients on the transplant waiting list. Working with OPOs, HHS will track changes in hospital referrals and consent rates. In addition, HHS will identify needed research on organ and tissue transplantation, barriers to donation, and activities to increase donation. The results of this research will be used to replicate activities which increase donation and practices that improve transplantation.

HHS agencies including HRSA, the National Institutes of Health, and the Health Care Financing Administration will conduct activities to identify the best approaches to increasing donation and priorities for future research, including a **National Research Conference on Organ and Tissue Donation** in spring, 1998.

The **National Minority Organ/Tissue Transplant Education Program (MOTTEP)**, a collaborative effort between NIH's Office of Research on Minority Health and the National Institute of Diabetes and Digestive and Kidney Diseases, is the first national program specifically designed to empower minority communities to become involved in education activities to increase the number of minority donors and transplant recipients. More minority organ donors are needed to increase the chances that a well-matched organ will be available to minorities waiting for transplants. Now in 15 sites across the country, MOTTEP's target audience represents the African American, Hispanic/Latino, Native American, Asian, Pacific Islander, and Alaskan Native populations. MOTTEP also includes a health promotion and disease prevention component, to reduce the incidence of conditions such as diabetes and hypertension that can lead to organ failure.

Finally, The **Department of Transportation's National Highway Traffic Safety Administration** is partnering with HHS to research the best approaches to encouraging donation and to communicate those findings to motor vehicle administrators, law enforcement officials, and emergency medical services personnel.

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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:

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Wash. Post; 12-17-98

Transplant Teenager Revels in Being Home

14-Year-Old Feels Like 'Million Bucks'

By AVRAM GOLDSTEIN
Washington Post Staff Writer

After a nine-month ordeal that sparked a national debate about how to allocate scarce donor organs, the Wheaton teenager who underwent multi-organ transplants a record-setting three times has come home.

Leaving behind the hospital routines, the long periods of sedation and the daily doses of up to 25 different drugs, 14-year-old Daniel Canal is down to seven medications and chattering away. Yesterday he climbed into his go-cart and wheeled around his neighborhood.

"My energy is considerably up," he said. "I feel great, like a million bucks—maybe a little more."

He marvels at being with his family for dinner, television time and computer games, and he is delighted to be sleeping in his own bed again.

Daniel is still working on walking long distances and will rely on a wheelchair until his stamina returns and the pain leaves his feet and ankles.

Daniel has four new organs: stomach, small intestine, pancreas and liver.

It took three attempts by Miami surgeons between May 15 and June 20 before he had a chance to survive. Two weeks after the first operation, Daniel's body violently rejected all four organs. Doctors tried again June 2, but that time the liver never functioned properly. The final surgery was successful.

Without fanfare Saturday, he and his mother, Lori, piled into her car at the Pittsburgh hospital where he had been recovering and made the drive to Maryland.

"All he kept saying was, 'Wooo, we're going home!' for four hours," she said. "It felt so bizarre to be going home to stay."

On Tuesday, they showed up unannounced at his old school, Eastern Middle, and then dropped



Daniel Canal is surrounded by his sister, Rebecca, his father, Victor, and his mother, Lori, at their home in Wheaton. Below, Daniel drives a go-cart. He says his energy is up; his doctor says he is moving faster than had been hoped.



by Montgomery Blair High School, where he expects to enroll as a freshman in the fall and where many of his old classmates attend school.

Lori Canal said their arrival at Blair interrupted meetings and classes, as staff members cried and some students seemed stunned.

"These kids could not believe it—they said, 'Danny's back!'" she said.

"They were shocked," Daniel said. "It was good to see familiar faces again."

After years of waiting for new organs, Daniel's condition became desperate in February, and he gained national attention by appearing at a Washington rally urging reform of the system used to allocate donor organs. In April, he moved to Pittsburgh to be closer to the large transplant program there, and he was called to Miami for the first operation on May 15.

Daniel remained in Jackson Children's Hospital for more than five months before returning to Pittsburgh to complete his recovery.

ery closer to his family.

Last week, a biopsy result was good and all his other vital signs were fine, Daniel said.

"He is moving faster than we ever hoped," said Andreas Tsakis, the University of Miami transplant surgeon who operated on Daniel despite criticism that the multiple operations were devoting too many donor organs to one person.

The main reason for organ shortage is the lack of public awareness and the suspicion of the public toward the way transplants are conducted," Tsakis said. "I think Danny with his example helped a lot of people understand how critical the organ shortage is. Rather than depriving anybody of organs ... through public education, he helped a lot of people he doesn't even know."

During his stay in Miami, Daniel's mother remained with him. For much of the time, his father, Victor, came home to his job at Walter Reed Army Medical Center, and Daniel's sister, Rebecca, stayed with relatives in California.

Yesterday they were back under one roof, just in time for the holidays.

"We're probably going to spend a quiet Christmas by ourselves," Daniel said. "Presenta don't really matter. Just being together is what counts. We've missed so much in the past few months, we can have Christmas till March."

OTHER NATIONAL INITIATIVE ACCOMPLISHMENTS

In the year since we launched this effort, over a dozen major health care, community, educational, religious, minority, professional, and government organizations have agreed to join HHS and the transplant community in efforts to increase the public's willingness to donate. Through their members, these partners reach Americans where they live, work, play, and worship. For the National Initiative, HHS has engaged in a number of activities. For example:

- o We teamed up with the Coalition on Donation to use its national "Share your life. Share your decision" message and to establish a toll-free number for a free brochure in English or Spanish at **1-888-90-SHARE** (1-888-907-4273). In addition, we created a new web site at **www.organdonor.gov** with information for both the public and professionals.
- o We convened a "**best practices**" conference held on April 1 and 2 in Arlington, Virginia to identify strategies that work in increasing donation and effective evaluation protocols for such interventions. We received more than 80 abstracts and heard 15 presentations on a wide variety of approaches to increasing donation, including strategies for reaching specific minority populations. The conference proceedings have been published.
- o We partnered with the U.S. Office of Personnel Management to launch a **Federal employee education campaign** and provided a package of materials to about 100 Federal agencies, including a **memorandum from Vice President Gore** and a video made for Federal employees. A number of federal agencies are placing donation messages on employee pay stubs and including donation information in newsletters, presentations, and health fairs.
- o We worked with the producers of the movie *Nicholas' Gift* and CBS to tape a ten-second **PSA with Vice President and Mrs. Gore** which aired on April 26 directly after the movie. The network estimates that the message reached up to 31 million viewers.
- o We worked with minority-based organizations to improve outreach to minority communities. Partners include the National Minority Organ and Tissue Transplant Education Program, the American Society of Minority Health and Transplant Professionals, the National Medical Association, and the United Network for Organ Sharing's Minority Affairs Committee.
 - We joined the Congress of National Black Churches, which represents 65,000 churches with over 20 million members, in convening a leadership meeting on May 12 and 13 in Washington, D.C. to build bridges between African-American clergy and the transplantation community in support of organ, tissue, and marrow donation. Over 200 people from across the United States participated, including representatives from many of the National Initiative's partner organizations.
 - We published articles on minority donation and transplantation in the *Journal for Minority Medical Students*, the HHS Office of Minority Health's *Closing the Gap* newsletter, and other minority publications.
- o We established a web site specifically for donor families, transplant recipients, and bereavement and transplant professionals in partnership with the National Donor Family Council of the National Kidney Foundation.



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

AUG 30 1999

MEMORANDUM

To: Devorah Adler
Domestic Policy Council

From: Lisa A. Gilmore *L. A. Gilmore*
Special Assistant to the Deputy Secretary

Subject: Update on the National Organ and Tissue Donation Initiative

In anticipation of a potential organ donation event, the attached pages describe the status of the National Organ and Tissue Donation Initiative and its progress on reaching the goal of a 20 percent increase in organ donation within two years of publication of the final hospital conditions of participation (COPs) regulation (published on June 22, 1998, effective as of August 21, 1998). If an organ donation event is scheduled for early in the week of September 20, it could include an announcement of the approximately 15 new awardees of HHS' \$5 million extramural support program to increase organ and tissue donation.

If you have any questions or require further information, please contact me at 202-690-6133 or at lgilmore@os.dhhs.gov. We are excited about the prospect of an event to highlight the administration's progress on this initiative. I look forward to discussing this opportunity with you soon.

Thank you.

Attachment

THE NATIONAL ORGAN AND TISSUE DONATION INITIATIVE

Update as of August 30, 1999

KEY POINTS

1. **Preliminary data for 1999 show cadaveric organ donation and transplantation on a par with 1998 while referrals of potential organ donors are up substantially following the launch of the Clinton administration's donation initiative in 1997, as well as new regulations implemented last year which require hospitals to report all deaths to organ procurement organizations (OPOs) (see page 3 for details on new data).**

Message: "More Americans are hearing about the need for organ donation, and more are responding with the gift of life. But we need to accelerate this trend. Organ donation saves lives, but the need for organs is still far greater than the supply. Too many patients still die while waiting for a transplant." – HHS Secretary Donna E. Shalala, April 16, 1999

2. **HHS is awarding about \$5 million in new grants in FY 1999 to fund projects for up to three years to implement and evaluate initiatives to increase donation (see page 3).**

Message: "In order to achieve new, significant increases, we must not only expand our outreach as we've already done – we must also increase the rate at which families and others consent to donation when asked. This new effort is aimed especially at learning what works best to increase consent rates." – HHS Deputy Secretary Kevin Thurm, May 24, 1999

3. **HHS will soon provide a new resource guide to all Medicare hospitals and organ procurement organizations (OPOs) in the nation to help them work together to support bereaved families facing the option of donation (see page 4).**

Under the provisions of HHS' revised COPs, potential donor families must be advised of their right to donate or not to donate, but hospitals may designate who approaches the family, specifically OPO staff and/or hospital staff who have received appropriate training. Persons who offer the option of donation should be able to comfort the family while helping them understand all of their options in the end-of-life decision-making process. HHS' new *Roles and Training for the Donation Process: A Resource Guide* will serve as a road map to help hospitals and OPOs develop the best training and collaborative approaches for working with bereaved families facing the option to donate and other end-of-life decisions.

ADDITIONAL ACTIVITIES

Upcoming Activities

- **The Organ Donor Leave Act** to extend the amount of leave in each calendar year available to federal employees who serve as living organ donors from 7 days to 30 days passed the House on July 27 and was introduced in the Senate on July 1. Leave for bone marrow donors would remain at 7 days. HHS and OPM began encouraging this legislative change in the fall of 1997 to more realistically reflect the time it takes to recover from organ donation surgery and to set an example for private-sector employers. We do not speculate that providing more leave time to federal employees would make them more likely to donate organs.

- HHS' Health Care Financing Administration (HCFA) and Health Resources and Services Administration (HRSA) will co-sponsor a **"lessons learned" conference** this fall to enable hospitals, OPOs, and others to share information about innovative approaches to implementation of the COPs, including effective referral, consent, education, and monitoring practices and the use of the resource guide, *Roles and Training for the Donation Process*.
- HHS will publish a **conference report on donor registries**, on both their current state and their potential for increasing consent for organ and tissue donation by identifying donors' commitments and communicating those commitments to the potential donor's family. The report will be completed within the next four months. The final report will include information on state actions regarding donor registries and an analysis of barriers and solutions based on the presentations at a two-day donor registry workshop (see below).
- For this year's fourth annual **National Donor Sabbath (NDS)** weekend, celebrated from November 12 to 14, HHS will give OPOs a total of more than 300,000 green ribbon pins/donor cards to facilitate their partnerships with local faith organizations. With the support of major faith and interfaith organizations, thousands of local congregations participate in NDS events each year to raise awareness of the need for organ/tissue donation.

Recent Activities

- Through an existing grant with the National Institutes of Health, the Louisiana Organ Procurement Agency and HHS co-sponsored a **donor registry workshop** on July 27-28, 1999 in New Orleans titled, "Are Donor Registries Advanced Directives? Developing, Modifying, Linking, and Supporting Statewide Donor Registries."
- HCFA and HRSA co-sponsored a **workshop on roles and training for the donation process** on June 28-29, 1999 in Baltimore for input into the resource guide (see page 4).
- HHS co-sponsored the August 1 **National Minority Donor Awareness Day**, an initiative of America's Blood Centers Foundation, The Marrow Foundation, the National Marrow Donor Program®, and the National Minority Organ and Tissue Transplant Education Program, with events in 22 cities to raise awareness of the need for blood, marrow, and organ donation.
- HHS Secretary Shalala and Deputy Secretary Thurm **hosted hundreds of young transplant recipients** and their families for lunch at HHS for the American Society of Transplantation's First Family Pledge Congress on April 14 with footage of the event included in HHS' **video news release** for National Organ and Tissue Donor Awareness Week, April 18-24.
- HHS **funded research on why families consent, or refuse to consent**, to the donation of organs of a loved one. 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. (National Initiative Fact Sheet, May 19, 1999)

BACKGROUND

New Data

Early estimates for the first half of 1999 show that organ donation is keeping pace with the higher rate of donation in 1998. Preliminary data not yet released by HHS and the United Network for Organ Sharing (UNOS) show that from January to June 1999, the number of cadaveric donors from whom at least one organ was recovered for the purpose of transplantation remained on a par with the same period in 1998, up just 0.1 percent to 2,856 donors in 1999 from 2,854 donors in 1998. Similarly, the number of cadaveric organs transplanted was little changed, down only 0.6 percent to 8,225 transplants in the first six months of 1999 versus 8272 transplants over the same period in 1998. Previously released UNOS data show for all of 1998, the number of cadaveric organ donors increased by 5.8 percent, the first substantial increase since 1995, rising from 5,478 donors in 1997 to 5,798 donors in 1998.

While organ donation has held steady, many more potential donors are being identified and more families have received the opportunity to donate following the launch of the administration's donation initiative in 1997, as well as the COPs' provisions implemented last year. According to provisional data compiled by the Association of Organ Procurement Organizations (AOPO) from all of the nation's OPOs, referrals of potential organ donors¹ nationally jumped by 21 percent (20.9 percent) during the first half of 1999 compared with the same period in 1998, an increase of more than 2,400 referrals. AOPO states, "this development undoubtedly reflects the immediate impact of the HCFA regulations published last fall mandating that hospitals notify OPOs in a timely manner about every hospital death or imminent deaths."

Initial indications are that the COPs are having a positive impact on tissue donation as well. Data collected from tissue banks by the Musculoskeletal Transplant Foundation suggests that tissue donation among its members has increased substantially since the new provisions took effect, up 60 percent from September 1998 through June 1999 compared with the same period a year earlier. Moreover, in a recent survey of American Association of Tissue Bank members, more than two-thirds rated the overall impact of the COPs on tissue donation as positive. More than half (56 percent) registered an immediate increase in tissue donors in the second half of 1998 when the provisions became effective compared with the first half of 1998.

New Grant Program Awardees

By mid- to late-September, HHS will award funding to approximately 15 projects through its new grant program titled, "Extramural Support Program: Model Interventions to Increase Organ and Tissue Donation." HHS Deputy Secretary Kevin Thurm launched the program at the annual meeting of the American Society of Transplantation and the American Society of Transplant Surgeons in Chicago this past May.

HRSA Administrator Claude Earl Fox, M.D., M.P.H. stated, "With more than 63,000 patients waiting for a donated organ, we need to find out what works best to increase organ donations and break down barriers to consent. We're asking organizations to collaborate on model programs with good evaluation protocols so they can be replicated across the country."

¹ AOPO's definition of potential organ donor referrals is as follows: "Referrals from hospitals serviced by your OPO, considered to have potential for organ donation (i.e., on a ventilator and brain death is present or imminent). DO NOT INCLUDE TISSUE DONOR ONLY REFERRALS."

The extramural program will support projects for up to three years to implement and evaluate initiatives to increase organ and tissue donation. Pilot projects will test the effectiveness of promising new "interventions," while replication projects will focus on implementing and testing at expanded or multiple sites those interventions already shown to be effective in more limited trials. All projects must include rigorous evaluation mechanisms. Performance measures are expected to address one or more of the following outcomes: (1) organ procurement, (2) consent rates for organ donation and/or, (3) declaration of intent to donate coupled with family notification of intent to become an organ donor. To look at ways to expand and diversify the donor pool to better meet the needs of those waiting for transplants, projects focusing on consent and variations in consent by race and ethnicity were especially encouraged. All applications were required to be submitted by a consortium of at least two organizations, with one having expertise in research and evaluation and the other in donation/transplantation.

New Resource Guide for Medicare Hospitals/OPOs on the Donation Process

HHS is developing this resource guide at the request of hospitals and OPOs seeking further guidance on the implementation of the COPs, specifically on the roles and training required of hospital staff involved in donation, including interaction with potential donor families. Research has shown that families' experiences in the hospital and with the donation process are significant factors in their decisions to donate or not to donate. This resource guide is designed to help improve the quality of that process.

Organizations providing their expertise and support to the resource guide include the American Association of Tissue Banks, American Hospital Association, American Medical Association, American Society of Minority Health and Transplant Professionals, Association of Organ Procurement Organizations, Eye Bank Association of America, Gift of Life Donor Program, National Donor Family Council, National Kidney Foundation, North American Transplant Coordinators Association, Transplant Recipients International Organization, Inc., and UNOS. Additional input came from a panel of more than 35 experts at a June 28-29, 1999 workshop in Baltimore, Maryland co-sponsored by HCFA and HRSA. The panel included representatives from hospitals, OPOs, tissue banks, and eye banks; bereavement specialists; clergy; donor family members; researchers; medical examiners; physicians; and nurses.

Partners

Thanks to the Coalition on Donation and the Saturn Corporation, we have additional partners who have not been widely announced. These include the AFL-CIO, the UAW, MBNA America Bank (which has just begun to issue credit cards promoting organ donation), Aetna U.S. Healthcare, and Kaiser Permanente.

I recommend public recognition of the ongoing joint efforts of the National Medical Association (NMA), the National Minority Organ and Tissue Transplant Education Program (MOTTEP), the American Society of Minority Health and Transplant Professionals and UNOS, all partners in the National Organ and Tissue Donation Initiative, to educate minority physicians on the need to increase minority donation and transplantation. Most recently, MOTTEP, the National Marrow Donor Program, and UNOS collaborated to present a session on African American transplantation issues at the National Medical Association's 1999 Annual Convention & Scientific Assembly in Las Vegas on August 11.

Celebrities

Possible celebrity participants for an event include: (1) singer Julio Inglesias, Jr. who has joined the Coalition on Donation, (2) Chicago Hope actor/singer Mandy Patinkin who is a cornea recipient and has promoted donation through the American Red Cross, (3) Olympic Gold Medalist Carl Lewis who heads the Coalition on Donation's Sports Council, is a long-time supporter of the Wendy Marx Foundation for Transplant Awareness, and is featured on our organ donation video for federal employees, and (4) Michael Jordan who has a national Coalition on Donation campaign bearing his image but we anticipate would require a direct invitation from the White House. This year, HHS sent Michael Jordan organ donation posters to dozens of federal agencies for display.

Finally, the James Redford Institute for Transplant Awareness has developed two films on organ donation/transplantation that could be highlighted at an event. The first film, called "FLOW," is an excellent 15-minute film about transplant awareness for teenagers. It has recently begun distribution through the Coalition on Donation and the Advertising Council along with an Educational Outreach Kit for use in the classroom (price of video and kit is \$25.00 with discounts for orders of 2 or more). The second film, a documentary titled "The Kindness of Strangers" is scheduled to air on HBO on August 18, 25, 27, 29 and 31. James Redford, Robert Redford's son, is a screenwriter in California and is a liver transplant recipient.

Budget

The administration's budget request for HRSA's Division of Transplantation is \$10 million in FY 2000, equal to its appropriation in FY 1999.

cc: Sarah Bianchi, Office of the Vice President
Elizabeth Summy, HHS Deputy Chief of Staff



Washington, D.C. 20201

MEMORANDUM

SEP 15 1999

To: Devorah Adler
Domestic Policy Council

From: Lisa A. Gilmore *L.A. Gilmore*
Special Assistant to the Deputy Secretary

Subject: Update on the National Organ and Tissue Donation Initiative

As you requested in our conference call on September 8, this memorandum provides further information on the National Organ and Tissue Donation Initiative ("National Initiative") in anticipation of an organ donation event next week. I am aware that the details and even the principals for the event are still in flux. There are, however, several critical steps we will need to take in coordination with the White House to meet your timetable for an event, for example, advance notification to the Congressional Liaison Office of the grant awardees, travel arrangements for speakers, and invitations to guests. Therefore, we would appreciate notification as soon as possible of the confirmed date and time of the event, the location, and the desired number of attendees. I can be reached at 202-690-6133 or at lgilmore@os.dhhs.gov. Please note for planning purposes that I am scheduled to be on annual leave this Friday and will be entertaining family at home this weekend. Thanks for all your hard work on this issue and this event!

NEW PUBLIC SERVICE ANNOUNCEMENTS (PSAs)

Five new television PSAs on organ donation – the winners of an annual competition conducted by Walt Disney subsidiary Buena Vista Television on behalf of the Coalition on Donation – could be announced at the event (Please see Tab A for additional information. I will deliver the PSAs to you this afternoon.) With sufficient advance notice, the PSAs could be broadcast by satellite on the day of the event for distribution to network and cable TV stations with Beta copies available at the event for press. Subsequent distribution will be conducted by the Coalition on Donation. The top winning PSA, "Heroes," produced by Studio City Productions, focuses on a child who, "has his Mom's smile...his Daddy's dimples, and the heart of a perfect stranger." Senior officials from PROMAX, Buena Vista, ABC News, etc. could be invited to the event, including a senior vice president who is a kidney transplant recipient. HHS has a memorandum of understanding with the Coalition on Donation to use its national Ad Council campaign, "Share your life. Share your decision." and to run the National Initiative's toll-free telephone number.

NEW PARTNER UPDATES

AFL-CIO and UAW

The AFL-CIO and the UAW have recently joined the National Initiative (please see Tab B for partnership letters). In addition to participating in the annual Saturn/UAW National Donor Day co-sponsored by HHS, the UAW is working with the American Red Cross Transplant Awareness Program (TAP) to promote organ and tissue donation throughout its membership. The UAW has over 1.3 million members throughout the United States and has pledged to raise awareness through events, its Solidarity membership magazine, and support from senior leaders. The Red Cross and UAW launched the TAP effort on Labor Day in Detroit, and transplant recipients who had received donated organs and tissue marched in the parade with TAP volunteers from the labor community. At the annual Laborfest event afterward, UAW President Steve Yokich kicked off the event by signing the First Family Pledge (part of the American Society of Transplant Surgeons' First Family Pledge Campaign). A feature article in the UAW Solidarity magazine will display the First Family Pledge and members will be asked to return a postage-paid post card to the Red Cross to show their support for the First Family Pledge. The UAW Local with the highest participation will be recognized for its strong commitment. TAP is a new program of the Red Cross that is being piloted with the UAW. It "taps" into the ability of organizations, corporations, and universities to use their communication networks to spread the word about the need for donation. For more information on TAP, please visit www.redcross.org/tissue/TAP <<http://www.redcross.org/tissue/TAP>>. The Red Cross also has B-roll footage and photographs from the kick-off event.

MBNA America

MBNA America, in partnership with the Coalition on Donation, began issuing a new VISA credit card several months ago to promote organ and tissue donation (See Tab C for picture of card and more information and a letter of partnership with the National Initiative). While the card is being niche-marketed to more than 100,000 individuals interested in donation, including organ procurement organizations, health professionals and patients, it has not been "publicly" announced. Individuals interested in applying for the card can call 1-800-523-7666 but must reference the priority code "VYIV."

ADDITIONAL PARTNERSHIP UPDATES

American Hospital Association (AHA)

The AHA continues to be supportive of the National Initiative (see Tab D for letter from AHA's Executive Vice President for Government and Public Affairs Rick Pollack). Most recently, Karen Milgate of the AHA participated in the HRSA/HCFA two-day workshop on the "Roles and Training for the Donation Process: A Resource Guide." At the Association of Organ Procurement Organization's annual meeting in June, Ms. Milgate told the audience that she was looking forward to working with HRSA and HCFA on the upcoming "best practices" conference on the hospital conditions of participation for organ, tissue, and eye donation.

TRANSPLANT RECIPIENT SPEAKERS

We have yet to confirm the availability of possible speakers for the event but anticipate no problems identifying and securing options for your consideration. For your consideration thus far:

A 17-year-old Caucasian female heart transplant recipient. She was kept alive for a year with a mechanical assist to her heart and received a heart transplant on June 22 of this year. She is now in high school. She recently made a local public appearance with singer Julio Inglesias, Jr., but it did not garner much press. The Coalition on Donation reached her father but is waiting for a call back from her so we can put her name forward to you.

Morgan Wooten, basketball coach, DeMatha High School, Hyattsville, Maryland. As you may have heard from press in recent years, Mr. Wooten, the second-winningest high school basketball coach in high school basketball history, received a liver transplant in 1996. Since then, he has hosted at least two invitational basketball tournaments to benefit local donation efforts. The Washington Regional Transplant Consortium is trying to contact him.

Other options. Another option for the event is to have the first-ever meeting between a transplant recipient and the donor family member(s). We did this with an 8-year-old marrow recipient and his donor at an event at HHS, and it received substantial local press. The “pro” is that it’s very visual and dramatic. The “con” is that it can overshadow other announcements.

REGIONAL CONFERENCES ON PROMISING STRATEGIES IN THE IMPLEMENTATION OF THE HOSPITAL CONDITIONS OF PARTICIPATION (COPs) (FORMERLY THE “BEST PRACTICES CONFERENCE”)

HHS is planning a series of at least four regional conferences beginning in early December of this year to: (1) bring together hospital staff and transplant professionals from hospitals as well as tissue and eye banks to share promising implementation strategies and promote discussion and collaboration, and (2) to orient participants to *Roles and Training for the Donation Process: A Resource Guide* which outlines resources for training staff designated to offer the donation option to potential donor families. The conferences will host 100-150 participants, and the format will be highly interactive. Speakers will include Federal staff who will provide an overview of the COPs, the National Initiative, and the *Resource Guide*. Several three-to-five-person panels with individuals from local Medicaid/Medicare hospitals, organ procurement organizations, tissue and eye banks, and donor families will discuss specific issues related to various aspects of the COPs. The first two conferences will be held in the Northeast (New York) and South (Atlanta) with the remaining conferences expected in the Midwest (most likely Chicago), West (San Francisco and/or Los Angeles), and possibly again in the South (Dallas). HHS will seek additional input from the AHA and other relevant national organizations in the planning of the conference. HCFA’s four regional coordinators for the COPs will help organize the conferences.

ADDITIONAL DATA

As you requested, we were able to obtain preliminary data on the number of organs donated, which fell 0.5 percent from January to June 1999 compared with the same period in 1998. We typically release data on organ donors and organ transplants, not organs donated. We recommend reporting the preliminary data you received in the August 30 memorandum which showed a 0.1 percent increase in cadaveric organ donors and a 0.6 percent decrease in cadaveric organ transplants in the first six months of 1999 versus the same six months in 1998.

In addition, the American Association of Tissue Banks just completed (as of September 3) a new survey of AATB-accredited tissue banks. The results are inconclusive regarding the impact of the COPs on tissue donation, but the general direction is positive. The tissue banks reported an overall increase of 19 percent in tissue donors in the first six months of 1999 versus the first six months of 1998 (before versus after implementation of the COPs): 58 percent of the tissue banks reported an increase, 40 percent reported a decrease, and 2 percent reported no change. The survey had a 96 percent response rate.

NEW CLINICAL RESEARCH PROGRAM ON IMMUNE TOLERANCE

The National Institutes of Health will be awarding a new contract for a new research program on immune tolerance. Since the Tolerance Network contract will not be awarded until the week of September 27, this may be more appropriate as a mention in the Deputy Secretary's remarks. The update is as follows: "Federally-supported medical research may also help to alleviate the shortage of donor organs by developing new methods to prevent and treat rejection. For example, this month the National Institutes of Health, in partnership with the Juvenile Diabetes Foundation International, will establish a new, 7-year clinical research program to study promising approaches to improve therapy for many immune system disorders, including rejection of transplanted kidneys. The goal of this Collaborative Network for Clinical Research on Immune Tolerance is to achieve permanent graft survival, thereby eliminating or substantially reducing the need for repeat transplants. Since about one-third of kidney transplants are repeat transplants, this would result in a significant reduction in the number of patients waiting for a transplant and an increase in the number of patients able to receive a transplant."

Attachments:

Tab A: Background on new PSAs (PSAs on VHS to be hand delivered today)

Tab B: Letter from John J. Sweeney, President, AFL-CIO to Secretary Shalala

Letter (unsigned) from UAW President Stephen P. Yokich to Deputy Secretary Thurmon
UAW's March 1999 resolution concerning organ donation

Tab C: Background in MBNA American/Coalition on Donation organ donation credit card

Letter from MBNA Senior Vice President Michael J. Flynn to Secretary Shalala

Tab D: Letter from AHA Executive Vice President for Government and Public Affairs Rick Pollack to Secretary Shalala

Tab E: Article on transplant recipient Morgan Wooten's first basketball invitational on behalf of organ donation

cc: Sarah Bianchi, Office of the Vice President
Elizabeth Summy, HHS Deputy Chief of Staff

TAB A

Coalition on Donation

Battle of the Promo Cutters *Benefits Coalition on Donation*

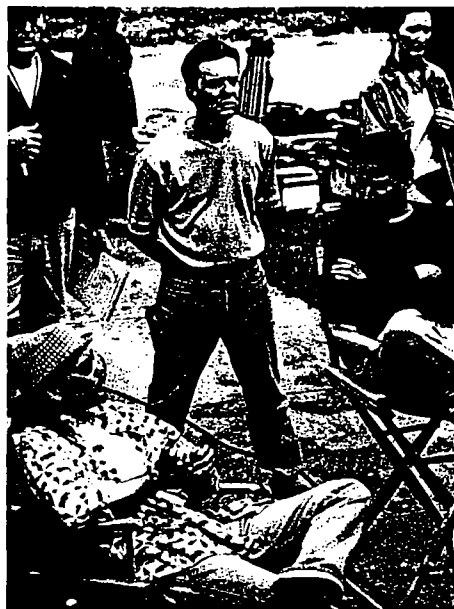
Some of the most creative talent in the film industry came together at the Battle of the Promo Cutters to promote the need for organ donation.

For the third straight year, the Walt Disney subsidiary Buena Vista Television conducted The Battle of the Promo Cutters during PROMAX's annual meeting. PROMAX is an international organization of promotion and marketing professionals in the electronic media, dedicated to increasing the effectiveness of promotion and marketing within the industry.

The annual competition attracts industry leaders and challenges them to produce 30-second PSAs for the benefit of a worthy cause.

Thanks to a Buena Vista employee who visited the UNOS Web site after seeing it aired on a national news program this year, Walt Disney, Buena Vista Television and PROMAX joined in the effort to increase awareness for organ and tissue donation by choosing the Coalition on Donation as the beneficiary of this year's competition.

The five creative teams selected to participate in this year's competition: Fox Broadcasting, Studio City Productions



Director George Flanigen, seated on left, confers with Peter Martin, center, and Sal Sardo, of Buena Vista Television during filming for PROMAX footage.

(both in Los Angeles, Calif.), Friedland Jacobs Communications (Burbank, Calif.), BBC Television (London, England), and Encore Media Group (Littleton, Colo.).

Each team was provided with identical footage filmed this spring by award-winning Deaton Flanigen Productions that captured images conveying the Coalition's message. Armed with the footage, marketing objectives and the message, the teams were given four weeks to craft their entries.

During the Promo Cutters session in June, the five teams presented their work.

The 3,000-member audience was then asked to vote for the PSA that most successfully communicated the Coalition's message. This year's winner of the Battle of the Promo Cutters III was the entry "Heroes" produced by Studio City Productions. The winning spot focused on a child who "has his Mom's smile... his Daddy's dimples, and the heart of a perfect stranger."

"Watching the teams challenge their contemporaries to join in the efforts to increase donation was truly amazing," said David Fleming, executive director of the Coalition. "You just can't buy that kind of promotion."

All five PSAs have been donated to the Coalition and are being edited for distribution. Leaders at the Coalition say they hope the spots will be released for broadcast as early as this fall.

Buena Vista TV / Walt Disney Organ Donation Selected for PSA Competition

Five of the top creative teams in the country are given the same footage and mission: Produce a powerful public service announcement. How will each group face the challenge? What techniques will they use to breathe life into their spot? And who will win the Battle of the Promo Cutters?

Placing first is obviously the goal of each group. But none of the teams will be the true winner. That honor, this year, belongs to the approximately 60,000 individuals on the UNOS patient waiting list for a solid organ transplant and the many others awaiting life enhancing tissue transplants. The theme of this year's PSA "battle" is the need for organ and tissue donation.

Sponsored by Buena Vista Television and PROMAX—a professional broadcast association with 2,000 member organizations -- the Battle of the Promo Cutters explores how different creative approaches (editing techniques, music and graphics) can change the "personality" and effectiveness of the same message. At the same time, the competition benefits a social cause by producing five PSAs that will be made available to their members and to the Coalition on Donation.

"This is really great news," said UNOS President William Pfaff, M.D., regarding the selection of organ and tissue donation as this year's competition theme. "This is exciting because it makes organ and tissue donation the focus of a competition that has been known to create some of the most innovative PSAs in the country."

Each creative team will produce a 30-second PSA encouraging donation based on family discussion. The winner will be asked to provide an additional 15-second spot. Spots are to be cut using raw footage provided by Buena Vista Television, together with music, graphics and voice-over, if necessary.

During the judging, to be held at the PROMAX annual meeting in San Francisco June 10, a representative from each creative team will explain the group's vision and creative objective, followed by a screening of the PSA. The audience will vote as to which spot they consider most successful.

Participants in this year's competition are Fox Broadcasting Company, Studio City Productions, Encore Media Group, Friedland Jacobs Communications and BBC Television.

UNOS and the Coalition on Donation have worked with Buena Vista Television to ensure that the raw footage to be provided to the creative teams is in keeping with the light, upbeat tone of the current Coalition/Ad Council PSAs. The Coalition logo, "Share your life. Share your decision.SM", and the toll-free phone number for brochures will be included in the footage.

UNOS contributed \$40,000 to the cost of producing the footage. Buena Vista Television and Walt Disney are matching the investment.

"Our affiliation with Buena Vista Television and PROMAX is yet another great opportunity to get organ and tissue donation in the public's mind," stated Coalition Executive Director David Fleming. "Not only are we going to end up with five PSAs, but all PROMAX members will be exposed to the cause at their annual meeting. This could influence the networks to broadcast the PSAs with increased frequency and during prime viewing hours."

All five PSAs will be made available through the Coalition on Donation, and local coalitions and others will be able to purchase media time for these spots. Information on how to order the PSAs will be published in *UNOS Update*. □

Calendar of Public Events To Increase Organ and Tissue Donation

Event Submission Form

National and regional events submitted will be included on the calendar of public events to increase organ and tissue donation. (Professional meetings are listed on the UNOS calendar.) Please copy this form to use with future submissions.

Please type or print

Date of event: _____

Name of event: * _____

Description (15 word max.)

Location: _____

Contact name: _____

Contact phone number, email or web site:

Submitted by

Name: _____

Phone number: _____

Organization: _____

Date: _____

* Please note that events listed must be of national or multi-state.

Organ & Tissue

COALITION ON DONATION

Share your life. Share your decision.®

Fax forms to Linda Lawson at 804-323-7343

TAB B

American Federation of Labor and Congress of Industrial Organizations



815 Sixteenth Street, N.W.
Washington, D.C. 20006
(202) 637-5000
<http://www.aflcio.org>

EXECUTIVE COUNCIL

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Stephen P. Yokich
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Leon Lynch
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Sandra Feldman
Bobby L. Harnage, Sr.
Michael E. Monroe

Morton Bahr
John J. Barry
Michael Sacco
Gloria T. Johnson
J. Randolph Babbitt
Michael Goodwin
Carroll Haynes
Douglas J. McCarron
Robert E. Wages
Edward L. Fire
R. Thomas Battenbarger
Stuart Appelbaum

April 20, 1999

The Honorable Donna E. Shalala, Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Shalala,

On the eve of National Organ and Tissue Donor Awareness Week, I'm pleased to add the AFL-CIO to the long list of organizations supporting the Administration's National Organ and Tissue Donation Initiative. I am particularly pleased to be joining with the UAW, which has taken the lead among unions in supporting this initiative with National Donor Day, and will be encouraging other AFL-CIO affiliates to do the same.

As a co-founder of the Administration's Initiative, along with Vice President Gore, I want to thank you for your leadership on a health issue of such importance to American working families.

Best wishes.

Sincerely,

John J. Sweeney
President

cc: Stephen Yokich

JJS:GMS:socq





Solidarity House

8000 EAST JEFFERSON AVE.
DETROIT, MICHIGAN 48214
PHONE (313) 926-5000
FAX (313) 823-6016

INTERNATIONAL UNION, UNITED AUTOMOBILE, AEROSPACE & AGRICULTURAL IMPLEMENT WORKERS OF AMERICA—UAW

STEPHEN P. YOKICH, *PRESIDENT*

RUBEN BURKS, *SECRETARY-TREASURER*

VICE-PRESIDENTS: ELIZABETH BUNN • RON GETTELFINGER • BOB KING • JACK LASKOWSKI • RICHARD SHOEMAKER

April 1, 1999
Via Facsimile

To: Lisa Gilmore

From: Chuck Gayney, Director, UAW Social Security Department

RE: National Organ and Tissue Donation Initiative

Attached is a copy of Steve Yokich's letter to Kevin Thurm. I trust this is sufficient for your needs.

I've also attached a copy of the UAW Resolution on Health Care which was adopted by our delegates last Tuesday at our Collective Bargaining Convention.

CG:df
opeiu494
Att.
c: Jim Carpenter

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UAW PRESIDENT'S OFF.

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NATIONAL DONOR DAY

March 31, 1999

Kevin Thurin
Deputy Secretary
U.S. Department of Health and Human Services
Fax (202) 690-7755

Deputy
Dear Secretary Thurin,

The UAW takes great pride in being founder and a primary force in National Donor Day. This year's drive in February increased both blood donations and bone marrow typings for entry into the National Marrow Donor Registry by nearly 50% over the inaugural 1998 National Donor Day event.

In concert with our National Donor Day commitment, the UAW is pleased to join the National Organ and Tissue Donation Initiative and lend its support to National Organ and Tissue Donor Awareness Week, April 18-24. We will assist by getting the word out to UAW members across America of the critical need for organs for transplantation. We know that at any given time those awaiting organ transplant include union brothers and sisters.

We applaud the efforts of the U.S. Department of Health and Human Services in assisting with National Donor Day, and we recognize that your Initiative is one-in-the-same with National Donor Day in its goal of building public awareness of the need for life-saving organ and tissue donation. Working together, we can make a very real impact in helping the over 60,000 persons who currently await organ transplant, and we look forward to the whole of AFL-CIO joining the National Organ and Tissue Donation Initiative as well.

Yours truly,

Stephen P. Yokich
President

6320 Carnegie Avenue, Suite 1600 Woodland Hills, CA 91367 USA Telephone: (800) 738-1617 Fax (818) 595-1012

MAR 31 '99 15:44

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PAGE 12

HEALTH CARE

For almost half a century, the UAW has been at the forefront of progressive change in health benefits coverage. Our efforts at the bargaining table and in the policy arena have helped lead the way to important and cutting edge advances in health care coverages.

The ongoing crisis in health care costs continues to pressure our negotiated benefits and programs while also eating away at wage gains and job security protections. In this round of bargaining, we must continue to work to assure that health protection begins when work begins and continues through layoffs, disability and any other circumstances that cause loss of coverage. That should encompass benefits for new family configurations, including coverages for dependents up to age 25 and domestic partner relationships.

The health care cost crisis is aggravated by employer practices designed essentially to save money through cost-shifting to workers and beneficiaries by means of copayments, deductibles and premium sharing and the elimination of previously covered benefits. Numerous employers are also using changes in Financial Accounting Standards Board rules for post-retirement benefits as an excuse to cut retiree benefits.

Employers are not the only payers seeking to shift costs and cut benefits. Funding for the Medicare program has been substantially cut. Medicare beneficiaries are increasingly confused and unprotected by managed care options and defined contribution plans that have been poorly implemented and inadequately funded. Health Maintenance Organizations are also pulling out of markets or slashing benefits or both. Just last fall, HMOs abandoned over 400,000 seniors because of funding cutbacks in the Medicare program.

As cost pressures push private employers and public payers and conservative policy makers to pursue cost-shifting, benefit cutbacks and a privatization agenda, our tasks are clear: We must vigilantly protect our hard-won gains from employer and government attacks by holding the line on cost sharing and stepping up our demands for improved quality and access.

One critical consumer area largely neglected by the health system is organ donation. Today, thousands of people die and thousands more are on organ donor waiting lists even though, for many conditions, enough organs are available to meet demand. Though the government has recently taken tentative steps in this area, our bargaining efforts can promote awareness and education on this issue among UAW members and families as well as in the broader community.

The UAW helped pioneer the development of quality standards for managed care plans. These standards have been largely adopted by the major managed care accreditation bodies and form the basis for UAW HMO qualification status. Today, the UAW is raising the quality bar even further. We are working to assure that HMOs, and other delivery systems, implement evidence-based guidelines that eliminate inappropriate variation in care so that, for example, a woman diagnosed with breast can-

Resolution adopted March 31, 1999 at UAW
Collective Bargaining Convention.

cer in Los Angeles will not face a different set of treatment options than a woman with the same diagnosis living in Buffalo. We are working to put reliable consumer information about physicians, facilities and outcomes into the hands of UAW members and families through various report card projects. And we are developing voluntary wellness programs for patients with, or at risk for, certain chronic conditions such as diabetes, heart disease and asthma. Affected members and their families can access information and resources to help them manage and improve their health status.

Over the past several years, pharmaceutical research has resulted in some truly important and remarkable technological advances in the biomedical sciences. Not only are new drugs leading to more effective, less invasive treatment and reduced hospitalizations, but they are also proving to be powerful agents of prevention. As costs and utilization are shifted from the hospital care sector to the pharmaceutical component, many employers are using higher drug costs as an excuse to raise copays and deductibles in our prescription drug programs, thereby shifting those costs to workers while ignoring the cost savings and benefits of shorter hospital stays. Such shell games must be resisted.

Improving the quality of health care for UAW members and families requires vast quantities of data and sophisticated information technologies for interpreting such data. But while health information technology promises quality and cost improvement, it also threatens privacy and confidentiality. The same information that identifies an individual for improvement in care, can also potentially identify a person for other purposes. Limited data is needed for audit purposes. All other patient-identifiable data must remain in the clinical care setting, and severe penalties must be established for its misuse.

The UAW has pioneered a program that links evidence-based medical science to community health status improvement: the "Community Health Care Initiatives." This program is coordinated by the UAW Center for Community Health Care Initiatives. Together with employers, government, purchasers, providers, consumers and other interested parties, the UAW has been encouraging and initiating collaborative community activity and organization to bring health care resources into balance with a community's needs. Focusing on quality and access to care, a community working together can reform the delivery system to provide a better quality of life, enhance access, and encourage cost-effective use of resources for the benefit of the entire community.

Pilot projects have been initiated by CHCI in six communities with major UAW represented employers. It is anticipated that these community initiatives will stimulate reform of the entire health care delivery system at the place health care services are actually delivered — in the community — and help achieve the goal of high quality, cost-effective health care for all.

Though the health care scene changes daily, we must continue to pay attention to what matters most. We must protect the health care coverage of retirees and working families and we must continue to protect our hard won gains from employer attacks by negotiating programs that improve quality, control costs, assure access

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to care and hold the line on cost sharing. High quality care, delivered in an appropriate and timely manner, on the basis of scientific evidence, is the best way to contain costs.

Areas of focus for this round of bargaining will include:

- Updating and expanding coverages to include new developments and health care technologies, closing gaps in existing coverages and adjusting benefit entitlements for increases in inflation.
- Resisting employer efforts to shift additional costs to workers and restoring wages and benefits lost from past cost shifting.
- Continuing and expanding of the Community Health Care Initiative activities in the pilot sites, establishing of new CHCI sites, and including all UAW employers within the CHCI program.
- Expanding efforts to collect and disseminate easily understood information about health plans, professionals and facilities.
- Establishing in all UAW collective bargaining agreements the right to confidentiality of health information, including the right to review and amend records.
- Establishing organ donation committees at each UAW facility.
- Assuring access to pharmaceutical innovation and drug therapies while promoting appropriateness, effectiveness and affordability.
- Increasing to 25 the age for which health care coverage is extended to dependents.
- Extending health care coverage to domestic partners.
- Addressing the issue of AIDS in the workplace and the community, providing safe workplaces for those workers most often exposed to the virus, and assuring health coverages keep up with technology and the changing nature of the disease.
- Expanding and improving benefits at nonmajor employers to include the full array of benefit plans and financing and delivery options as found at major employers.
- Providing continuing health care coverage in the case of full or partial plant/workplace closings as a benefit in all UAW collective bargaining agreements.
- Preserving the right to a choice of health care providers that assures access to appropriate, high-quality health care.

TAB C

Did you
KNOW

Take CHARGE with the Coalition on Donation and MBNA

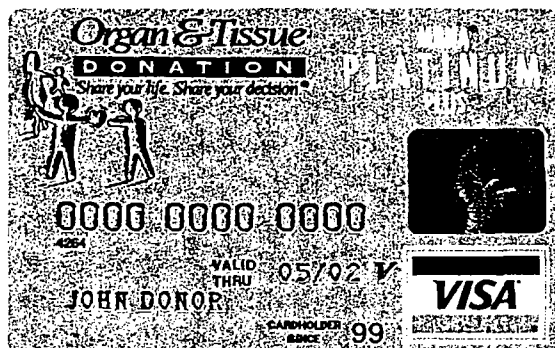
... you may now purchase, or have sponsored, local advertising space for Ad Council materials. To avoid eroding your current level of support, the Ad Council recommends offering this incentive to your best local supporters. Where possible, leverage a purchase of space using non-Ad Council spots (such as the PROMAX PSA's) and negotiate additional donated placements for Ad Council spots.

If a sponsor's name is to appear, they must be approved by the Ad Council. The Ad Council logo and tracking codes must be removed from all paid advertisements. Formal guidelines will be distributed soon.

The Coalition on Donation has partnered with MBNA, one of the nations leading specialty credit card companies in a win-win opportunity for the transplant community. With the development of the new MBNA/Coalition on Donation Visa credit card, thousands can now benefit from your purchasing power.

When you use this card, and with no extra cost to you, a portion of MBNA's profits will be contributed to the Coalition on Donation to help fund public education efforts. Credit availability can reach as high as \$100,000 and there is no annual fee!

The card features the "Share your life. Share your decision" logo and the "dolls" prominently displayed. The \$100,000 credit limit makes this is an ideal card for corporate as well as personal accounts. Talk to your co-workers about this great opportunity to support public education



for organ and tissue donation. In addition, every time the card is presented to a merchant you have an opportunity to educate the public about the need for donation.

To apply for your card, call 1-800-523-7666, and be sure to reference the Coalition on Donation priority code: VYIV.

Organ & Tissue

COALITION ON DONATION

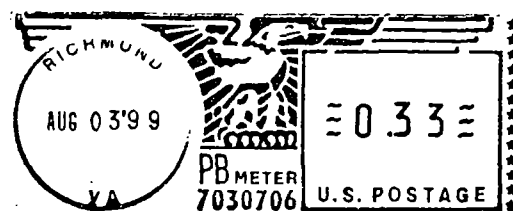
Share your life. Share your decision.

1100 Boulders Parkway
Richmond, Virginia 23225-8770

Organ & Tissue

Share your life. Share your decision.

PRECEDENCE



Lisa Gilmore
US Department of Health and Human Services
200 Independence Ave., S. W., Rm. 614G
Washington, DC 20201

Are you an organ & tissue donor

Nexus is a bi-monthly publication of the Coalition on Donation. Copyright © 1999, Coalition on Donation, 1100 Boulders Parkway, Suite 500, Richmond, Virginia 23225-8770; Phone: 804-330-8620.



JNA Marketing Systems, Inc

333 McCormick Road

mt Valley, Maryland 21031

March 30, 1999

Hon. Donna E. Shalala
Secretary of Health and Human Services
Washington, D.C. 20101

Dear Secretary Shalala:

In the fall of 1998, MBNA America Bank and The Coalition on Donation joined forces to help raise awareness about the need for organ & tissue donation and to help benefit the more than 60,000 Americans waiting for life saving organ transplants.

Our commitment to the cause of organ and tissue donation led to the joint development of The Coalition on Donation Visa credit card program. By having supporters use The Coalition on Donation Visa card, MBNA America Bank contributes a portion of the purchases to fund efforts to educate the public about the critical need for organ & tissue donors.

As a member of The Coalition on Donation, MBNA America Bank is honored to join the National Organ and Tissue Donation Initiative. We look forward to being a part of the solution to solving this national health crisis.

Sincerely,

A handwritten signature in black ink, appearing to read "Michael J. Flynn".

Michael J. Flynn
Senior Vice President

TAB D



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SECRETARY
ATTN: ENTER

April 2, 1999

The Honorable Donna Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Shalala:

As National Organ and Tissue Donor Awareness Week approaches, the American Hospital Association would like to take this opportunity to applaud the President's and your efforts to heighten awareness of the critical need for increased organ donation. Your willingness to use your resources to reach out to the communities involved in organ donation has sparked a new and positive discussion on the best strategies for encouraging more donations.

Those who work in hospitals witness first hand the miracle of successful donation and the tragedy and frustration of families whose loved ones do not receive organs in time. Because of these experiences, our members work hard to ensure that all potential donors or their families are identified and given the opportunity to donate. In addition to their own individual efforts, hospitals collaborate with their organ procurement organization partners to develop even better methods for increasing organ donations.

However, the efforts of those directly involved are not enough. Your efforts to increase public understanding and awareness through the National Organ and Tissue Donation Initiative are critical. Thank you for your leadership on this issue. We look forward to a continuing partnership.

Sincerely,

A handwritten signature in black ink that reads "Rick Pollack". The signature is fluid and cursive, with the first letters of the first and last names being capitalized.

Rick Pollack
Executive Vice President
Government and Public Affairs

Washington, DC Center for Public Affairs

Chicago, Illinois Center for Health Care Leadership

Liberty Place, Suite 700
325 Seventh Street, N.W.
Washington, DC 20004-2802
(202) 638-1100

04/05/1999 - 0842

TAB E

Transplant Tournament.390
Big game features coaches with transplants

WASHINGTON (AP) The cause of organ donation will be the big winner when two of the nation's high school basketball powers both coached by transplant recipients square off Jan. 29.

A game between DeMatha High School of Hyattsville, Md., ranked third by USA Today, and No. 15 Anderson High of Anderson, Ind., will highlight the one-day DeMatha Invitational. Proceeds go to the Mid-Atlantic Coalition on Donation.

"Organ donation saved my life. It was a big opportunity for me to give something back," said Anderson coach Ron Hecklinski.

Hecklinski and DeMatha's Morgan Wootten underwent lifesaving liver transplant operations in the summer of 1996.

In July 1996, Wootten, 65, collapsed at his basketball camp at Mount St. Mary's College in Emmitsburg, Md. He had been diagnosed several years earlier with primary biliary cirrhosis, an autoimmune disease extremely rare in men.

Just days later he received the transplant that saved his life.

"We're very indebted to anything that helps promote" organ donation, said Wootten, the second-winningest high school basketball coach in history with more than 1,000 victories over four decades.

Hecklinski, 42, was diagnosed in 1988 with primary sclerosing colongitis, which scars the liver and eventually renders it nonfunctional. There is no cure, and by July 1996, Hecklinski's condition had deteriorated to the point that a transplant was required.

Hecklinski received his transplant about a month after the effects of his liver disease began to worsen.

"A 20-year-old kid in a motorcycle accident died in Kentucky to save my life," Hecklinski said.

The game, to be played at the new MCI Center in downtown Washington, will pit one of the country's elite programs against one of the best from basketball-rich Indiana.

Anderson has won three Indiana state titles and has produced four Indiana Mr. Basketball winners.

A Wootten-coached DeMatha team has never played a team from Indiana. In fact, in all of his travels as a basketball coach, Wootten said he has never seen an Indiana team play.

"I've got to tell you that in Indiana, we use six guys," Hecklinski joked.

Tickets can be purchased by calling 202-432-SEAT.
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Sports America
is organizing
event. Press
conference held
on 1-7-98

Wash Post Sports
section



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILEDATE March 1, 1999

TO: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):

Ms. Deborah Adler
DPC
(202) 456-5707

FROM: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):



U.S. Department of Health and Human Services
Office of the Secretary

LISA A. GILMORE, MSW, MBA
Special Assistant to the Deputy Secretary

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RECIPIENT'S FAX NUMBER (202) 456-5557NUMBER OF PAGES TO SEND (INCLUDING COVER SHEET): 10

COMMENTS:

As requested, I'm out
for the rest of the day.

Thanks!

Lisa

NATIONAL ORGAN AND TISSUE DONATION INITIATIVE
Update as of March 1, 1999

UPCOMING ANNOUNCEMENTS

FY99 Extramural Support Program to Increase Organ and Tissue Donation

HHS will issue a request for applications to allocate up to \$5 million for 15-20 projects through a new extramural support program to increase organ availability for transplantation. The purpose of the program is to provide federal resources to implement, evaluate, and disseminate model interventions with the greatest potential for yielding a verifiable and demonstrable impact on donation rates and which are replicable, transferable, and feasible in practice. This program will help intensify and bolster efforts to increase donation, as well as illuminate through careful project design and evaluation, the types of methods and strategies that result in a greater likelihood of donation. Applicants must be part of a "consortium" of at least one group that has research and design expertise and at least one other organization (e.g., organ procurement organization or other transplant/donation-related organization, public health or other government agency, hospital, or community- or faith-based organization).

Significant Increase in Organ Donation in 1998

Preliminary estimates by the United Network for Organ Sharing indicate that (cadaveric) organ donation rose by 6 percent in 1998 (final data available in a week or two). Organ donation was fairly flat over the previous two years, rising by just 1.1 percent each year.

UPCOMING EVENTS

First Family Pledge Congress on Organ and Tissue Donation

What: Reg and Maggie Green will introduce transplant kids from each state (200 children ages 2 to 9) who will give awards to Congressional members. Press invited. HHS has been asked to host the children for a lunch at HHS from noon to 2:00 p.m. (potential photo-op).

When: Wednesday, April 14, 1999

Who: American Society of Transplant Surgeons, American Red Cross Tissue Services, North American Transplant Coordinators Association

Invited: Vice President Al Gore, Mrs. Elizabeth Dole

The 1999 National Donor Recognition Ceremony

What: An annual HHS program to honor America's organ and tissue donors with a special presentation by David Satcher, M.D., Ph.D., Assistant Secretary for Health and Surgeon General. Press invited. Participants include living donors; family and friends of living and deceased donors; recipients; transplant professionals; and the general public. Vice President Gore spoke at the 1997 ceremony.

When: Sunday, April 18, 1:00 p.m. - 2:30 p.m. (workshops on April 17)

Where: Marriott Wardman Park Hotel, 2660 Woodley Road, N.W.

Invited: Walter Payton, former NFL player who is waiting for a liver transplant is planning to attend (health permitting, is now too sick to travel).

National Organ and Tissue Donor Awareness Week

What: Annual week-long event nationwide to encourage organ and tissue donation.
President Clinton issues annual proclamation.

When: April 18 - 24, 1999

National Minority Donor Awareness Day

What: Celebration/encouragement of minority donation. May link with one-year anniversary of effective date (August 21) for the HCFA Hospital Conditions of Participation for Organ Donation if verifiable increase in donation available.

When: August 1, 1999

Who: National Minority Organ and Tissue Transplant Education Program, The Marrow Foundation, HHS

ADDITIONAL UPDATESAdministration Marks Biggest Federal Effort Ever to Promote Organ and Tissue Donation

The second year of the National Initiative will mark the biggest effort the federal government has ever made to increase organ and tissue donation. The Omnibus Consolidated and Emergency Supplemental Appropriations Act provides \$10 million for Fiscal Year (FY) 1999 to HHS for organ transplant activities, approximately \$7.2 million more than the FY 1998 appropriation. After providing adequate funds to support the Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients contracts and related activities, approximately \$7 million FY 1999 appropriation provided to HHS for organ transplant activities will be available for organ donation activities.

HHS To Hold Expert Workshop and Best Practices Conference to Support Implementation of Hospital Conditions of Participation for Organ Donation

HHS continues to coordinate effective implementation of the HCFA Hospital Conditions of Participation for Organ Donation. Future activities will include:

- A 1.5-day workshop on June 7-8 in Baltimore, Maryland with about 20 experts to develop recommended training guidelines for staff who the hospital designates to discuss donation with the families of potential donors.
- A conference on September 13-14 in Baltimore, Maryland for hospitals and organ procurement organizations to maximize use of best practices and to exchange information about successful strategies to increase donation, including effective referral, consent, education, and monitoring practices

BACKGROUND

The Critical Need for Organ Donors Continues to Grow

Rapid medical and scientific advances have enabled many thousands of Americans to receive the gift of life through transplantation, but the number of donated organs still falls critically short of the need. While more than 20,000 Americans per year receive organ transplants, about 4,000 people die in the U.S. each year -- about 11 every day -- while waiting for a donated organ. Today, nearly 60,000 people are on the national organ transplant waiting list.

Although an estimated 8,000-15,000 deaths per year could result in organ donation, only 5,475 deaths resulted in donation in 1997. A 1996 study indicated that of all potential donations: 32 percent of families agreed to donation; 36 percent of families denied consent for donation; and in 27 percent of cases, either potential donors were not identified or no request was made to the family. (Another 5 percent eventually proved to be medically unsuitable.)

OTHER NATIONAL INITIATIVE ACCOMPLISHMENTS

In the year since we launched this effort, over a dozen major health care, community, educational, religious, minority, professional, and government organizations have agreed to join HHS and the transplant community in efforts to increase the public's willingness to donate. Through their members, these partners reach Americans where they live, work, play, and worship. For the National Initiative, HHS has engaged in a number of activities. For example:

- o We teamed up with the Coalition on Donation to use its national "Share your life. Share your decision" message and to establish a toll-free number for a free brochure in English or Spanish at **1-888-90-SHARE** (1-888-907-4273). In addition, we created a new web site at **www.organdonor.gov** with information for both the public and professionals.
- o We convened a "**best practices**" conference held on April 1 and 2 in Arlington, Virginia to identify strategies that work in increasing donation and effective evaluation protocols for such interventions. We received more than 80 abstracts and heard 15 presentations on a wide variety of approaches to increasing donation, including strategies for reaching specific minority populations. The conference proceedings have been published.
- o We partnered with the U.S. Office of Personnel Management to launch a **Federal employee education campaign** and provided a package of materials to about 100 Federal agencies, including a **memorandum from Vice President Gore** and a video made for Federal employees. A number of federal agencies are placing donation messages on employee pay stubs and including donation information in newsletters, presentations, and health fairs.
- o We worked with the producers of the movie *Nicholas' Gift* and CBS to tape a ten-second **PSA with Vice President and Mrs. Gore** which aired on April 26 directly after the movie. The network estimates that the message reached up to 31 million viewers.

- o We worked with minority-based organizations to improve outreach to minority communities. Partners include the National Minority Organ and Tissue Transplant Education Program, the American Society of Minority Health and Transplant Professionals, the National Medical Association, and the United Network for Organ Sharing's Minority Affairs Committee.
 - We joined the Congress of National Black Churches, which represents 65,000 churches with over 20 million members, in convening a leadership meeting on May 12 and 13 in Washington, D.C. to build bridges between African-American clergy and the transplantation community in support of organ, tissue, and marrow donation. Over 200 people from across the United States participated, including representatives from many of the National Initiative's partner organizations.
 - We published articles on minority donation and transplantation in the *Journal for Minority Medical Students*, the HHS Office of Minority Health's *Closing the Gap* newsletter, and other minority publications.
- o We established a web site specifically for donor families, transplant recipients, and bereavement and transplant professionals in partnership with the National Donor Family Council of the National Kidney Foundation.

NATIONAL INITIATIVE CALENDAR FOR 1999

January	February	March	April	May	June
	11: National Donor Day event at HHS, Washington, D.C. 13: National Donor Day hosted by Saturn/UAW.	Provide draft management plan to partners for feedback.	Early April: Publish Federal Register notice and announce RFAs for Extramural Program (date can be moved up) 18: National Donor Recognition Ceremony, D.C. (Dr. David Satcher) 18-24: National Organ and Tissue Donor Awareness Week.		7-8: Expert Workshop on Designated Requestor Training, Baltimore, MD.

July	August	September	October	November	December
	1: National Minority Donor Awareness Day (MOTTEP-founded). 21: One-year anniversary of Hospital Conditions of Participation for Organ Donation effective date.	Latest date for awarding extramural program grants. 13-14: Best Practices Conference: Successful Implementation of Hospital Conditions of Participation for Organ Donation. Implement college campus demonstration program.		12-14: Fourth Annual National Donor Sabbath. Draft second annual management plan.	15: Second anniversary of National Initiative.



News Release

For Immediate Release

Friday, Jan. 15, 1999



Hundreds of Transplant Recipients Age 2 to 9 Will Gather for Historic "First Family Pledge Congress" On Organ and Tissue Donation in Nation's Capital

WASHINGTON — More than 200 transplant kids from all 50 states, ranging in age from 2 to 9, will be flying into Washington on April 14th for the First Family Pledge Congress on Organ and Tissue Donation, where they will publicly thank Members of Congress from their state for demonstrating leadership in supporting the First Family Pledge organ and tissue donation initiative.

Vice President Al Gore and Elizabeth Dole, immediate past president of the American Red Cross, have been invited to deliver welcoming addresses to the kids — who all are alive and leading active lives today as a result of transplantation of hearts, lungs, kidneys, pancreases, livers, tissue and eyes.

The First Family Pledge Congress will mark the first time that transplant kids from all 50 states have come to Washington to encourage increased leadership support for organ and tissue donation, in hopes of saving the lives of the hundreds of kids who die each year while waiting for organs to become available.

At the First Family Pledge Congress, which will be held in the Senate Dirksen Auditorium, leading Congressional backers of organ and tissue donation expect to be able to announce that the effort they launched last summer to get Members of Congress to take the First Family Pledge has resulted in an unprecedented outpouring of Congressional support for organ and tissue donation.

"As a heart and lung transplant surgeon, I realize that any of us, or any member of our families, are at risk of needing a life-saving transplant," said Sen. William H. Frist, R-TN, one of the Congressional sponsors.

"One of the great tragedies happening to families across the country today is the needless loss of life because so few organs are available," said Sen. Edward M. Kennedy, D-MA.

"Those who donate organ, tissue and bone marrow are true heroes who give the gift of life," said Rep. C. W. Bill Young, R-FL, founder and champion of the National Marrow Donor Program. "I want to salute the organizers of the Congress on Organ and Tissue Donation for helping call public attention to the need for organ and tissue donors to expand the donor pool which ultimately will save more lives."

"We must do everything we can to promote the idea of organ donation," said Rep. Fortney (Pete) Stark, D-CA.

"The First Family Pledge Congress on Organ and Tissue Donation will provide another excellent opportunity to send the message and to personally meet with children whose lives have been saved by the Gift of Life," said Sen. Mike DeWine, R-OH.

During the Congress, Reg and Maggie Green, who donated their 7-year-old son Nicholas' organs and tissue after he was murdered in 1994 in Italy, will introduce transplant kids from each state, who will present special First Family Awards to the Members of Congress from that state who have signed the First Family Pledge.

Page 2

"Ten people die every day in this country, and tens of thousands of others — many of them children — continue to suffer because of the shortage of organ and tissue donations," Reg Green said. "We hope this unique event will dramatize the opportunity we all have to stop this terrible waste."

The First Family Pledge Congress is being organized by the American Society of Transplant Surgeons, the American Red Cross, and the North American Transplant Coordinators Organization.

"This First Family Pledge Congress is going to be the most important display of leadership support for organ and tissue donation ever to take place in this country," said Dr. Joshua Miller, president of the American Society of Transplant Surgeons.

"My hope is that all of the organizations that are committed to increasing donation — such as the Coalition on Donation, the Association of Organ Procurement Organizations, the National Kidney Foundation, The Partnership for Organ Donation, the American Society of Transplantation, the OPOs and transplant centers around the country — will join us now in a collaborative effort to make this Congress an unprecedented public success," Dr. Miller added.

"The Congress on Donation will be a defining event in the continuing effort to increase awareness of the importance of organ and tissue donation," said Dr. S. Randolph May, chief operating officer of American Red Cross Tissue Services. "Seeing hundreds of children whose lives have been saved because of transplantation will paint a very compelling picture for anyone who has not yet resolved this important issue with their loved ones. The American Red Cross Tissue Services is proud to be a part of this wonderful effort."

"The members and leadership of the North American Transplant Coordinators Organization are extremely proud to be a sponsor of this historic and important event," said Mary Ann Palumbi of Allegheny General Hospital in Pittsburgh, the President of NATCO. "Our members are those professionals who work on a daily basis with both the donor families and the transplant recipients, and therefore experience first hand the impact of organ and tissue donation. This event will once again bring to the public's attention the desperate need for organ and tissue donation, and in doing so, may save thousands of lives."

The Congress is also expected to conclude with an address by a leading African American on importance of increasing organ and tissue donation in minority communities.

The goal of the First Family Pledge campaign is to persuade Americans to discuss the miracle of transplantation and the importance of organ and tissue donation in the context of daily life. The campaign asks, "Just as you would hope that the gift of life would be available to your family in the event that a loved one is in need, won't you pledge as a family to make the same gift available to other families if the situation is reversed?"

Page 3

Surveys show that the overwhelming majority of Americans strongly favor donation of organs – such as kidneys, hearts, livers, lungs and pancreases – and tissue, such as corneas, heart valves, bone marrow and skin for grafts. But the ultimate decision on donation lies with next of kin, and unfortunately, they frequently are asked to make the crucial decision at a traumatic moment. All-too-often, without ever having discussed donation, the answer is "No."

"The beauty of the First Family Pledge campaign is its simplicity," said Dr. Miller. "It is simply an effort to get families to agree to apply the Golden Rule to organ and tissue donation, so tens of thousands of additional Americans can have their loved ones restored to healthy and happy lives."

The American Society of Transplant Surgeons is the professional organization representing the surgeons and scientists who for the past quarter century have taken the lead in developing transplantation from a pioneering procedure to an operation that now gives hundreds of men, women and children each week a new chance at life.

The American Red Cross Tissue Services supplies one-quarter of the nation's tissue for transplantation through its network of 15 tissue centers nationwide.

The North American Transplant Coordinators Organization is the largest group of transplant professionals in North America. Its membership includes both clinical and organ and tissue recovery coordinators, as well as specialists in public and professional education.

3/11/1999 From: The Lewin Group, 1-703-269-5501
1:33:37 To:

page: 2

DRAFT

Roles and Training for the Donation Process: A Resource Guide

Outline

A. Introduction

1. *Background and Purpose of the Resource Guide*
2. *Principles of the Resource Guide*
3. *Context of Family Advocacy: End-of-Life and Bereavement Care*

B. Basics of Organ, Tissue and Eye Donation

1. *Overview of the Donation Process*
2. *Structure of the Donation System*
 - a) *Roles of the OPTN, HCFA, HRSA/ DoT, OPOs, eye and tissue banks, and hospitals*
 - b) *Recent epidemiological information (OPTN and Scientific Registry data)*
 - c) *Federal legislative overview*
3. *Team Roles Involved In the Donation Process*
 - a) *Coordinate*
 - b) *Request*
 - c) *Support*

C. Training Programs

1. *Selecting Requestor Trainees*
2. *Components of a Training Program*
 - a) *Working as a team*
 - (1) *Matrix of training components and team roles*
 - (2) *Background knowledge for members of the donation team*
 - b) *Donation basics*
 - (1) *Donor dignity/ respect for the donor body*
 - (2) *Donor identification*
 - (3) *Assessing the potential donor*
 - (4) *Donation procedure and recovery*

DRAFT - August 10, 1999

8/11/1999 From: The Lewin Group, 1-703-269-5501
1:33:37 To:

page: 3

DRAFT

- (5) Understanding death (brain and cardiac)
- (6) Donor management
- c) *Tissue and eye donation*
 - (1) Non-heart beating donors
 - (2) Telephone requesting
- d) *Interacting with the family*
 - (1) Understanding families in grief
 - (2) Respecting the potential donor family
 - (3) Communication skills
 - (4) Developing background knowledge of family and potential donor
 - (5) Continuous assessment of the family dynamic/ modification of approach
 - (6) Cultural, religious, and spiritual factors and sensitivity
 - (7) Informed consent/ respecting family decisions
 - (8) "Top (ten? twenty?)" questions
- e) *Obtaining a medical and social history*
- f) *Documentation*
- g) *Evaluation of the process*
 - (1) Event debrief
 - (2) Feedback from donor and non-donor families
 - (3) Communication among hospital, OPO, and eye/ tissue banks

DRAFT – August 10, 1999

8/11/1999 From: The Lewin Group, 1-703-269-5501

page: 4

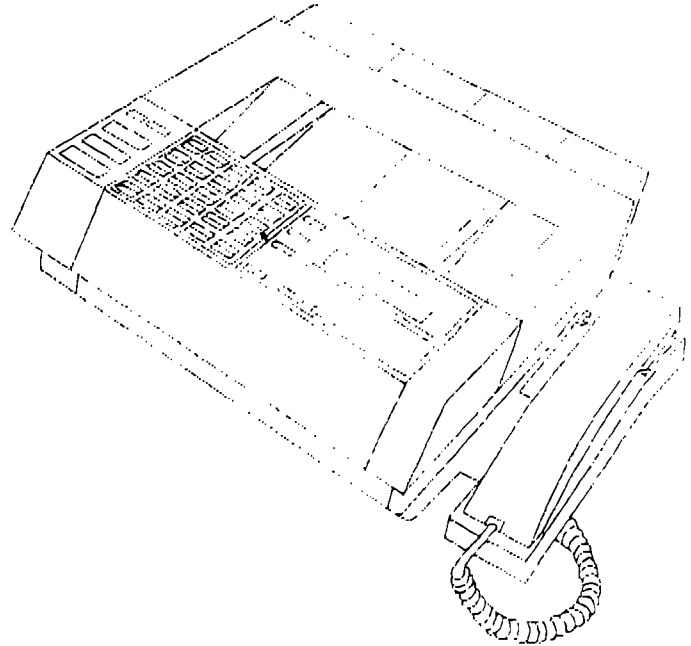
1:33:37 To:

DRAFT**D. Innovative Practices**

- 1. *Washington Hospital Center's Family Advocacy Program***
- 2. *Memorial Medical Center's Bereavement Center***
- 3. *Lifelink of Georgia Designated Minority Requestor Program***
- 4. *Albany Medical Center's "MOD Squad"***

E. Resource List for Training Programs**F. References**

DRAFT - August 10, 1999

EXECUTIVE OFFICE OF THE PRESIDENT**Office of Management and Budget****Veterans Affairs/Personnel Division****FAX COVER SHEET****DATE:** _____**TO:** Devorah Adler**AGENCY:** _____**FAX NUMBER:** _____**PHONE NUMBER:** _____**FROM:** Armine Noe / Lisa Fairhall**Personnel, Postal and EXOP Branch****PHONE NUMBER:** 395-2765**FAX NUMBER:** 202/395-5738**COMMENTS:** For Dan Mendelson**Number of Pages (including this page)** _____

To: Jack Lew

From: Dan Mendelson

Subject: White House Event Supporting Organ Donor Leave for Federal Employees

Cc: Sylvia Mathews, Josh Gotbaum

House passage last week of the H.R. 457, Organ Donor Leave Act has given us an opportunity to aggressively promote the Administration's support for organ donation. The bill encourages Federal employees to donate organs by increasing the amount of paid leave available to Federal employees for organ donation to thirty days a year. I recommend that we arrange a White House event centered around organ donation policy, where the President could either: (1) urge swift action by the Senate to enact the bill; or (2) implement the bill's content through Executive action.

This event would also enable us to send a strong signal on organs distribution in advance of the appropriations season. As you know, we were unable to remove the rider in the FY 1999 Omnibus which halted HHS's implementation of a new regulation to improve the allocation of organs. Despite some very positive substantive developments including the release of the mandated IOM study that supported the HHS position, we have been engaged in unproductive discussions with UNOS and advocates for regional organ allocation systems. Because these groups know that the appropriators are considering reinstating the moratorium, they have not negotiated in good faith. A strong signal that we support a national allocation system could really help increase the productivity of these discussions.

We have developed two options for a White House event supporting organ donor leave for Federal employees: 1) a Presidential statement, urging swift passage of the leave bill, and 2) an executive memorandum, urging agencies to begin implementing expanded availability of excused absence (administrative leave) for this purpose without delay. These options, which are discussed below, reflect input from the Office of Personnel Management, the Department of Health and Human Services, and the West Wing.

Background

Under current law, Federal employees may take up to seven days of paid leave (not counting against annual or sick leave) for an absence associated with bone marrow or organ donation. A recent survey of doctors indicates that seven days is insufficient for organ donations other than bone marrow transplants, due to longer recovery periods. The Senate Governmental Affairs Committee reported out the identical bill to H.R. 457 (S. 1334 -- Akaka (D-HI)) today, August 3. Agencies already have the discretion to approve paid excused leave in excess of seven days for these purposes, but no reliable information is available on the extent to which excused absence has been requested or approved for organ donation. The costs of either option would be negligible.

Options

1) Presidential statement. The President could immediately release a statement urging the Senate to act quickly on the Organ Donor Leave Act.

Pros: Emphasizes President's commitment to these issues, without ruffling Congressional feathers.

Demonstrates support for permanent law change favorable to Federal employees.

Cons: Does not urge or direct agencies to change their behaviors in any way.

Act may not pass this year

2) Executive Memorandum: The President could issue a memorandum to the heads of all agencies, urging them to immediately give effect, administratively, to the intent of the pending Organ Donor Leave Act, by approving excused absence of up to 30 days a year for employees who donate organs. In addition, the Presidential announcement accompanying the Memorandum could commend Congress for its work on the Organ Donor Leave Act, and urge them to quickly enact the legislation. Of course, we would need to include Cummings in the event and commend him on his work.

Pros: Gives immediate effect to intent of the legislation.

Allows President to show leadership by establishing organ donation as a priority.

Cons: Limits effect of memorandum to duration of this Administration.

Provides no statutory entitlement to the leave; approval would be at agency's discretion.

Could slow or stop enactment of a permanent legislative solution.

Recommendation: I recommend Option 2. Chris approves of doing "something" but I have not yet engaged him on the specifics of the options, pending your review. If you prefer option 1, we should get the statement out before recess. Option 2 could potentially be executed during recess. Please let me know how you would like to proceed.

UKAF 1

The White House**MEMORANDUM FOR HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES****SUBJECT: Paid Time Off for Organ Donation**

Each year almost 4,000 patients die while waiting for an organ to become available for them (an average of 11 people a day). Currently, more than 63,000 Americans are waiting for an organ transplant. Many of these deaths could have been avoided if there were a sufficient supply of donor organs.

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

Under current law, in addition to annual or sick leave, a Federal employee to use up to 7 days of paid leave each year to serve as a bone-marrow or organ donor. Recent surveys of doctors and hospitals indicate that the existing limit, while adequate for bone-marrow donation, is clearly insufficient for organ transplant procedures (e.g., kidney transplant), which typically require a longer period for recovery. Recently, the House of Representatives passed a bill, the Organ Donor Leave Act, that increases the amount of paid time off that may be used for organ donation to 30 days. I applaud this action and encourage the Senate to take speedy action to make this benefit permanent for all Federal employees.

While I expect enactment of this legislation soon, each day that goes by means the difference between life and death to potential organ recipients. Therefore, today I ask the heads of executive departments and agencies to immediately increase the amount of paid time off available for organ donation from 7 to 30 days each year by using their discretion to excuse from duty, without charge to leave or loss of pay, those Federal employees who serve as organ donors for any period beyond the 7 days of paid leave currently provided by law when additional time is needed for treatment or recovery.

It is an American tradition to work together to meet our challenges. As the Nation's largest employer, the Federal Government has a responsibility to be a leader by helping to make it possible for its employees to choose to participate in this life saving effort.

WILLIAM J. CLINTON

SEP-01-1999 12:04 AND VAP PERSONNEL POLICY 202 333738 F.01/04

EXECUTIVE OFFICE OF THE PRESIDENT
Office of Management and Budget
Veterans Affairs/Personnel Division

FAX COVER SHEET

DATE: _____

TO: Devorah Adler

AGENCY: _____

FAX NUMBER: _____

PHONE NUMBER: _____

FROM: Armine Noe / Lisa Fairhall

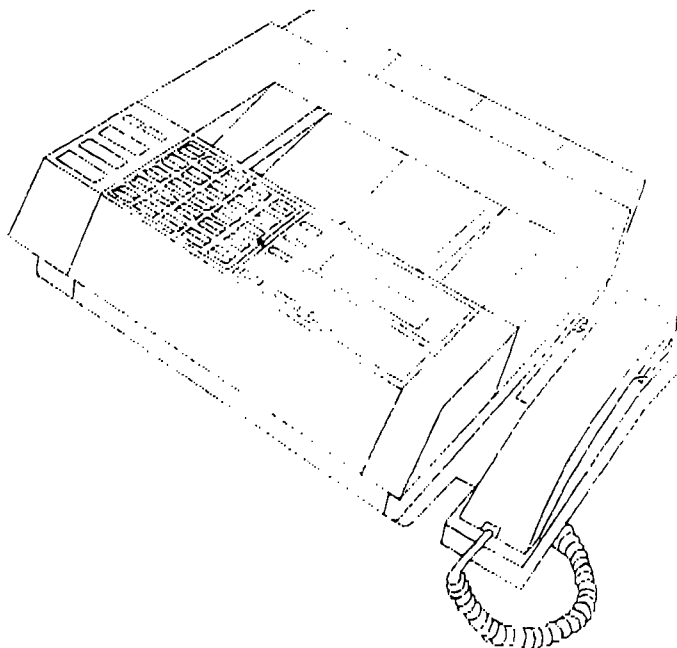
Personnel, Postal and EXOP Branch

PHONE NUMBER: 395-7765

FAX NUMBER: 202/395-5738

COMMENTS: For Dan Mendelson

Number of Pages (including this page) _____



SEP-01-1999 12:04 UID VAF PERSONNEL FULTON 202 3333135 P.02/04

To: Jack Lew

From: Dan Mendelson

Subject: White House Event Supporting Organ Donor Leave for Federal Employees

Cc: Sylvia Mathews, Josh Gotbaum

House passage last week of the H.R. 457, Organ Donor Leave Act has given us an opportunity to aggressively promote the Administration's support for organ donation. The bill encourages Federal employees to donate organs by increasing the amount of paid leave available to Federal employees for organ donation to thirty days a year. I recommend that we arrange a White House event centered around organ donation policy, where the President could either: (1) urge swift action by the Senate to enact the bill; or (2) implement the bill's content through Executive action.

This event would also enable us to send a strong signal on organs distribution in advance of the appropriations season. As you know, we were unable to remove the rider in the FY 1999 Omnibus which halted HHS's implementation of a new regulation to improve the allocation of organs. Despite some very positive substantive developments including the release of the mandated IOM study that supported the HHS position, we have been engaged in unproductive discussions with UNOS and advocates for regional organ allocation systems. Because these groups know that the appropriators are considering reinstating the moratorium, they have not negotiated in good faith. A strong signal that we support a national allocation system could really help increase the productivity of these discussions.

We have developed two options for a White House event supporting organ donor leave for Federal employees: 1) a Presidential statement, urging swift passage of the leave bill, and 2) an executive memorandum, urging agencies to begin implementing expanded availability of excused absence (administrative leave) for this purpose without delay. These options, which are discussed below, reflect input from the Office of Personnel Management, the Department of Health and Human Services, and the West Wing.

Background

Under current law, Federal employees may take up to seven days of paid leave (not counting against annual or sick leave) for an absence associated with bone marrow or organ donation. A recent survey of doctors indicates that seven days is insufficient for organ donations other than bone marrow transplants, due to longer recovery periods. The Senate Governmental Affairs Committee reported out the identical bill to H.R. 457 (S. 1334 -- Akaka (D-HI)) today, August 3. Agencies already have the discretion to approve paid excused leave in excess of seven days for these purposes, but no reliable information is available on the extent to which excused absence has been requested or approved for organ donation. The costs of either option would be negligible.

SEP-01-1999 12:05 OMB VAP PERSONNEL POLICY 202 3333738 P.03/04

Options

1) Presidential statement. The President could immediately release a statement urging the Senate to act quickly on the Organ Donor Leave Act.

Pros: Emphasizes President's commitment to these issues, without ruffling Congressional feathers.

Demonstrates support for permanent law change favorable to Federal employees.

Cons: Does not urge or direct agencies to change their behaviors in any way.

Act may not pass this year

2) Executive Memorandum: The President could issue a memorandum to the heads of all agencies, urging them to immediately give effect, administratively, to the intent of the pending Organ Donor Leave Act, by approving excused absence of up to 30 days a year for employees who donate organs. In addition, the Presidential announcement accompanying the Memorandum could commend Congress for its work on the Organ Donor Leave Act, and urge them to quickly enact the legislation. Of course, we would need to include Cummings in the event and commend him on his work.

Pros: Gives immediate effect to intent of the legislation.

Allows President to show leadership by establishing organ donation as a priority.

Cons: Limits effect of memorandum to duration of this Administration.

Provides no statutory entitlement to the leave; approval would be at agency's discretion.

Could slow or stop enactment of a permanent legislative solution.

Recommendation: I recommend Option 2. Chris approves of doing "something" but I have not yet engaged him on the specifics of the options, pending your review. If you prefer option 1, we should get the statement out before recess. Option 2 could potentially be executed during recess. Please let me know how you would like to proceed.

202 3333738 P.04/04
UKAF 1

The White House

MEMORANDUM FOR HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES

SUBJECT: Paid Time Off for Organ Donation

Each year almost 4,000 patients die while waiting for an organ to become available for them (an average of 11 people a day). Currently, more than 63,000 Americans are waiting for an organ transplant. Many of these deaths could have been avoided if there were a sufficient supply of donor organs.

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

Under current law, in addition to annual or sick leave, a Federal employee to use up to 7 days of paid leave each year to serve as a bone-marrow or organ donor. Recent surveys of doctors and hospitals indicate that the existing limit, while adequate for bone-marrow donation, is clearly insufficient for organ transplant procedures (e.g., kidney transplant), which typically require a longer period for recovery. Recently, the House of Representatives passed a bill, the Organ Donor Leave Act, that increases the amount of paid time off that may be used for organ donation to 30 days. I applaud this action and encourage the Senate to take speedy action to make this benefit permanent for all Federal employees.

While I expect enactment of this legislation soon, each day that goes by means the difference between life and death to potential organ recipients. Therefore, today I ask the heads of executive departments and agencies to immediately increase the amount of paid time off available for organ donation from 7 to 30 days each year by using their discretion to excuse from duty, without charge to leave or loss of pay, those Federal employees who serve as organ donors for any period beyond the 7 days of paid leave currently provided by law when additional time is needed for treatment or recovery.

It is an American tradition to work together to meet our challenges. As the Nation's largest employer, the Federal Government has a responsibility to be a leader by helping to make it possible for its employees to choose to participate in this life saving effort.

WILLIAM J. CLINTON



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

August 3, 1999

To: Jack Lew

From: Dan Mendelson 

Subject: White House Event Supporting Organ Donor Leave for Federal Employees

Cc: Sylvia Mathews, Josh Gotbaum

House passage last week of the H.R. 457, Organ Donor Leave Act has given us an opportunity to aggressively promote the Administration's support for organ donation. The bill encourages Federal employees to donate organs by increasing the amount of paid leave available to Federal employees for organ donation to thirty days a year. I recommend that we arrange a White House event centered around organ donation policy, where the President could either: (1) urge swift action by the Senate to enact the bill; or (2) implement the bill's content through Executive action.

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WILLIAM J. CLINTON

PRESIDENTIAL STATEMENT

Each year almost 4,000 patients die while waiting for an organ to become available for them (an average of 11 people a day). Currently, more than 63,000 Americans are waiting for an organ transplant. Although most Americans approve of organ donation, too few share the gift of life when the opportunity arises. Many of these deaths could have been avoided if there were a sufficient supply of donor organs.

Under current law, in addition to annual or sick leave, a Federal employee, may use up to 7 days of paid leave in each calendar year to serve as a bone-marrow or organ donor. Recent surveys of doctors and hospitals indicate that the existing limit is clearly insufficient for organ transplant procedures (e.g., kidney transplant).

On July 26, 1999, the House passed a bill, the Organ Donor Leave Act, that increases the amount of time Federal employees that may be used for organ donation to 30 days. This Administration and the American people applaud this action. By increasing the amount of days allotted for organ donation, this bill will encourage nearly 2 million Federal employees to set an example for our nation by participating in this life saving effort. The bill will also eliminate the financial burden placed on those Federal employees who are willing to make a personal sacrifice for others in their time of need.

Today, I am calling on the Senate to take speedy action in support of the Organ Donor Leave Act. In return, I pledge to the American people that I will do everything in my power to fully support the organ donor program by encouraging Federal employees throughout this great country to take advantage of this expanded benefit so that this needless loss of life can be eliminated.

DATE: 4/2-99

**U.S. DEPARTMENT OF
HEALTH & HUMAN SERVICES**
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200 INDEPENDENCE AVENUE, SW
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**OFFICE OF THE ASSISTANT SECRETARY FOR LEGISLATION
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TO: Chris/Devora ☒ RICHARD J. TARPLIN
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PHONE: 456-5560 ☐ ROSE CLEMENT LUSI
FAX: 456-5557 ☐ ALICE ARTIS
TOTAL PAGES _____ ☐ HAZEL FARMER
(INCLUDING COVER): 8 ☐ EDWARD WHITLEY
☐ FRANKIE MELTON

REMARKS:

Lets discuss whether we can
use this to build Frist into
WH organ donation event (if its happening)
Rich

THE GIFT OF LIFE CONGRESSIONAL MEDAL ACT OF 1999
March 2, 1999

Mr. FRIST. Mr. President, I take great pleasure today in introducing the Gift of Life Congressional Medal Act of 1999. With this legislation, which doesn't cost taxpayers a penny, Congress has the opportunity to recognize and encourage potential donors, and give hope to over 52,000 Americans who have end-stage disease. As a heart and lung transplant surgeon, I saw one in four of my patients die because of the lack of available donors. Public awareness simply has not kept up with the relatively new science of transplantation. As public servants, we need to do all we can to raise awareness about the gift of life.

Under this bill, each donor or donor family will be eligible to receive a commemorative Congressional medal. It is not expected that all families, many of whom wish to remain anonymous, will take advantage of this opportunity. The program will be coordinated by the regional organ procurement organizations [OPO's] and managed by the entity administering the Organ Procurement and Transplantation Network. Upon request of the family or individual, a public official will present the medal to the donor or the family. This creates a wonderful opportunity to honor those sharing life through donation and increase public awareness. Some researchers have estimated that it may be possible to increase the number of organ donations by 80 percent through public education.

Any one of us, or any member of our families, could need a life saving transplant. We would then be placed on a waiting list to anxiously await our turn, or our death. The number of people on the list has more than doubled since 1990 -- and a new name is added to the list every 18 minutes. In my home State of Tennessee, 62 Tennesseans died in 1998 while waiting, and more than 775 people are in need of a transplant. Nationally, because of a lack of organs, close to 5,000 listed individuals died in 1998.

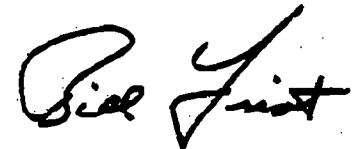
However, the official waiting list reflects only those who have been lucky enough to make it into the medical care system and to pass the financial hurdles. If you include all those reaching end-stage disease, the number of people potentially needing organs or bone marrow, very likely over 120,000, becomes staggering. Only a small fraction of that number would ever receive transplants, even if they had adequate insurance. There simply are not enough organ and tissue donors, even to meet present demand.

Federal policies surrounding the issue of organ transplantation are difficult. Whenever you deal with whether someone lives or dies, there are no easy answers. There are between 15,000 and 20,000 potential cadaveric donors each year, yet inexcusably, in 1997 there were only some 5,400 actual donors. That's why we need you to help us educate others about the facts surrounding tissue and organ donation.

Mr. President, there has been unprecedented cooperation, on both sides of the aisle, and a growing commitment to awaken public compassion on behalf of those who need organ transplants. It is my very great pleasure to introduce this bill on behalf of a group of Senators who have already contributed in extremely significant ways to the cause of organ transplantation. And we are proud to ask you to join us, in encouraging people to give life to others.

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S.L.C.

106TH CONGRESS
1ST SESSION**S.** _____

IN THE SENATE OF THE UNITED STATES

Mr. FRIST (for himself, Mr. JEFFORDS, Mr. DORGAN, Mr. LEVIN, Mrs. MURRAY, Mr. DEWINE, Mr. MURKOWSKI, Mr. THURMOND, Mr. DURBIN, and Mr. INOUE) introduced the following bill; which was read twice and referred to the Committee on _____

A BILL

To establish a congressional commemorative medal for organ donors and their families.

1 *Be it enacted by the Senate and House of Representu-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the "Gift of Life Congres-
5 sional Medal Act of 1999".

6 **SEC. 2. CONGRESSIONAL MEDAL.**

7 The Secretary of the Treasury shall design and strike
8 a bronze medal with suitable emblems, devices, and in-
9 scriptions, to be determined by the Secretary of the Treas-
10 ury, to commemorate organ donors and their families.

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1 **SEC. 3. ELIGIBILITY REQUIREMENTS.**

2 (a) IN GENERAL.—Any organ donor, or the family
3 or family member of any organ donor, shall be eligible for
4 a medal described in section 2.

5 (b) DOCUMENTATION.—The Secretary of Health and
6 Human Services shall direct the entity holding the Organ
7 Procurement and Transplantation Network (hereafter in
8 this Act referred to as "OPTN") to contract to—

9 (1) establish an application procedure requiring
10 the relevant organ procurement organization, as de-
11 scribed in section 371(b)(1) of the Public Health
12 Service Act (42 U.S.C. 273(b)(1)), through which an
13 individual or their family made an organ donation,
14 to submit to the OPTN contractor documentation
15 supporting the eligibility of that individual or their
16 family to receive a medal described in section 2; and

17 (2) determine, through the documentation pro-
18 vided, and, if necessary, independent investigation,
19 whether the individual or family is eligible to receive
20 a medal described in section 2.

21 **SEC. 4. PRESENTATION.**

22 (a) DELIVERY TO THE SECRETARY OF HEALTH AND
23 HUMAN SERVICES.—The Secretary of the Treasury shall
24 deliver medals struck pursuant to this Act to the Secretary
25 of Health and Human Services.

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1 (b) DELIVERY TO ELIGIBLE RECIPIENTS.—The Sec-
2 retary of Health and Human Services shall direct the
3 OPTN contractor to arrange for the presentation to the
4 relevant organ procurement organization all medals struck
5 pursuant to this Act to individuals or families that, in ac-
6 cordance with section 3, the OPTN contractor has deter-
7 mined to be eligible to receive medals under this Act.

8 (c) LIMITATION.—

9 (1) IN GENERAL.—Except as provided in para-
10 graph (2), only 1 medal may be presented to a fam-
11 ily under subsection (b). Such medal shall be pre-
12 sented to the donating family member, or in the case
13 of a deceased donor, the family member who signed
14 the consent form authorizing, or who otherwise au-
15 thorized, the donation of the organ involved.

16 (2) EXCEPTION.—In the case of a family in
17 which more than 1 member is an organ donor, the
18 OPTN contractor may present an additional medal
19 to each such organ donor or their family.

20 SEC. 5. DUPLICATE MEDALS.

21 (a) IN GENERAL.—The Secretary of Health and
22 Human Services or the OPTN contractor may provide du-
23 plicates of the medal described in section 2 to any recipi-
24 ent of a medal under section 4(b), under such regulations

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1 as the Secretary of Health and Human Services may
2 issue.

3 (b) LIMITATION.—The price of a duplicate medal
4 shall be sufficient to cover the cost of such duplicates.

5 **SEC. 6. NATIONAL MEDALS.**

6 The medals struck pursuant to this Act are national
7 medals for purposes of section 5111 of title 31, United
8 States Code.

9 **SEC. 7. GENERAL WAIVER OF PROCUREMENT REGULA-**
10 **TIONS.**

11 No provision of law governing procurement or public
12 contracts shall be applicable to the procurement of goods
13 or services necessary for carrying out the provisions of this
14 Act.

15 **SEC. 8. SOLICITATION OF DONATIONS.**

16 (a) IN GENERAL.—The Secretary of the Treasury
17 may enter into an agreement with the OPTN contractor
18 to collect funds to offset expenditures relating to the issu-
19 ance of medals authorized under this Act.

20 (b) PAYMENT OF FUNDS.—

21 (1) IN GENERAL.—Except as provided in para-
22 graph (2), all funds received by the Organ Procure-
23 ment and Transplantation Network under subsection
24 (a) shall be promptly paid by the Organ Procure-

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1 ment and Transplantation Network to the Secretary
2 of the Treasury.

3 (2) LIMITATION.—Not more than 5 percent of
4 any funds received under subsection (a) shall be
5 used to pay administrative costs incurred by the
6 OPTN contractor as a result of an agreement estab-
7 lished under this section.

8 (c) NUMISMATIC PUBLIC ENTERPRISE FUND.—Not-
9 withstanding any other provision of law—

10 (1) all amounts received by the Secretary of the
11 Treasury under subsection (b)(1) shall be deposited
12 in the Numismatic Public Enterprise Fund, as de-
13 scribed in section 5134 of title 31, United States
14 Code; and

15 (2) the Secretary of the Treasury shall charge
16 such fund with all expenditures relating to the issu-
17 ance of medals authorized under this Act.

18 (d) START-UP COSTS.—A 1-time amount not to ex-
19 ceed \$55,000 shall be provided to the OPTN contractor
20 to cover initial start-up costs. The amount will be paid
21 back in full within 3 years of the date of the enactment
22 of this Act from funds received under subsection (a).

23 (e) NO NET COST TO THE GOVERNMENT.—The Sec-
24 retary of the Treasury shall take all actions necessary to

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1 ensure that the issuance of medals authorized under sec-
2 tion 2 results in no net cost to the Government.

3 **SEC. 9. DEFINITIONS.**

4 In this Act:

5 (1) **ORGAN.**—The term “organ” means the
6 human kidney, liver, heart, lung, pancreas, and any
7 other human organ (other than corneas and eyes)
8 specified by regulation of the Secretary of Health
9 and Human Services or the OPTN contractor.

10 (2) **ORGAN PROCUREMENT AND TRANSPLAN-**
11 **TATION NETWORK.**—The term “Organ Procurement
12 and Transplantation Network” means the Organ
13 Procurement and Transplantation Network estab-
14 lished under section 372 of the Public Health Serv-
15 ice Act (42 U.S.C. 274).

16 **SEC. 10. SUNSET PROVISION.”**

17 This Act shall be effective during the 5-year period
18 beginning on the date of the enactment of this Act.



FACSIMILE

From the Immediate Office of the Secretary Executive Secretariat

To: Dan Mendelson
Fax#: 395-~~5648~~ 5631
Re: _____
Date: 1-21-99

Pages: including this cover sheet _____

From the desk of:

☐ LaVarne Burton	☒ Jackie White
☐ Sandy Bart	☐ John Gallivan
☐ Kimberly Harold	☐ Carlos McCormick
☐ Christy Quigley	☐ Martina Varnado
☐ Mirtha Beadle	☐ Ann White
☐ Scott Boule	☐ Melvin Whitfield
☐ LaJuana Caldwell	☐ Other _____
☐ Carlos Cano	
☐ Sean Donohue	
☐ Neleen Eisenger	
☐ Lorraine Fishback	
☐ Johnathan Frieber	

Comments: _____

U.S. Department of Health and Human Services
Immediate Office of the Secretary- Executive Secretariat

200 Independence Avenue SW
Washington, DC 20201
Fax: 205-8870 or 205-2135

HHS NEWS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

FOR IMMEDIATE RELEASE
January 22, 1999

Contact: HRSA Press Office
301-443-3376

Report Shows Significant Waiting Time Disparities for Organ Transplant Recipients

The Department of Health and Human Services today released a report showing wide disparities in the length of time patients wait for organ transplants in different geographic areas of the United States. Organ allocation policies in effect during the period covered by the report were a significant cause of the disparities, HHS said. And while some changes in these policies have been made, fundamental improvements are still needed to ensure fair treatment for patients.

The 1997 Report of the OPTN: Waiting List Activity and Donor Procurement is the first publication by the organ transplant network to include data on local waiting times. For the largest category of patients, waiting times ranged from 46 days in Iowa to 721 days in western Pennsylvania.

"This report contains some of the strongest evidence yet that our nation's organ transplantation system needs improvement," HHS Secretary Donna E. Shalala said. "It makes clearer than ever that patients can be disadvantaged by the simple fact of where they live and at what transplant center they are listed.

"Our organ transplant system doesn't have to work that way, and it shouldn't," Secretary Shalala said. "Organs donated for transplantation should go to patients on the basis of medical criteria, not geography. Organs should not be denied to patients who need them simply because of arbitrary boundaries that have no medical rationale."

Under HHS regulations published last year, transplant professionals would be required to develop new policies for the transplant network to replace current allocation rules. The new policies would help assure that organs would go to patients with greatest medical need, in accordance with sound medical judgment and effective use of the organs. The current rules often require organs to be used in the local area where they have been procured, instead of being provided to patients with higher medical need, even when such patients may be located in nearby areas. HHS' regulations are set to take effect on Oct. 21, 1999, and the Institute of Medicine has been asked by Congress to review the effect of the regulations.

- MORE -

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The current allocation rules are a primary cause of the disparity in waiting times for organs in different parts of the nation, and these rules result in higher-than-necessary number of deaths among those who are waiting for organs, according to HHS' Health Resources and Services Administration. A reformed system that allocated organs on the basis of medical criteria, without arbitrary geographic constraints, would result in more organs for those with greatest medical need, and thus would result in fewer deaths, according to HRSA.

Today's report provides numerous examples of the disparities, measured according to several different categories of patients. In some cases there are significant differences in waiting times even between adjacent areas. For example, the median waiting time for liver transplant patients with similar medical status was 439 days in the Baltimore area, compared with 147 days in nearby Washington, D.C.

For patients with blood type O (representing about 47 percent of all liver transplant patients), the median waiting time was 511 days in New York City, while the median waiting time in bordering northern New Jersey was 56 days. Iowa, with the shortest waiting time among all 66 organ procurement areas at 46 days, compared with neighboring Nebraska at 596 days. *(Editors: A map showing type O waiting times is available.)*

"An organ that could save a life may be literally stopped at the border, and denied to a patient for non-medical reasons," Secretary Shalala said. "Because of organ allocation rules that put geography ahead of medical need, the more urgent patient in one area may be unable to get a liver for transplantation, even when it comes available in the state or the city next door. That's not in the best interest of patients or those who care for them."

Significant differences also existed in organ recovery activity, with some organ procurement organizations reporting significantly higher rates than others. HHS took action last year to require the nation's hospitals to report virtually all deaths to their local organ procurement organization (OPO), thus providing more opportunity for OPOs to contact the families of potential donors and increase organ donation nationwide. In addition, the pending HHS regulation that would require changes in organ allocation policy would also help provide a fairer system for patients, regardless of differences in OPO recovery rates.

Today's study includes data on local waiting times across the country for patients placed on a transplant waiting list during two periods of time: 1993 to 1995 for kidneys, and 1994 to 1996 for pancreas, kidney-pancreas, hearts, livers and lungs. The report also documents the number of registered patients transplanted, organ recovery rates from 1994 to 1996 for each OPO, and waiting list activity (additions and removals) for each transplant program nationwide.

Median waiting times differ significantly for all organs depending upon where a patient lives or is listed, as well as patient characteristics such as medical urgency, blood type, age, race and, for kidneys, immune sensitization.

- MORE -

- 3 -

In addition to biologic factors, waiting times appear to be influenced by the demographics of an OPO area, rates of donation, OPO donation request and consent procedures, and transplant center registration and organ acceptance policies.

"This report is a step forward, but it is still not the kind of timely and user-friendly information that patients and their physicians really need," said HRSA Administrator Claude Earl Fox, M.D., M.P.H. "Our goal is for future reports to present more current information in a form that is more understandable for patients, their families and their physicians, including waiting time data for each transplant center."

The report released today totals 2,400 pages in seven separate volumes. It was produced by the United Network for Organ Sharing, a private, nonprofit organization based in Richmond, Va., under contract with HRSA, the HHS agency responsible for administering the organ transplantation system. The pending HHS regulation also requires more current information from the organ transplant network.

Today's report includes an executive summary and six additional organ-specific volumes with tables on OPO-specific median waiting times, number of patients transplanted and donor procurement activity, as well as waiting list activity (with additions and removals) for each transplant center. A graphical analysis is presented on median waiting time data. Because greatly variable circumstances surround waiting times, many OPOs accepted the offer to include a narrative explaining the issues affecting their waiting times and donor procurement activity. Each volume has a user's guide containing frequently asked questions, and background on statistical methods, data collection and analysis and the multiple issues that impact waiting times.

The new report should be used in conjunction with *The 1997 Report of Center Specific Graft and Patient Survival Rates*, released by HHS in December 1997, which provides historical data on actual and expected survival rates for nearly 100,000 transplants. It showed overall survival rates for transplants at an all-time high, with three-year patient survival rates ranging from 75.9 percent for lung recipients, to 81.2 percent for heart-lung, to more than 90 percent for kidney, liver, heart and pancreas.

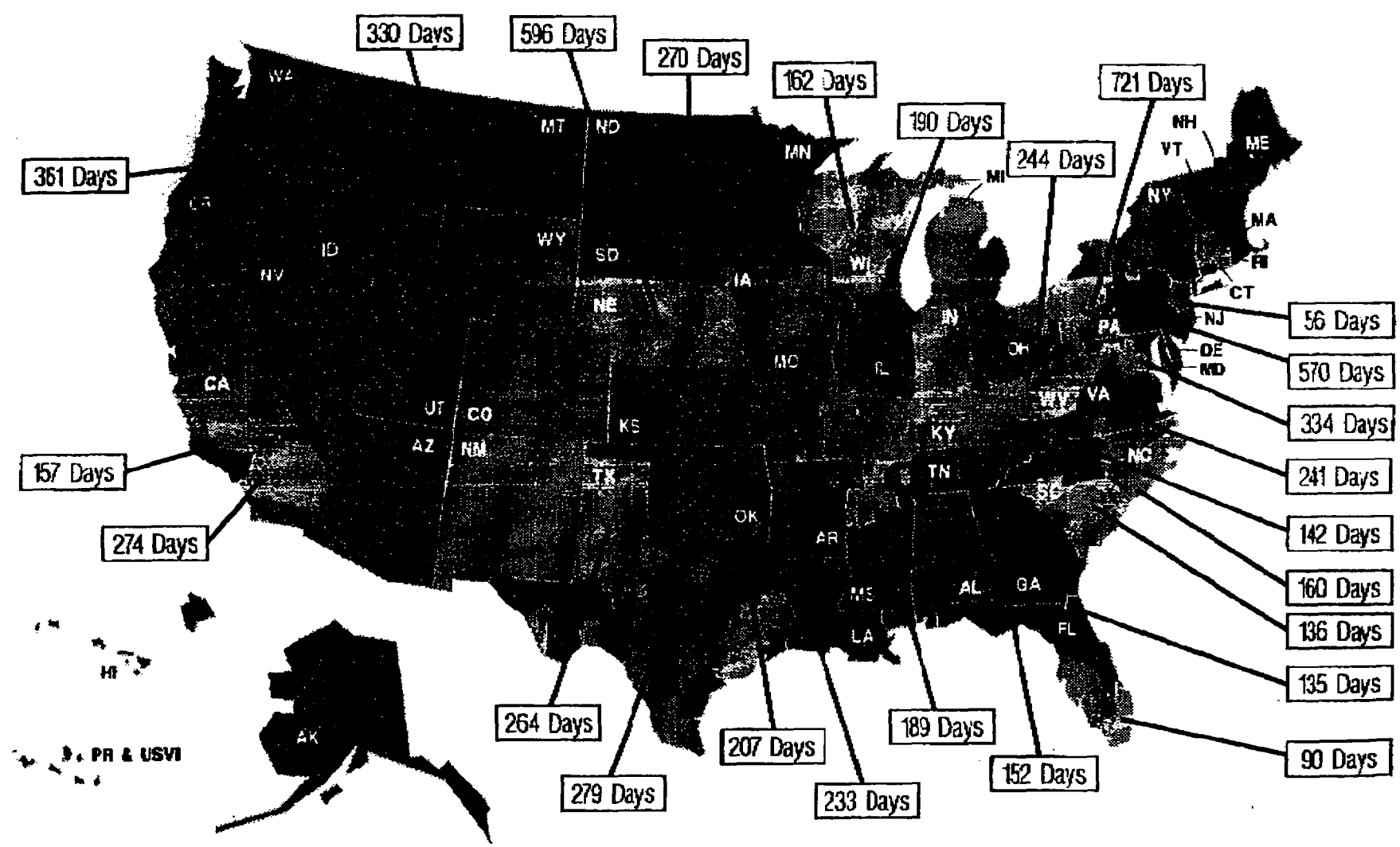
The executive summary of *The 1997 Report of the OPTN: Waiting List Activity and Donor Procurement* can be accessed from UNOS' World Wide Web site at www.unos.org. Organ-specific volumes may be ordered by calling UNOS at 804-330-8541. For specific volumes of the report, purchasers will be required to pay shipping and handling charges.

Other reports, including *The 1997 Report of Center Specific Graft and Patient Survival Rates* and *The Annual Report of the OPTN and Scientific Registry*, are also available on the UNOS Web site.

###

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

Waiting Times for Liver Transplants Vary Widely



Source: 1997 Report of the OPTN: Waiting List Activity and Donor Procurement, Blood Type O Patients.

DUKE UNIVERSITY MEDICAL CENTER



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILEDATE November 4, 1998

TO: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):

Karen Wang for Sarah BianchiDPC(202) 456-5572

FROM: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):

Lisa Gilmore
Special Assistant to the Deputy Secretary
Department of Health & Human Services202/690-6133FAX: 202/690-7755RECIPIENT'S FAX NUMBER (202) 456-5557NUMBER OF PAGES TO SEND (INCLUDING COVER SHEET): 3

COMMENTS:

As requested. I'm leaving
at 11:30 am today for a meeting
but will be available again
tomorrow morning. Thanks.

Lisa



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

MEMORANDUM

NOV - 4 1998

TO: Sarah Bianchi

From: Lisa A. Gilmore *L. A. Gilmore*

Subject: Update on August 25, 1998 letter from Congressman Stokes on the National Organ and Tissue Donation Initiative

As you requested, the following is an update on the request from Congressman Stokes for the participation of minority-based organizations in the planning and implementation phases of the National Organ and Tissue Donation Initiative ("National Initiative"). If you have any questions, please call me at 202-690-6133 before 11:30 a.m. today or anytime on Thursday or Friday.

- The National Minority Organ and Tissue Transplant Education Program (MOTTEP), funded by HHS, has been identified in the National Initiative materials (press release and fact sheet) as a partner in the National Initiative since its launch on December 15, 1998.
- MOTTEP, the American Society of Minority Health and Transplant Surgeons (ASMHTP), the UNOS Minority Affairs Committee, the Georgia Coalition on Donation, and other minority-based organizations and individuals are currently assisting HHS in the development of a minority donation strategy as part of the National Initiative. HHS staff have met with Dr. Clive Callender, Principal Investigator and Founder of MOTTEP, on several occasions. HHS staff have also made presentations on the National Initiative at meetings of the ASMHTP membership; the UNOS Minority Affairs Committee chaired by Dr. Callender; and other organizations where feedback on the initiative was solicited and received.
- Dr. Clive Callender has told HHS staff that he is now "very satisfied with our process" on the National Initiative. He told me yesterday that he will call Fredette West in Congressman Stokes' Office to convey this message when Dr. Callender returns to his office next week.
- The contributions of minority-based organizations have been highlighted as key components of the National Initiative. For example, Vice President Al Gore announced the partnership between HHS and the Congress of National Black Churches (CNBC), a coalition of eight historically black denominations representing 65,000 churches with over 20 million members, at the 1997 National Donor Recognition Ceremony in Washington, D.C. HHS sponsored a meeting on May 12-13, 1998 to build bridges between CNBC affiliates and transplant organizations for organ, tissue, and marrow donation. In addition, HHS' Office of Minority Health's May 1998 *Closing the Gap* newsletter issue on the National Initiative included an article on MOTTEP. HHS also published several articles on minority donation and transplantation in the Winter 1998 *Journal for Minority Medical Students*.

Memorandum to S. Bianchi

November 4, 1998

Page 2

- An op-ed on minority donation for National Donor Sabbath Weekend, November 13-15, by HHS Deputy Secretary Kevin Thurm and CNBC Executive Director Sullivan Robinson will be sent to African-American press next week.
- We have worked with MOTTEP and UNOS to provide materials on the MOTTEP/UNOS/ASMHTP partnership with the National Medical Association and the Student National Medical Association for inclusion in an upcoming mailing to the American Medical Association state chapters.

THE GIFT OF LIFE CONGRESSIONAL MEDAL ACT OF 1999
March 2, 1999

Mr. FRIST. Mr. President, I take great pleasure today in introducing the Gift of Life Congressional Medal Act of 1999. With this legislation, which doesn't cost taxpayers a penny, Congress has the opportunity to recognize and encourage potential donors, and give hope to over 52,000 Americans who have end-stage disease. As a heart and lung transplant surgeon, I saw one in four of my patients die because of the lack of available donors. Public awareness simply has not kept up with the relatively new science of transplantation. As public servants, we need to do all we can to raise awareness about the gift of life.

Under this bill, each donor or donor family will be eligible to receive a commemorative Congressional medal. It is not expected that all families, many of whom wish to remain anonymous, will take advantage of this opportunity. The program will be coordinated by the regional organ procurement organizations [OPO's] and managed by the entity administering the Organ Procurement and Transplantation Network. Upon request of the family or individual, a public official will present the medal to the donor or the family. This creates a wonderful opportunity to honor those sharing life through donation and increase public awareness. Some researchers have estimated that it may be possible to increase the number of organ donations by 80 percent through public education.

Any one of us, or any member of our families, could need a life saving transplant. We would then be placed on a waiting list to anxiously await our turn, or our death. The number of people on the list has more than doubled since 1990 -- and a new name is added to the list every 18 minutes. In my home State of Tennessee, 62 Tennesseans died in 1998 while waiting, and more than 775 people are in need of a transplant. Nationally, because of a lack of organs, close to 5,000 listed individuals died in 1998.

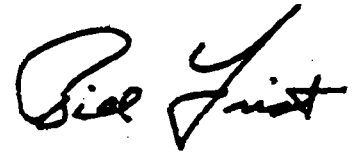
However, the official waiting list reflects only those who have been lucky enough to make it into the medical care system and to pass the financial hurdles. If you include all those reaching end-stage disease, the number of people potentially needing organs or bone marrow, very likely over 120,000, becomes staggering. Only a small fraction of that number would ever receive transplants, even if they had adequate insurance. There simply are not enough organ and tissue donors, even to meet present demand.

Federal policies surrounding the issue of organ transplantation are difficult. Whenever you deal with whether someone lives or dies, there are no easy answers. There are between 15,000 and 20,000 potential cadaveric donors each year, yet inexcusably, in 1997 there were only some 5,400 actual donors. That's why we need you to help us educate others about the facts surrounding tissue and organ donation.

Mr. President, there has been unprecedented cooperation, on both sides of the aisle, and a growing commitment to awaken public compassion on behalf of those who need organ transplants. It is my very great pleasure to introduce this bill on behalf of a group of Senators who have already contributed in extremely significant ways to the cause of organ transplantation. And we are proud to ask you to join us, in encouraging people to give life to others.

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S.L.C.

106TH CONGRESS
1ST SESSION**S.** _____

IN THE SENATE OF THE UNITED STATES

Mr. FRIST (for himself, Mr. JEFFORDS, Mr. DORGAN, Mr. LEVIN, Mrs. MURRAY, Mr. DEWINE, Mr. MURKOWSKI, Mr. THURMOND, Mr. DURBIN, and Mr. INOUE) introduced the following bill; which was read twice and referred to the Committee on _____

A BILL

To establish a congressional commemorative medal for organ donors and their families.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the "Gift of Life Congres-
5 sional Medal Act of 1999".

6 **SEC. 2. CONGRESSIONAL MEDAL.**

7 The Secretary of the Treasury shall design and strike
8 a bronze medal with suitable emblems, devices, and in-
9 scriptions, to be determined by the Secretary of the Treas-
10 ury, to commemorate organ donors and their families.

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1 **SEC. 3. ELIGIBILITY REQUIREMENTS.**

2 (a) IN GENERAL.—Any organ donor, or the family
3 or family member of any organ donor, shall be eligible for
4 a medal described in section 2.

5 (b) DOCUMENTATION.—The Secretary of Health and
6 Human Services shall direct the entity holding the Organ
7 Procurement and Transplantation Network (hereafter in
8 this Act referred to as “OPTN”) to contract to—

9 (1) establish an application procedure requiring
10 the relevant organ procurement organization, as de-
11 scribed in section 371(b)(1) of the Public Health
12 Service Act (42 U.S.C. 273(b)(1)), through which an
13 individual or their family made an organ donation,
14 to submit to the OPTN contractor documentation
15 supporting the eligibility of that individual or their
16 family to receive a medal described in section 2; and

17 (2) determine, through the documentation pro-
18 vided, and, if necessary, independent investigation,
19 whether the individual or family is eligible to receive
20 a medal described in section 2.

21 **SEC. 4. PRESENTATION.**

22 (a) DELIVERY TO THE SECRETARY OF HEALTH AND
23 HUMAN SERVICES.—The Secretary of the Treasury shall
24 deliver medals struck pursuant to this Act to the Secretary
25 of Health and Human Services.

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1 (b) DELIVERY TO ELIGIBLE RECIPIENTS.—The Sec-
2 retary of Health and Human Services shall direct the
3 OPTN contractor to arrange for the presentation to the
4 relevant organ procurement organization all medals struck
5 pursuant to this Act to individuals or families that, in ac-
6 cordance with section 3, the OPTN contractor has deter-
7 mined to be eligible to receive medals under this Act.

8 (c) LIMITATION.—

9 (1) IN GENERAL.—Except as provided in para-
10 graph (2), only 1 medal may be presented to a fam-
11 ily under subsection (b). Such medal shall be pre-
12 sented to the donating family member, or in the case
13 of a deceased donor, the family member who signed
14 the consent form authorizing, or who otherwise au-
15 thorized, the donation of the organ involved.

16 (2) EXCEPTION.—In the case of a family in
17 which more than 1 member is an organ donor, the
18 OPTN contractor may present an additional medal
19 to each such organ donor or their family.

20 SEC. 5. DUPLICATE MEDALS.

21 (a) IN GENERAL.—The Secretary of Health and
22 Human Services or the OPTN contractor may provide du-
23 plicates of the medal described in section 2 to any recipi-
24 ent of a medal under section 4(b), under such regulations

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1 as the Secretary of Health and Human Services may
2 issue.

3 (b) LIMITATION.—The price of a duplicate medal
4 shall be sufficient to cover the cost of such duplicates.

5 **SEC. 8. NATIONAL MEDALS.**

6 The medals struck pursuant to this Act are national
7 medals for purposes of section 5111 of title 31, United
8 States Code.

9 **SEC. 7. GENERAL WAIVER OF PROCUREMENT REGULA-**
10 **TIONS.**

11 No provision of law governing procurement or public
12 contracts shall be applicable to the procurement of goods
13 or services necessary for carrying out the provisions of this
14 Act.

15 **SEC. 8. SOLICITATION OF DONATIONS.**

16 (a) IN GENERAL.—The Secretary of the Treasury
17 may enter into an agreement with the OPTN contractor
18 to collect funds to offset expenditures relating to the issu-
19 ance of medals authorized under this Act.

20 (b) PAYMENT OF FUNDS.—

21 (1) IN GENERAL.—Except as provided in para-
22 graph (2), all funds received by the Organ Procure-
23 ment and Transplantation Network under subsection
24 (a) shall be promptly paid by the Organ Procure-

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1 ment and Transplantation Network to the Secretary
2 of the Treasury.

3 (2) LIMITATION.—Not more than 5 percent of
4 any funds received under subsection (a) shall be
5 used to pay administrative costs incurred by the
6 OPTN contractor as a result of an agreement estab-
7 lished under this section.

8 (c) NUMISMATIC PUBLIC ENTERPRISE FUND.—Not-
9 withstanding any other provision of law—

10 (1) all amounts received by the Secretary of the
11 Treasury under subsection (b)(1) shall be deposited
12 in the Numismatic Public Enterprise Fund, as de-
13 scribed in section 5134 of title 31, United States
14 Code; and

15 (2) the Secretary of the Treasury shall charge
16 such fund with all expenditures relating to the issu-
17 ance of medals authorized under this Act.

18 (d) START-UP COSTS.—A 1-time amount not to ex-
19 ceed \$55,000 shall be provided to the OPTN contractor
20 to cover initial start-up costs. The amount will be paid
21 back in full within 3 years of the date of the enactment
22 of this Act from funds received under subsection (a).

23 (e) NO NET COST TO THE GOVERNMENT.—The Sec-
24 retary of the Treasury shall take all actions necessary to

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1 ensure that the issuance of medals authorized under sec-
2 tion 2 results in no net cost to the Government.

3 **SEC. 9. DEFINITIONS.**

4 In this Act:

5 (1) **ORGAN.**—The term “organ” means the
6 human kidney, liver, heart, lung, pancreas, and any
7 other human organ (other than corneas and eyes)
8 specified by regulation of the Secretary of Health
9 and Human Services or the OPTN contractor.

10 (2) **ORGAN PROCUREMENT AND TRANSPLAN-**
11 **TATION NETWORK.**—The term “Organ Procurement
12 and Transplantation Network” means the Organ
13 Procurement and Transplantation Network estab-
14 lished under section 372 of the Public Health Serv-
15 ice Act (42 U.S.C. 274).

16 **SEC. 10. SUNSET PROVISION.**

17 This Act shall be effective during the 5-year period
18 beginning on the date of the enactment of this Act.

WRIGHT, LINDSEY & JENNINGS LLP
200 West Capitol Avenue, Suite 2200
Little Rock, Arkansas 72201-3699

(501) 371-0808

FACSIMILE COVER SHEET

PLEASE DELIVER IMMEDIATELY

Chris

I don't know if
it is too late to
do anything
about this, but
thought you
should have.

Date: October 21, 1998

Fax No.: 202/456-2983 *Bruce*

TO: Mr. Bruce Lindsey

FROM: John R. Tisdale

Our Fax No.: (501) 376-9442

TOTAL PAGES INCLUDING THIS PAGE: 8

REMARKS:

Confirmation: ☐ by Regular Mail ☐ by Expedited Mail ☐ None

DOCUMENT TRANSMITTED:

Ref. No. 11665-32730

Atty No. 27

If all pages not received, please contact: Melissa Courtway at (501) 212-1331

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MEMORANDUM

TO: Bruce Lindsey
FROM: John Tisdale
DATE: October 21, 1998
RE: Section 213 of the Omnibus Budget Act

There are some minor modifications which should be made to this provision of the Act if the study to be conducted is to consider the benefits to patients rather than only the benefits to transplant centers. I have marked the changes on the copy of the wording of the Act as it has been provided to me, and have initialled those changes. The most important change is on page 2 of the faxed material on line 19. Specifically, the study should include a review of the impact of various allocation systems on patient deaths while awaiting transplant and total patient life years saved. These are two criteria which are very important to patients and are considered now by HHS and the OPTN when they evaluate allocation systems.

The second most important change is on page 5 of the faxed material on line 8. The phrase "and state laws" should be deleted. With this language in the statute, it appears that state law could override the requirements of this Act and prohibit disclosure of information to HHS or the Institute of Medicine.

The next change is on page 3 of the faxed materials on line 8. This change directs that the Institute of Medicine will deliver its report both to the Secretary and to the Congressional Committees. I think this was an oversight since the legislation nowhere provides that the IOM will give a copy of the report to the Secretary.

As I mentioned to you last night, I was a spectator yesterday at a meeting of the UNOS Liver and Intestine Committee in Dallas. At that meeting, the Chair of the Committee stated that the strategy for UNOS during this one year moratorium is to pass a reauthorization of the National Organ Transplant Act which will restrict or eliminate any rulemaking authority of the Secretary with respect to the policies of the OPTN.

Thanks for your help. With respect to these changes, I would anticipate that none of them should be controversial, except possibly the elimination of the reference to state laws.

JRT:mc

FROM HMK&S

(THU) 10.15' 98 14:38/ST. 14:37/NO. 4261808006 P 2

10-16-98 17:42 From
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T-200 P.02/10 P-400

1 **SEC. [218].** (a) The final rule entitled "Organ Pro-
2 curement and Transplantation Network", promulgated by
3 the Secretary of Health and Human Services on April 2,
4 1998 (63 FR 16296 et seq.) (relating to part 121 of title
5 42, Code of Federal Regulations), shall not become effec-
6 tive before the expiration of the 1-year period beginning
7 on the date of the enactment of this Act.

8 (b)(1) The Institute of Medicine (under contract with
9 the Comptroller General ~~of the United States~~) in
10 consultation with the Secretary and with the Organ Pro-

11 curement and Transplantation Network (in this section re-
12 ferred to as the "OPTN"), shall conduct a review of the
13 current policies of the OPTN and the final rule specified
14 in subsection (a) in order to determine the following:

15 (A) The potential impact on access to trans-
16 plantation services for low-income populations and
17 for racial and ethnic minority groups. With respect
18 to State policies in carrying out the program under
19 title XIX of the Social Security Act, the determina-
20 tion made under this subparagraph shall include de-
21 termining the impact of such policies regarding pay-
22 ment for services for patients that are provided to
23 the patients outside of the States in which the pa-
24 tients reside.

Organ Pro-
curement
and Trans-
plantation
Network
(the "OPTN")

FROM HMK&S

10-16-98

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(B) With respect to organ procurement organizations (qualified under section 371 of the Public Health Service Act):

(i) The potential impact on the ability of the organizations to facilitate an appropriate rate of organ donation within the service areas of the organizations.

(ii) The reasons underlying the variations in performance among such organizations.

~~THE POTENTIAL IMPACT OF SHARING OF ORGANS BASED ON MEDICAL CRITERIA INSTEAD OF GEOGRAPHY ON THE ABILITY OF THE ORGANIZATIONS TO FACILITATE AN APPROPRIATE RATE OF ORGAN DONATION WITHIN THE SERVICE AREAS OF THE ORGANIZATIONS.~~

(C) The potential impact on waiting times for organ transplants, including determinations specific to the various geographic regions of the United States, and if practicable, waiting times for each transplant center by organ and medical status category. The determination made under this subparagraph shall include determining the impact of recent changes made by the OPTN in patient listing criteria and in measures of medical status.

(D) The potential impact on patient survival rates and organ failure rates which lead to re-transplantation, including any variance by income status, ethnicity, gender, race, or blood type.

(E) The potential impact on the costs of organ transplantation services.

yes

deaths while awaiting transplant, total life years saved and

FROM HMK&S

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10-14-98 17:42 From

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T-000 P.04/10 P-000

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1 (F) The potential impact on the liability, under
 2 State laws and procedures regarding peer review, of
 3 members of the OPTN.

4 (G) The potential impact on the confidential
 5 status of information that relates to the transplan-
 6 tation of organs.

7 ~~Not later than May 1, 1999, the Comptroller~~
 8 (H) Not later than May 1, 1999, the Comptroller

9 General of the United States shall submit to the congres-
 10 sional committees specified in subparagraph (B) a report
 11 describing the results of the review conducted under para-
 12 graph (1).

13 (B) The congressional committees referred to in sub-
 14 paragraph (A) are the Committee on Commerce of the
 15 House of Representatives, the Committee on Appropria-
 16 tions of the House, the Committee on Labor and Human
 17 Resources of the Senate, and the Committee on Appro-
 18 priations of the Senate.

19 (c)(1) Beginning promptly after the date of the enact-
 20 ment of this Act, the Secretary may conduct a series of
 21 discussions with the OPTN in order to resolve issues
 22 raised by the final rule referred to in subsection (a).

23 (2) The Secretary and the OPTN may utilize the
 24 services of a mediator in conducting the discussions under
 25 paragraph (1). An individual may not be selected to serve
 as the mediator unless the Secretary and the Network

*Recommendation
 if any, to change
 existing policies
 and the final
 rule.*

*Secretary
 and the*

FROM HMK&S

(THU) 10. 15' 98 14:38/ST. 14:37/NO. 4261808006 P. 5

10-16-98 17:42 P:MP
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T-200 P.05/10 F-400

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1 both approve the selection of the individual to so serve,
 2 and the individual agrees that, not later than June 30,
 3 1998, the individual will submit to the congressional com-
 4 mittees specified in subsection (b)(2)(B) a report describ-
 5 ing the extent of progress that has been made through
 6 the discussions under paragraph (1).

7 (d)(1) Beginning on the date of enactment of this
 8 Act, the OPTN shall provide to the Secretary, the Insti-
 9 tutes of Medicine, and the Comptroller General, upon re-
 10 quest, any data necessary to assess the effectiveness of
 11 the Nation's organ donation, procurement and organ allo-
 12 cation systems, or to assess the quality of care provided
 13 to all transplant patients, and analysis of such data (as
 14 determined by the OPTN to be) scientifically and clinically

15 valid manner. *If necessary, THE OPTN may provide additional data*
 16 *as they deem appropriate.*

17 (2) The OPTN shall make available to the public
 18 timely and accurate program-specific information on the
 19 performance of transplant programs. These data shall be
 20 updated as frequently as possible, and the OPTN shall
 21 work to shorten the time period for data collection and
 22 analysis in producing its center-specific outcomes report,
 23 Such data shall also include such other cost or perform-
 24 ance information including but not limited to transplant
 25 program-specific information on waiting time within medi-
 cal status, organ waitings, and refusal of organ offers.

*including severely
 adjusted survival
 rates
 long term*

FROM HMK&S

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10-10-98 17:42 From

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(1)
 1 (e) Data provided under subsection (d) shall be
 2 specific (if possible) to individual transplant centers and
 3 must be determined by the OPO to be scientifically and
 4 clinically valid. *mon*

5 (2) Any disclosure of patient specific medical informa-
 6 tion under subsection (d) shall be subject to the restric-
 7 tions contained in the Freedom of Information Act, the
 8 Privacy Act, and State laws. *and*

9 (g) Of the amount appropriated in title II for "Op-
 10 ERATION OF THE SECRETARY-GENERAL DEPARTMENTAL MAN-
 11 AGEMENT", \$500,000 shall, not later than 90 days after
 12 the date of the enactment of this Act, be transferred to
 13 the Comptroller General for purposes of carrying out the
 14 studies required as specified in this section.

15 (h) For purposes of this section:

16 (1) The term "Comptroller General" means the
 17 Comptroller General of the United States.

18 (2) The term "Organ Procurement and Trans-
 19 plantation Network" means the network operated
 20 under section 272 of the Public Health Service Act.

21 (3) The term "Secretary" means the Secretary
 22 of Health and Human Services.