

File Organ Donor



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILE

DATE February 24, 1998

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

*Mr. Chris Jennings
DPC
(202) 456-5560*

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

Kevin Thurm
Deputy Secretary
DHHS

202/690-6133

RECIPIENT'S FAX NUMBER 202) 456-5557

NUMBER OF PAGES TO SEND (INCLUDING COVER SHEET): 3

COMMENTS:



THE DEPUTY SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

FEB 24 1998

NOTE TO CHRIS JENNINGS

As we discussed, here are several upcoming opportunities for the President and Vice President to participate in follow-up activities for the National Organ and Tissue Donation Initiative. These activities would be linked to National Organ and Tissue Donor Awareness Week, April 19-25. I look forward to discussing these opportunities with you at your earliest convenience.

I. CBS TV movie *Nicholas' Gift*

- A. Advance screening of *Nicholas' Gift*: An invitation-only screening of this movie during the week of April 19 provides the opportunity to both recognize and encourage commitments by major corporations to promoting organ and tissue donation among their employees, as the Vice President challenged them to do when he announced the new federal employee education effort. *Nicholas' Gift*, starring Jamie Lee Curtis and Alan Bates, dramatizes the story of Reg and Maggie Green, a California couple who inspired a major increase in donation in Italy when they donated their seven-year-old son's organs after he had been shot in the head by highway bandits while on a family vacation in 1994. Seven children and adults received Nicholas' organs and tissues. The movie will air on CBS on Sunday, May 3 at 9:00 p.m. with an expected audience of 30 million viewers. Screening participants would include senior corporate officials, Congressional members, ambassadors from Italy and Japan, Jamie Lee Curtis, and Reg and Maggie Green.
- B. Public service announcement (PSA): The producers of *Nicholas' Gift* and Jamie Lee Curtis have expressed their desire for the President or Vice President to appear with Ms. Curtis in a 15-second PSA to air with *Nicholas' Gift*. The PSA would include a toll-free hotline (1-800-355-SHARE) for callers to receive a free brochure and donor card and HHS' Web site (www.organdonor.gov).

II. Federal Employee Education Campaign

- A. Memorandum to all federal agency heads: A memorandum from the President or Vice President would galvanize the federal agencies to participate in this new effort. A *Federal Kit* with implementation materials, including donation messages for pay slips, would be included with the memorandum. A draft memorandum is attached.
- B. Satellite broadcast to all federal employees: A 30-second pre-taped message by the President or Vice President could be included in a 5-7 minute video on donation to be broadcast to all federal employees via satellite on April 1. The video, to be produced with Media Technologies, will air during a 90-minute OPM broadcast on "leaving the federal government." The video would be disseminated to federal agencies for later use.



Kevin Thurm

DRAFT

MEMORANDUM TO HEADS OF DEPARTMENTS AND INDEPENDENT AGENCIES

From: President Clinton or Vice President Gore

Subject: Organ and Tissue Donation

Last December, Vice President Al Gore and Health and Human Services Secretary Donna E. Shalala launched the National Organ and Tissue Donation Initiative. This initiative includes a new effort by the Federal government to increase awareness of organ and tissue donation among Federal employees. As we approach National Organ and Tissue Donor Awareness Week, April 19 - 25, I ask for your commitment in making Federal employees more aware of how they can become potential donors, bringing hope to those in desperate need of life-saving assistance.

Despite medical advances in transplantation and widespread support for donation, thousands of opportunities to donate and save lives are missed each year, often because families do not know about the wishes of their loved ones or because families are not asked to donate. Through a broad national partnership of public, private, and voluntary organizations, the National Organ and Tissue Donation Initiative aims to educate and inspire more individuals and families to make personal decisions about donation; to indicate their decisions on donor cards, driver's licenses, wills or living wills; to discuss their donation decisions with family members; and to say yes when asked to donate. Even with a signed donor card or other document, next-of-kin are asked to provide consent for donation.

The decision to become a potential donor is, of course, a private one. With proper information, however, employees and their families will be in a better position to make informed decisions. To implement employee education efforts, we are sending your Director of Personnel information that can be used to inform employees about organ and tissue donation, including donation messages for employee pay slips. A copy of this information is enclosed. Employees who want more information and a donor card also may contact the initiative's toll-free hotline (1-888-90-SHARE) or Web site (www.organdonor.gov).

Thank you for your support in this effort to provide Federal employees the opportunity to demonstrate their generosity and their commitment to the welfare of this Nation. Together, we can answer the hopes of many more Americans waiting for a second chance at life.

Enclosure

BILL FRIST
TENNESSEE

*File
Organ
Reallocated*

COMMITTEES:
Commerce, Science, and Transportation
Budget
Labor and Human Resources
Small Business
Foreign Relations

United States Senate
WASHINGTON, DC 20510-4205

December 19, 1997

The Honorable Donna Shalala
Secretary
Department of Health and Human Services
200 Independence Ave., SW
Washington, DC 20201

Dear Secretary Shalala:

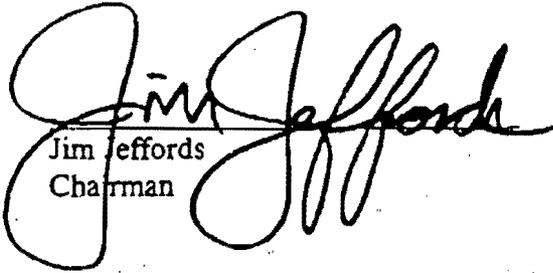
It is our understanding that the Department of Health and Human Services may soon issue a final rule governing the operation of the Organ Procurement and Transplantation Network (OPTN), following the proposed rule of September, 1994. While we applaud progress on the rulemaking, we are very concerned with the possibility that the final rule could be used as a vehicle for the Secretary to direct the allocation of life saving organs.

When Congress developed the National Organ Transplant Act, it did so with knowledge that the path prescribed for management of the federal interest in transplantation was unique. Recognizing the limitations of statute and regulation to respond adequately to the fast pace of biotechnological advances, we directed the Secretary to contract with a private entity who would devise allocation policy. In order to foster public trust, we believe it is important that allocation remain one step removed from the political sphere. We do not believe the Secretary should direct the distribution of organs via the impending rule.

As Chairman of the Senate Labor and Human Resources Committee, and the Subcommittee on Public Health and Safety, respectively, we have heard from our colleagues regarding their grave concerns with this impending rule. They have expressed reservations about the fact that the upcoming action may be an interim final rulemaking, despite the fact that the final rule may contain significant new provisions that did not appear in the proposed rule. Because organ transplantation is a highly-sensitive and consensus-driven field, we believe any major changes from the proposed rule should have ample opportunity for public comment before they are implemented. In addition, the publication of this controversial rule during a Congressional recess, and in proximity to the holiday season, when Members of Congress will not be able to be adequately briefed as to content of the regulation, does not indicate the level of confidence in the regulation which we expect and desire.

Finally, we want to commend and applaud your Department on the recent series of meetings between officials of the Department, HRSA, and UNOS, that were held in an effort to resolve several important issues such as the release of sensitive medical data and organ donation. We believe that communication between the Department and the OPTN needs to be improved, and that doing so will significantly reduce the ongoing friction between the two. We feel that building on this type approach is the best way to find the most fair and effective way to structure America's system of organ transplantation.

Sincerely,



Jim Jeffords
Chairman



Bill Frist, M.D.
Chairman, Subcommittee

12/23/97/0010

Congress of the United States
Washington, DC 20515

*Kevin T.
Exec Sec.*

January 14, 1998

The Honorable Donna Shalala
Secretary
Department of Health and Human Services
200 Independence Ave., SW
Washington, DC 20201

EXEC SECRETARY
COMMUNICATIONS
CONTROL CENTER

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Dear Secretary Shalala:

It is our understanding that the Department of Health and Human Services may soon issue a final rule governing the operation of the Organ Procurement and Transplantation Network (OPTN), following the proposed rule of September, 1994. While we applaud progress on the rulemaking, we are very concerned with the possibility that the final rule could be used as a vehicle for the Secretary to direct the allocation of life saving organs. ①

We strongly believe that the prescribed role for management of the federal interest in transplantation is unique. Recognizing the limitations of statute and regulation to respond adequately to the fast pace of biotechnological advances, the National Organ Transplant Act directs the Secretary to contract with a private entity who must devise allocation policy. In order to foster public trust, we believe it is important that allocation remain one step removed from the political sphere. We do not believe the Secretary should direct the distribution of organs via the impending rule. ①

We have serious reservations about the fact that the upcoming action may be an interim final rulemaking, despite the fact that the final rule may contain significant new provisions that did not appear in the proposed rule, which was subject to public comment. Because organ transplantation is a highly-sensitive and consensus-driven field, we believe any major changes from the proposed rule should have ample opportunity for public comment before they are implemented. In addition, we request a thorough Member's briefing before publication of this rule, and hope that we can find a time when interested members will be in town. ② ③

Finally, we want to commend and applaud your Department on the recent series of meetings between officials of the Department, HRSA, and UNOS, that were held in an effort to resolve several important issues such as the release of sensitive medical data and organ donation. We believe that communication between the Department and the OPTN needs to be improved, and

that doing so will significantly reduce the ongoing friction between the two. We feel that building on this type approach is the best way to find the most fair and effective way to structure America's system of organ transplantation.

Mike Davis

Bill Coz

Michael E. Egan

John Glenn

Don Coats

T. Hutchinson

Liz Stevens

Steve Lett

Sam Jeffade

Tom Campbell

Jim McGray

Hyk Wohl

Tom White

John Warner

Susan Collins

Robert A. Neelands

Joe Frost

Tom Blunt

John Breaux

Al McClure

Kevin Hatch

Ally

Billy Jyn

Ray Bailey Fitchman

Pat Helling

Hal Goodly

Edward W. Tynan

Spencer T. Tynan

John C. Tynan

Robert J. Tynan

ROBIN

Walter G.

Jefferson

Dendell Tynan

Mary J. Tynan

Robert F. Bennett

Strom Thurmond

Richard Shelby

Paul Coverdell

Lloyd Spence

Barry Goldwater

Paul Thurston

John

FORTNEY PETE STARK
THIRTEENTH DISTRICT, CALIFORNIA

COMMITTEES:
WAYS AND MEANS
JOINT ECONOMIC

CONGRESS OF THE UNITED STATES
HOUSE OF REPRESENTATIVES
WASHINGTON, D.C. 20515

January 30, 1998

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

Dear Secretary Shalala:

We understand the Department of Health and Human Services may soon issue a final rule governing the operation and management of the Organ Procurement and Transplantation Network (OPTN). We believe the critical needs of transplant patients throughout the country will be well-served by the Department's rulemaking and urge the publishing of the final rule as soon as possible.

The goal of the National Organ Transplant Act of 1984 (NOTA) was to ensure fair, equitable and efficient distribution of organs to critically ill people nationwide. To accomplish this goal, NOTA created a unique public-private partnership between the OPTN and HHS. The OPTN was directed to establish "medical criteria for the allocation of organs." (See the December 18, 1989 "General Notice" and the September 8, 1994 "Notice of Proposed Rulemaking" in the Federal Register.) But NOTA gives specific authority regarding allocation to the OPTN only with regard to establishing medical criteria, which we believe leaves a clear and important goal for HHS.

The issuance of a final rule or interim final rule on allocation was properly anticipated in the Notice of Proposed Rulemaking. The three days of hearings the Department held in December 1996 provided an opportunity for comments from those who wished to submit them, as did the official comment period for the proposed rule. There has been ample opportunity for public comment on the issue since the hearings, and we are confident that HHS has given careful thought to the issues raised by patients, transplant professionals, Members of Congress and the public.

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SECRETARY
DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTRAL CENTER

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The Honorable Donna Shalala
Page Two

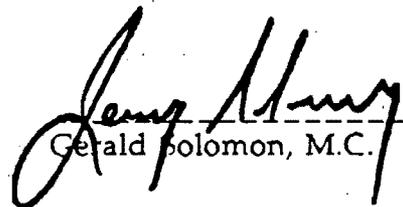
January 30, 1998

Thousands of critically ill patients are waiting for a national organ allocation system which distributes organs in a fair and objective manner. Sadly, many of the patients who will benefit most when you issue a final rule do not have very much time. We trust you will take their needs into account and issue the rule promptly.

Sincerely,



Pete Stark, M.C.



Gerald Solomon, M.C.



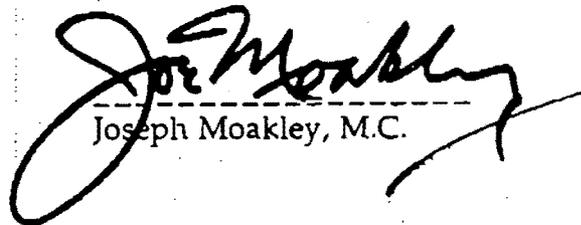
James Greenwood, M.C.



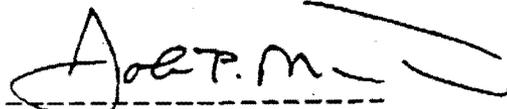
William Coyne, M.C.



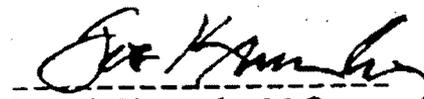
Ian Christensen, M.C.



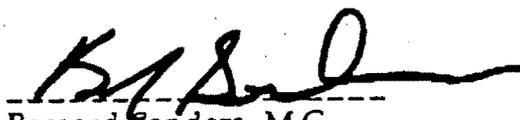
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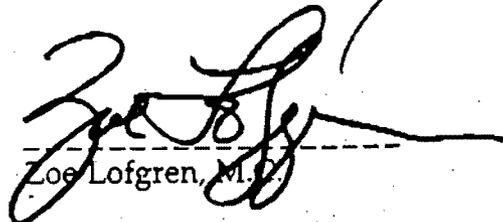
John Murtha, M.C.



Joseph Kennedy, M.C.



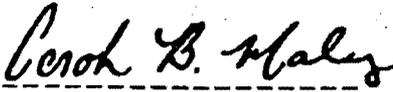
Bernard Sanders, M.C.



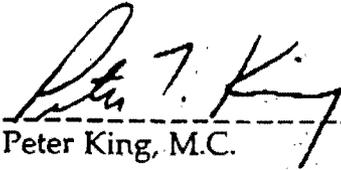
Zoe Lofgren, M.C.

The Honorable Donna Shalala
Page Three

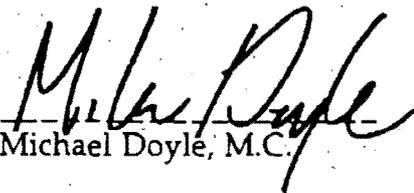
January 30, 1998



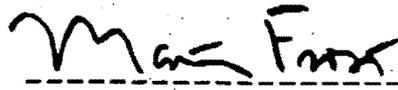
Carolyn Maloney, M.C.



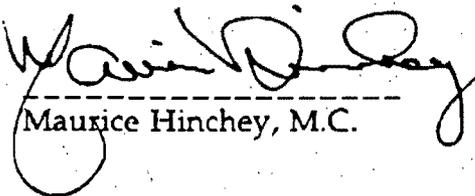
Peter King, M.C.



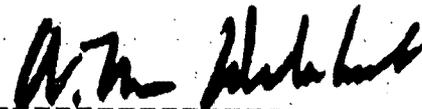
Michael Doyle, M.C.



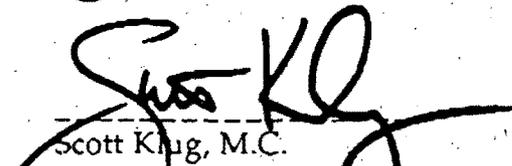
Martin Frost, M.C.



Maurice Hinchey, M.C.



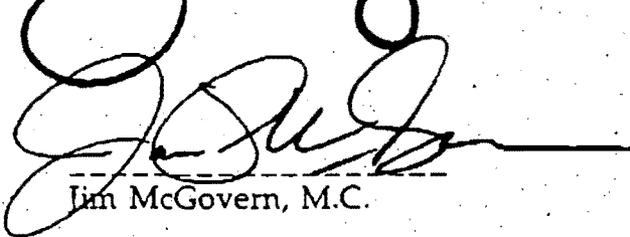
William Delahunt, M.C.



Scott Klug, M.C.



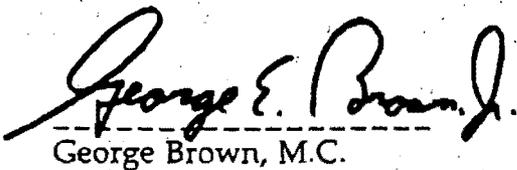
Mark Foley, M.C.



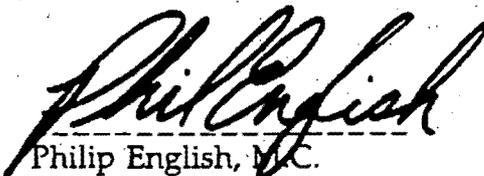
Jim McGovern, M.C.



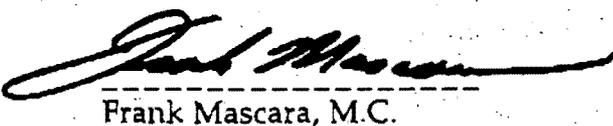
Eliot Engel, M.C.



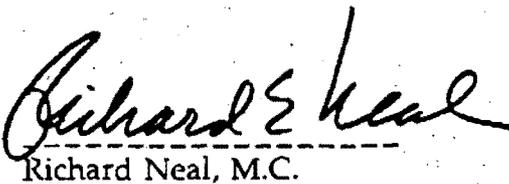
George Brown, M.C.



Philip English, M.C.



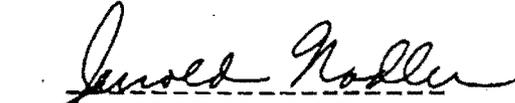
Frank Mascara, M.C.



Richard Neal, M.C.

The Honorable Donna Shalala
Page Four

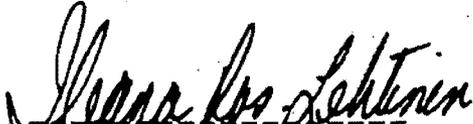
January 30, 1998



Terrold Nadler, M.C.



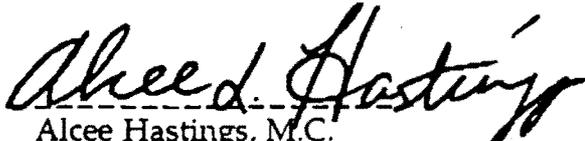
John Olver, M.C.



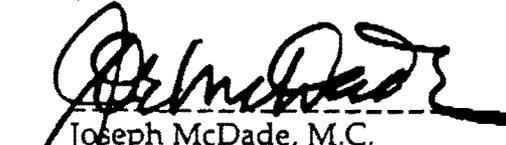
Heana Ros-Lehtinen, M.C.



Max Sandlin, M.C.



Alcee Hastings, M.C.



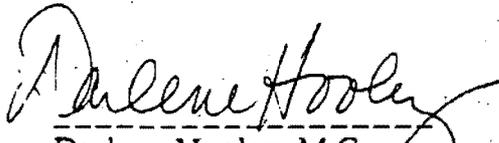
Joseph McDade, M.C.



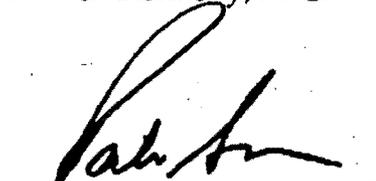
Lucille Roybal-Allard, M.C.



Patrick Kennedy, M.C.



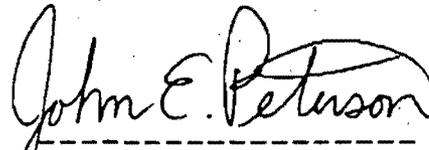
Darlene Hooley, M.C.



Porter Goss, M.C.



John Baldacci, M.C.



John Peterson, M.C.



Robert Matsui, M.C.



Transplant Recipients
International Organization, Inc.
800-TRIO-386

1000 Sixteenth St., NW Suite 602
Washington, DC 20036-5705
Phone 202-293-0980 Fax 202-293-0973

RECEIVED
 FEDERAL SECRETARY
 COMMUNICATIONS
 CONTROL CENTER
 98 JAN 29 11:20

January 28, 1998

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

Dear Secretary Shalala:

As a nation-wide organization of transplant candidates, recipients, donors and their families, and others associated with the transplant process, we applaud your work to issue a final rule governing the operation and management of the Organ Procurement and Transplantation Network (OPTN). It has been our consistent position that any final rule should maximize patient welfare. We are concerned that much of the focus of the current debate seems to be centered on the interest of transplant centers rather than the needs of transplant candidates and their families. It also is our belief that changes only in organ allocation rules will unlikely produce significant improvements in patient outcomes until we achieve concurrent improvements in organ donation rates. In this regard we urge you to continue to develop initiatives to seek further improvement in this critical area. With nearly sixty thousand lives waiting for a life saving transplant, we as a society need to explore every avenue to ensure an equal and equitable chance for all of them.

On behalf of transplant candidates, recipients and their families, as well as the donor families who are members of our organization, we welcome any action by HHS to improve the current system of rules governing transplantation issues. In addition to the contentious allocation issue, there are many other areas in which existing policies (or lack thereof) can be dramatically improved by the timely issuance of a final rule governing the operation of the OPTN. We are aware that you have been receiving considerable input from interested organizations and individuals on the issuance of the final rule. **Our simple request is that you apply only one criterion to the final rule: will this improve the chances of those waiting and the outcome of those transplanted with this scarce national resource?**

Respectfully,

Lisa R. Kory

Lisa R. Kory
Executive Director

cc: C. Earl Fox, M.D., Acting Administrator, Health Resource Services Administration
Board of Directors

12/19/97 FRI 14:51 FAX

X 6210
7088

002

BILL FRIST
TENNESSEE

COMMITTEES:

Commerce, Science, and Transportation

Budget

Labor and Human Resources

Small Business

Foreign Relations

United States Senate

WASHINGTON, DC 20510-4205

Organ Allocation File

December 19, 1997

The Honorable Donna Shalala
Secretary
Department of Health and Human Services
200 Independence Ave., SW
Washington, DC 20201

Dear Secretary Shalala:

It is our understanding that the Department of Health and Human Services may soon issue a final rule governing the operation of the Organ Procurement and Transplantation Network (OPTN), following the proposed rule of September, 1994. While we applaud progress on the rulemaking, we are very concerned with the possibility that the final rule could be used as a vehicle for the Secretary to direct the allocation of life saving organs.

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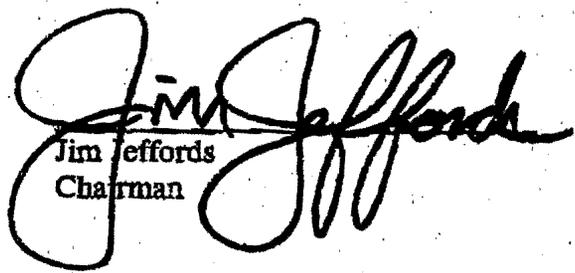
As Chairman of the Senate Labor and Human Resources Committee, and the Subcommittee on Public Health and Safety, respectively, we have heard from our colleagues regarding their grave concerns with this impending rule. They have expressed reservations about the fact that the upcoming action may be an interim final rulemaking, despite the fact that the final rule may contain significant new provisions that did not appear in the proposed rule. Because organ transplantation is a highly-sensitive and consensus-driven field, we believe any major changes from the proposed rule should have ample opportunity for public comment before they are implemented. In addition, the publication of this controversial rule during a Congressional recess, and in proximity to the holiday season, when Members of Congress will not be able to be adequately briefed as to content of the regulation, does not indicate the level of confidence in the regulation which we expect and desire.

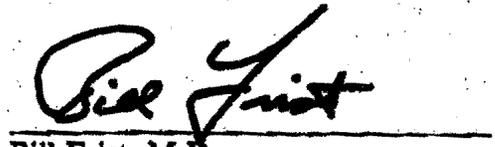
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Finally, we want to commend and applaud your Department on the recent series of meetings between officials of the Department, HRSA, and UNOS, that were held in an effort to resolve several important issues such as the release of sensitive medical data and organ donation. We believe that communication between the Department and the OPTN needs to be improved, and that doing so will significantly reduce the ongoing friction between the two. We feel that building on this type approach is the best way to find the most fair and effective way to structure America's system of organ transplantation.

Sincerely,


Jim Jeffords
Chairman


Bill Frist, M.D.
Chairman, Subcommittee

**Statements Supporting the Vice President for Launching the Clinton Administration's New Initiative to Increase Organ Donation
December 15, 1997**

"We appreciate the Vice President's long-standing leadership on this issue, and support the proposed public-private partnerships to improve public awareness of the need for organ donation, and the effort of the government to show leadership as an employer by providing information on organ donation to federal employees."

American Hospital Association

"We applaud Vice President Gore and Secretary Shalala for the Administration's leadership in addressing this critical public health issue. The AMA is encouraged by the Administration's commitment to use the bully pulpit to highlight the importance of organ donation."

American Medical Association

"Our goal as a nation should be for all individuals to know the options they have for organ donation, and to have discussed these options with their loved ones -- we will continue to support the Administration's efforts in this area."

American Academy of Family Physicians

"The National Association of Children's Hospitals applauds the efforts of the Administration to raise public awareness of the need for new efforts to improve the supply of organs for transplantation."

National Association of Children's Hospitals

"Mr. Vice President, the American College of Physicians congratulates you and Secretary Shalala for committing the Administration to a new effort to increase organ donation. We are pleased that you have recognized the need for public/private partnership in this area."

American College of Physicians

**Statements Supporting the Vice President for Launching the Clinton Administration's New Initiative to Increase Organ Donation
December 15, 1997**

"We appreciate the Vice President's long-standing leadership on this issue, and support the proposed public-private partnerships to improve public awareness of the need for organ donation, and the effort of the government to show leadership as an employer by providing information on organ donation to federal employees."

American Hospital Association

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American Medical Association

"Our goal as a nation should be for all individuals to know the options they have for organ donation, and to have discussed these options with their loved ones -- we will continue to support the Administration's efforts in this area."

American Academy of Family Physicians

"The National Association of Children's Hospitals applauds the efforts of the Administration to raise public awareness of the need for new efforts to improve the supply of organs for transplantation."

National Association of Children's Hospitals

"Mr. Vice President, the American College of Physicians congratulates you and Secretary Shalala for committing the Administration to a new effort to increase organ donation. We are pleased that you have recognized the need for public/private partnership in this area."

American College of Physicians

“The transplant community has no better friend than Al Gore. He has been a staunch advocate for patients seeking transplants, their families and friends. I want to offer my full support for the Vice President’s initiatives. I want to congratulate him for continuing to strive to improve this nation’s performance in helping those who need transplants. And I want to thank him for his unwavering determination to do what is necessary to ensure that organ and tissue donation in this country reflect the core values of choice, altruism, and voluntarism.”

Arthur Caplan
Center for Bioethics
University of Pennsylvania

“I look forward to your presentation on Monday and to improvements in organ procurement and transplantation as a result of the initiatives that you and Secretary Shalala plan to propose.”

James Childress
Former Vice Chair of the National Organ
Transplantation Task Force
Kyle Professor of Religious Studies
Professor of Medical Education
Member, National Bioethics Advisory Committee

“The Association of Organ Procurement Organizations is aware of your long interest in organ transplantation and the important role you played in the passage of the National Organ and Transplantation Act when you were in the Senate. [We] will do our part to make this initiative a resounding success. We applaud and thank you for your interest in organ and tissue donation.”

Association of Organ Procurement Organizations

“We are very pleased that you are personally involved in this effort to increase organ donation in America. We remember very favorably your strong leadership when you were in the House and Senate.... Mr. Vice President, we stand ready to serve as a partner to assist you and the President in all ways possible to increase organ donation so that the 56,000 Americans currently on waiting lists will have access to the “gift of life.”

American Society of Transplant Physicians

"I appreciate the opportunity to applaud your efforts to increase organ (and tissue) donation in the United States... We are very excited about the Clinton Administration's involvement in this initiative as the organ shortage is truly at a national crisis level and impacts significantly on the health of thousands of Americans."

North American Transplant Coordinators Organization

"Thank you very much for giving the transplant community the needed support and direction in these proposed initiatives. I am particularly pleased with this effort because minorities are disproportionately represented on transplant waiting lists across the nation."

American Society of Minority Health and Transplant Professionals

"We are grateful that you recognize that the shortage of donor organs and tissues is a serious public health issue. We look forward to working with you to encourage Americans to discuss donation with their families and to save the lives of patients awaiting lifesaving transplants."

Organ and Tissue Coalition on Donation

"We applaud the Vice President's efforts to increase the awareness of the American public about organ donation. Your long history of support is recognized and appreciated."

United Network for Organ Sharing

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The Administration will continue to work to identify the best approaches to increasing donation and priorities for future research. In this regard, the Department of Health and Human Services will hold a National Research Conference on organ and tissue donation in the spring of 1998 to discuss the best practices for increasing organ donation.

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"The Association of Organ Procurement Organizations is aware of your long interest in organ transplantation and the important role you played in the passage of the National Organ and Transplantation Act when you were in the Senate. [We] will do our part to make this initiative a resounding success. We applaud and thank you for your interest in organ and tissue donation."

Association of Organ Procurement Organizations

"We are very pleased that you are personally involved in this effort to increase organ donation in America. We remember very favorably your strong leadership when you were in the House and Senate.... Mr. Vice President, we stand ready to serve as a partner to assist you and the President in all ways possible to increase organ donation so that the 56,000 Americans currently on waiting lists will have access to the "gift of life."

American Society of Transplant Physicians

"I appreciate the opportunity to applaud your efforts to increase organ (and tissue) donation in the United States... We are very excited about the Clinton Administration's involvement in this initiative as the organ shortage is truly at a national crisis level and impacts significantly on the health of thousands of Americans."

North American Transplant Coordinators Organization

"Thank you very much for giving the transplant community the needed support and direction in these proposed initiatives. I am particularly pleased with this effort because minorities are disproportionately represented on transplant waiting lists across the nation."

American Society of Minority Health and Transplant Professionals

"We are grateful that you recognize that the shortage of donor organs and tissues is a serious public health issue. We look forward to working with you to encourage Americans to discuss donation with their families and to save the lives of patients awaiting lifesaving transplants."

Organ and Tissue Coalition on Donation

"We applaud the Vice President's efforts to increase the awareness of the American public about organ donation. Your long history of support is recognized and appreciated."

United Network for Organ Sharing

**Remarks for Vice President Al Gore
Announcement of National Organ Donor Initiative
Monday, December 15, 1997**

I thank Rev. Downs and Dr. Herrera for their powerful testimony. It was a story very similar to these that first engaged me in the cause of organ and tissue donation. Fifteen years ago, a family in my state of Tennessee sought my help in finding a liver donor for their dying child. I did everything I could to help that family, but I wanted to do more to help every family caught in those awful circumstances.

This led to my role in sponsoring and helping to pass the National Organ Transplant Act of 1984.

That crucial law -- along with subsequent legislation I was honored to work on -- has created a national system for recovering and distributing organs -- a system families now rely upon. We have come a long way since 1984. But we cannot rest. Not when 10 people a day are losing their lives waiting for an organ. Not when we can save those lives with a little more effort, a little more information, a little more partnership.

That's why I am proud to announce today our new National Organ and Tissue Initiative, which we believe will significantly increase the number of organ and tissue donors across the country.

First, I am pleased to announce several prominent new members in a national partnership committed to increasing organ and tissue donation. The American Medical Association and the American Association of Family Physicians have agreed to encourage their members to discuss organ donation with patients. The American Bar Association will encourage its members to discuss organ donation with clients during the preparation of wills and estate planning. And the American Red Cross -- already one of the nation's largest providers of human tissue -- has pledged to continue an aggressive campaign to encourage organ and tissue donation.

These organizations will join the Coalition on Donation, the Department of Health and Human Services, and many longtime partners in the clergy, the transplant community, the health care community, and the business community to ensure that organ and tissue donation is discussed and expanded all across America. These partners are here with us today, and I thank them for their commitment to this cause.

Second, we are taking a significant new federal action to help increase organ and tissue donation. Currently, 27% of all families of potential donors are never even approached about donation. We are addressing this issue in the context of a new Reinventing Government effort that will streamline requirements on our hospitals.

Specifically, we are proposing a regulation to ensure that health care providers commit to a family-sensitive process -- along with Organ Procurement Organizations -- to encourage organ donation when it is appropriate to do so. We hope to work with the entire transplant community -- physicians, hospitals, transplant coordinators, patient and donor groups -- to see that the final regulation ensures that all families in those circumstances are offered the option of organ donation.

Third, I am pleased to announce a new effort by the Federal government to increase awareness of organ and tissue donation among federal employees. All of the major cabinet agencies have agreed to send out six messages a year to their employees -- some to be included with employee pay stubs.

These messages encouraging organ and tissue donation will reach 1.5 million people and their families. I challenge all private sector employers to follow our example.

Finally, I am pleased to announce that the Department of Health and Human Services will sponsor a conference this spring, to help identify the practices that are most effective in encouraging donation.

Here on the eve of the 21st Century, advances in science, medicine, and technology have brought us great life-saving powers, but also a keen awareness of our life-saving limits: no matter how impressive our technology, we still cannot create a human heart -- a liver, a lung, a kidney.

We cannot even preserve them outside a living body for more than a few hours. That means the power of our newest technology depends upon the strength of our oldest values: Love of life. Love of neighbor. And in this holiday season, the spirit of giving and community.

Those values are strong in America. Surveys have shown that almost all Americans support organ donation, and families almost always consent to organ donation when loved ones have expressed that wish. But not all families have thought about organ donation or discussed it. In fact, only half of those who want to be organ donors have told their families about their decision.

That's why we're here today: To make a public commitment to inform every American about the life-giving opportunity of organ and tissue donation. To make sure all willing organ donors inform their families. And to make sure when families are informed and willing, the loss of life for one can result in the gift of life for many.

Our partnership is large, our mission lofty -- but our message is very simple: "Share your life; share your decision."
Thank you very much.

Organ Donation Announcement

Room 450, OEOB

11:10 a.m. - 11:45 a.m., Monday, December 15, 1997

File
organ
donation

**Meeting requested by HHS, Chris Jennings and Toby Donenfeld.
Briefing prepared by Toby Donenfeld.**

EVENT

You will announce the following Administration efforts to increase organ donation: 1) a partnership with the American Medical Association, the American Bar Association, the American Red Cross and other business, health, community and religious organizations to raise awareness of organ donation and increase the number of organ and tissue donors, 2) proposed regulation to ensure that families are asked whether their loved ones choose to be organ donors; (this regulation implements part of the 1986 law you authored), 3) all of the major Cabinet Agencies (14), plus the Executive Office of the President have committed to provide their employees with organ donation information six times a year, including through their pay stubs, and 4) HHS will host a conference in the Spring of 1998 to discuss best practices for increasing organ and tissue donation. *(Please see attached fact sheet for further information on the announcements).*

This event is open press. Approximately 150 transplant organizations, hospitals, physicians, consumers and other health groups will be in attendance.

LOGISTICS (As of this writing, subject to change)

- You will be briefed in en route to the OEOB by Toby Donenfeld and Chris Jennings.
- You, Secretary Shalala, Senator Byron Dorgan, Dr. Alfredo Herrera and Reverend Canon Downs will be announced on stage.
- Secretary Shalala makes remarks.
- Senator Dorgan, co-chair of the Congressional task force on organ donation, will make brief remarks.
- Dr. Alfredo Herrera, a donor father makes remarks.
- Rev. Canon Downs, a heart donor recipient makes remarks and introduces you.
- You make remarks, shake hands in the front row and depart.

YOUR ROLE/CONTRIBUTION

- This event provides you with the opportunity to continue your leadership on the issue of organ donation and to highlight the new effort to increase awareness and the number of organ donors.

PROGRAM NOTES

- Program Participants

Senator Byron Dorgan

Senator Dorgan is the co-chair of the Congressional Task Force on Organ Donation and was the sponsor of the legislation that led to 65 million Americans receiving organ and tissue donation information with their tax refunds this year.

Dr. Alfredo Herrera

Dr. Herrera is a practicing pediatrician living in Ellicott City, Maryland. Dr. Herrera is the father of four children. His 16 year-old son Christian died in an automobile accident in December, 1994. Christian had told his father that he wanted to be an organ donor, so he donated his heart, two lungs, two kidneys, liver, pancreas and two corneas, giving life to seven people and giving sight to two others. Dr. Herrera is very involved in efforts to educate teens and their parents about safe driving skills and is actively involved in organ donation, is a member of the Board of Trustees fothe Transplant Resource Center of Maryland.

Reverend Canon Downs

Reverend Downs, Rector of St. Timothy's Episcopal Church in Washington, D.C. received a heart from one of his parishoners, after she suffered a brain aneurism. This parishoner had told her mother that if she had two hearts, she would have given one to Rev. Downs. Downs has spoken out about organ donation since his transplant.

ATTACHMENTS

- Your remarks (to be provided on Monday morning).
- Fact sheet on the announcements.

VICE PRESIDENT GORE LAUNCHES NEW ORGAN AND TISSUE DONATION INITIATIVE

December 15, 1997

Today, the Vice President is announcing a series of new Administration initiatives to increase organ donation. These initiatives, which build on the Administration's longstanding efforts to improve awareness about organ donation and are led by the Department of Health and Human Services, include: (1) new unprecedented private/public partnerships with businesses, consumers, physicals, health care organizations and others to increase awareness about organ donation across the country; (2) a commitment from the Federal government to do its share, by sending out six messages per year to its employees about organ donation; (3) a proposed regulation to ensure health care providers commit to a patient/family-sensitive process to encourage, where appropriate, organ donation; and (4) an ongoing commitment from the Administration to improve donation, including a conference at the Department of Health and Human Services this spring to examine the best ways to encourage donation.

BACKGROUND

More than 20,000 Americans each year receive organ transplants that save or enhance their lives. However, 4,000 Americans people die each year, approximately 10 per day waiting for an organ transplant. Today, more than 55,000 people are on the national organ transplant waiting list.

Only about half of Americans who want to become an organ donor have told their families of their wishes. The latest national Gallup study indicates that nearly all Americans would consent to donation if they know their loved one had requested it. Currently, when families are asked if their loved one wants to be an organ donor, only about half give consent, and often, its because the family does not know their loved ones' wishes. Another study found that 27 percent of families of potential donors were never approached about donation. Today the Vice President is announcing a series of new initiatives to help ensure that families have discussed the issue of becoming an organ donor and to ensure that family members of potential organ donors are asked to consider donation. These initiatives include:

An Unprecedented Commitment for New Private/Public Partnerships to Increase Awareness. The Vice President and Secretary Shalala are announcing a series of partnerships the federal government has made with organizations to promote organ donation.

The American Medical Association and The American Academy of Family Physicians have made a new commitment to encourage physicians to make organ donation materials available their offices and to discuss donation with their patients.

The American Red Cross will use its extensive community outreach network to expand upon its current public awareness and education efforts on behalf of tissue and organ donation.

The American Bar Association will make a new commitment to encourage attorneys to discuss organ donation with their clients during estate planning through the distribution of materials, by providing continuing legal education programs, and through the encouragement of state and local bar associations to adopt resolutions resolution that urge attorneys to get involved in donor education efforts.

These new partners join others who have already made impressive commitments to improve awareness about organ donation including: **the Congress of National Black Churches, the Union of American Hebrew Congregations, The U.S. Chamber of Congress, the Washington Business Group on Health, the Home Depot, the American Association of Health Plans, the American Nurses Association, and the American College Health Association.**

A New Commitment From the Federal Government To Do Its Share to Increase Awareness About Organ Donation.

All fourteen major Cabinet Agencies and the Executive Office of the President have agreed to provide their employees with information about organ donation six times per year, including information about donation on employee pay stubs. This effort will reach 1.5 million of federal employees as well as their families. The Administration also challenges all private entities to spread awareness about organ donation to their employees.

A New Proposed Regulation to Ensure Families Discuss Organ Donation.

The Vice President is also announcing a proposed regulation by the Health Care Financing Administration (HCFA) to revise its conditions of participation for Medicare hospitals to ensure that the families of potential donors are asked to consider donation. HHS will work closely with hospitals, OPOs, tissue banks and others in the transplant community to produce final rules that will ensure that opportunities for donation are not lost due to failure to identify potential donors. **The Joint Commission on the Accreditation of Healthcare Organizations**, which provides accreditation for most of the nation's hospitals, has also agreed to incorporate this approach.

Ongoing Efforts to Find New Ways to Increase Organ Donation.

The Administration will continue to work to identify the best approaches to increasing donation and priorities for future research. In this regard, the Department of Health and Human Services will hold a National Research Conference on organ and tissue donation in the spring of 1998 to discuss the best practices for increasing organ donation.

File organ donation



American Association of
HEALTH PLANS

AAHP Medical Affairs Department

1129 - 20th Street, NW, Suite 600
Washington, DC 20036-3421
202-778-3222
Fax: 202-778-3287

FAX TRANSMISSION COVER SHEET

Date: *12/12/97*

To: *Chris Jennings*

Fax: *456-7828*

Re: *Organ & Tissue Donations*

Sender: *Carmella Boechino*

YOU SHOULD RECEIVE 2 PAGE(S), INCLUDING THIS COVER SHEET. IF YOU DO NOT RECEIVE ALL THE PAGES, PLEASE CALL 202-778-~~3222~~ **3287**

Comments:



American Association of
HEALTH PLANS

Press Release

FOR IMMEDIATE RELEASE:
Monday, December 15, 1997

Contact: Don White (202) 778-3274
John Murray (202) 778-8496

HEALTH PLANS PARTNER WITH HHS TO INCREASE INFORMATION ABOUT ORGAN AND TISSUE DONATIONS

(Washington, D.C.) -- The American Association of Health Plans (AAHP) today announced a new partnership with the U.S. Department of Health and Human Services (HHS) to increase information about organ and tissue donations. As part of the new National Organ and Tissue Donation Initiative, AAHP will encourage health plans to offer their members educational materials on organ and tissue donation.

"AAHP and its member health plans congratulate the Administration for putting forward this important national initiative," stated AAHP President Karen Ignagni. "We recognize the value of national organ and tissue donation programs and look forward to contributing to an increased awareness of them."

AAHP will provide member health plans with information about how to become involved in the National Organ and Tissue Donation Initiative. Through this public awareness effort, health plans can help eliminate barriers to donation by communicating options to families and providing donor cards and other educational materials.

"Health plans are in an excellent position to educate patients about organ and tissue donation and help families broach this sensitive issue," added Ignagni.

The American Association of Health Plans represents over 1,000 HMOs, PPOs and similar plans that provide health care for more than 140 million Americans nationwide.

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File "Quality
Poll"

Kaiser/Harvard
National Survey of Americans'
Views on Managed Care

Questionnaire and National Toplines

November 5, 1997