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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. memo	Lisa Gilmore to Devorah Adler re: phone number (partial) (1 page)	12/18/1998	P6/b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20469

FOLDER TITLE:

Organ Donation [Folder 3]

2012-0463-S

rc804

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

DATE: 10-20-98

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
200 INDEPENDENCE AVE., SW
WASHINGTON, D.C. 20201

PHONE: (202) 690-7627FAX: (202) 690-7380

OFFICE OF THE ASSISTANT SECRETARY FOR LEGISLATION
ROOM 416-G HUMPHREY BUILDING

FROM:

TO

: Chris Jennings

OFFICE

: _____

PHONE NO

: _____

FAX NO

: 456-5557

TOTAL PAGES

(INCLUDING COVER):

5☒

RICHARD J. TARPLIN

☐

HELEN MATHIS

☐

KEVIN BURKE

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SANDI EUBANKS BROWN

☐

ROSE CLEMENT LUSI

☐

ALICE ARTIS

☐

HAZEL FARMER

☐

EDWARD WHITLEY

REMARKS:

OCT-19-98 11:07 From: H & M 12E-400

T-478 P.02/06 Job-001

NATIONAL TRANSPLANT ACTION COMMITTEE
1760 SW. SKYLINE BLVD.
PORTLAND, OREGON 97221
(503) 203-8812
Fax (503) 203-8815

October 19, 19

Dear Member of Congress:

Please accept this flower in memory of Jordan Rosebar and on behalf of the 50,000 Americans on organ transplant waiting lists. In their interest, we urge you to oppose the omnibus spending bill when you vote tomorrow.

Over 4000 Americans died last year waiting for an organ transplant. New rules promulgated by HHS last spring could have prevented as many as 300 of these deaths next year. However, Appropriations Committee Chairman Bob Livingston inserted a rider in the House version of the Labor and Health and Human Services Appropriations bill, without any hearings, which delays those rules for one year. The rider was not included in the Senate version of the LHHS bill, and this is the second time that Mr. Livingston has intervened personally to postpone regulations which would save lives if they could take effect.

It is too late to save the life of Jordan Rosebar, an 18-month-old child who died in June while she was waiting for a liver and small intestine transplant. The night she died, two sets of organs were donated which could have saved Jordan's life. Both were used in their local regions despite Jordan's greater medical need. The organs were transplanted into other individuals who were not nearly as ill and who had other medical options still available to them.

Sadly, the story of Jordan Rosebar is not unique. Her death is due partly to the conscious intent to permit certain members of the organ transplant industry to take advantage of medical technology at the cost of American lives. Jordan Rosebar's death was unnecessary. Her only hope was an organ transplant, but when asked for help, the organ donation network in Louisiana would not do what was right to save her life.

More Jordan Rosebars will die because of the Livingston rider. Some of them will be your constituents. They are white, Hispanic, Asian, Native Americans and African Americans, although minorities are disproportionately injured by this rider. Many of those who die will be victims of hepatitis C. Your constituents will be more greatly damaged if there is no comprehensive organ transplant center in your state which can serve all your constituents' needs, regardless of the severity of their illness.

Mr. Livingston's rider is the ultimate example of "PORK." He has forced another delay in the implementation of HHS regulations that could prevent needless death. The decision to delay the regulations was a conscious back-room deal intended to protect the profits of Livingston's Louisiana transplant industry at the cost of your constituents' lives.

How could we allow Baby Jordan to die? Who will defend tomorrow's children?

Please contact Majority Leader Trent Lott and Speaker Newt Gingrich and let them know that you oppose inclusion of Livingston rider in the omnibus spending bill.

The Times-Picayune

OF LIFE AND DEATH



Jordan Rosebar died in Pittsburgh waiting for an organ transplant. A liver from Louisiana might have saved her, but it went somewhere else. Her story illustrates the excruciating difficulties faced in an ongoing debate over how best to choose who lives and who dies.

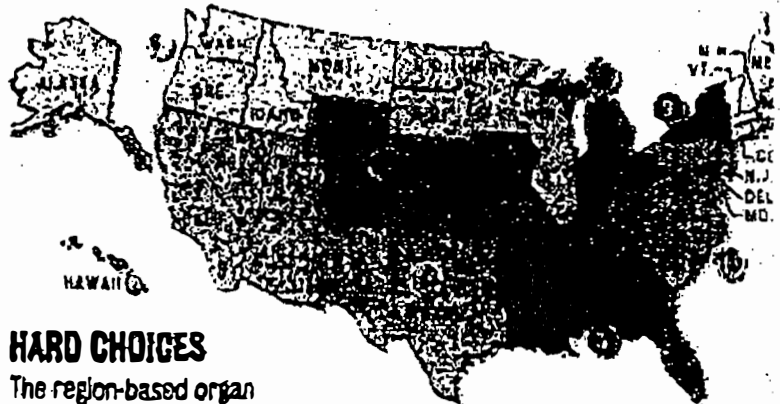
By BILL WALSH
Washington bureau

WASHINGTON — As Jordan Elizabeth Rosebar lay in a hospital bed in Pittsburgh, her insides collapsing, the organs that could save her life were ready and waiting in a New Orleans area hospital.

It was a stroke of luck that the liver and small intestine the 18-month-old girl needed were available at all, given that the donor had to be a biological match and, like her, a small child. Incredibly, two other child donors would be found in other parts of the country that day in early June, offering hope far beyond what Jordan's family and doctors had dared imagine.

But Jordan never got the organs she so desperately needed. She died waiting for

See ORGANS, A-22



HARD CHOICES

The region-based organ procurement system is under review.

How it works: An organ is first offered to one of 63 local donor regions. If there are no takers, it is offered next to states within one of 11 national regions (above), then finally nationwide.

Proposed change: Organs would go to the sickest person in the nation, regardless of region. But no such a list would be maintained, and who would make such decisions, has yet to be worked out. The new plan would benefit large regional transplant hospitals. Louisiana has challenged the proposal in federal court.

Organs: La. favors geographic system

From A-1

The transplant when chemicals, machines and prayers could no longer sustain her.

Louisiana doctors sent the organ to Atlanta under the current rules that give regional preference to who gets organs. Later, a flicker of hope from doctors in Alabama faded when the eat of the organs they had were given to someone else. In a final, frantic race to a nearby Pennsylvania hospital, a transplant team returned to the operating room too late.

The final day of Jordan's life demonstrates the complexities of a national organ disbursement procedure that is guided first by geography and second by the critical needs of the patient. It unmask the cruel difficulties inherent in trying to apply objective standards to decisions about who lives and who dies. It also reveals a distrust among transplant surgeons in different parts of the country who have found themselves pitted against one another as they vie for a limited supply of organs.

There is no escaping the fact that the shortage of donated organs has forced medical officials to make painful life-and-death decisions within a sometimes-awkward system. The emotional debate over how that system should operate recently came to a head as the Clinton administration prepared to issue rules this month that many believe will lead to a nationwide policy that provides organs to the "sickest first" and minimizes geographic considerations.

Louisiana has taken the lead to block that kind of system. The state wants to keep locally donated organs close to home, arguing that because its residents donate more generously than those in other states, they also deserve to reap the benefits. A lawsuit filed by the state to block the rules will be heard Wednesday in Baton Rouge by a federal court judge. The court has ordered the new rules put on hold pending the outcome of the hearing.

Also at stake in the battle is money. Large regional transplant centers such as the one in Pittsburgh have seen their business plummet in recent years as smaller hospitals have gotten into the transplant game. The larger centers are pushing the new national guidelines, while the smaller centers are fighting to retain the business they've gotten under the current rules.

With millions of dollars in profits at stake, the issue is

and the case of Jordan Rosebar reveals the complex medical, ethical and political contours of the coming debate.

A losing battle

From the start of her young life, it was apparent that Jordan could not live with the organs she started life with. She was born in Maryland three months premature and was "so small she could fit in the palm of my hand," her father, Marcus Rosebar, said.

She also was born without a usable intestine, and doctors had little choice but to remove most of it. She spent the first six months of her life in Children's Hospital in Washington, D.C., sustained with nutrients and medication pumped through her body. Unfortunately, the same treatment that kept her alive wreaked havoc on her liver. Over time, it began to deteriorate.

"We knew right at the beginning," Rosebar said. "The doctors told us that eventually she would need a transplant to live a normal life."

Rosebar knows better than most that "normal" is often relative when it comes to organ transplants. As a kidney transplant patient himself, the 27-year-old Washington native receives dialysis treatments twice a week. He knew that his daughter, the only child he has had with his high school sweetheart, wife Devona Watkins, would forever be in need of intense medical attention.

But for now, they were eager just to have her home, away from the sterile hospital environment. In May 1997, they got their wish. Jordan was sent home fitted with a special portable unit to pump fluids through her body 20 hours a day. She was fed with a tube fixed to her nose. It was cumbersome for the infant Jordan was entered on a national computer database as a patient at the University of Pittsburgh.

That meant that whenever a suitable organ became available in the six-state region around Pennsylvania, Jordan could get it unless there were sicker children on the list ahead of her. That's the cornerstone of the organ disbursement system: Organs are first offered within the region in which they are donated and then nationally if there are no takers.

For months, nothing happened.

Then on May 31, Jordan's parents got a call that organs were available. Jordan and her mother flew to Pittsburgh and Jordan's father took a bus to stand vigil with his family.

T-478 P.04/05 Job-001

gans. They had been donated and weren't working correctly. Jordan was in a perilous condition.

Out of desperation, her father, Dr. Kareem Abu-Elmagd, called a former colleague at the University of Miami. The Pittsburgh hospital had recently helped surgeons in Miami set of organs for a 13-year-old boy and Abu-Elmagd asked if they would return the favor. Would they list Jordan as a transplant candidate at their hospital?

The tactic, known as "cave listing," increases a patient's chances of getting an organ. Cave listing is frowned upon by some in the transplant community as underhanded, but it is not forbidden. The United Network for Organ Sharing, the organization that administers the organ policy, reports that more than 3,000 patients are listed at two hospitals. Some are listed at three.

"It's kind of a courtesy," Elmagd said. "We did it for the day before."

Abu-Elmagd requested that Jordan be listed at Miami "Status 1," the most dire condition, reserved for patients who will die within seven days without a transplant. The designation puts them near the head of the line for new organs.

Once again, Jordan was blessed with good fortune. Within hours, doctors in Miami got word that a liver and small intestine were available at West Jefferson Medical Center in Marrero.

Under Louisiana law, donated in-state must first be offered to local residents. In this case, no one in Louisiana needed them, so a search went for the neediest children in the state's southeastern region, starting from Louisiana to Mississippi. The University of Miami transplant center was at the top of the list.

What happened next is disputable. While it is clear that Louisiana Organ Procurement Agency refused to release organs to Pittsburgh doctors, reasons for the refusal differ.

Doctors in Pittsburgh said they were turned down because of rivalry between the two over organ transplantability. The University of Pittsburgh Medical Center, one of the transplant hospitals in the area, has led the charge for the "first" national standard.

"Just because it was Pittsburgh, all of a sudden there was a problem," said Abu-Elmagd.

OCT-19-98 11:10 From: H & H 12E-400

T-478 P.05/05 Job-001

JORDAN ROSEBAR'S FINAL DAYS

MAY 31

8-month-old Jordan undergoes a liver-small intestine transplant at University of Pittsburgh Medical Center.

JUNE 2

The organs fail. Surgeons ask University of Miami transplant center to list Jordan as a Status 1 transplant candidate.

JUNE 3

3:41 p.m. The Louisiana Organ Procurement Agency is notified that organs are available in Marrero. Under policy, it downloads the most current list seeking suitable recipient. None is found in Louisiana.

3:45 p.m. Louisiana Organ Procurement Agency calls Miami to say it has suitable organs. Miami says it has a Status 1 candidate, but Louisiana says Jordan's case is not on their list. Miami asks that Louisiana check the organ database again, so her case will pop up. Louisiana agency worker says she will ask a supervisor.

4 p.m. Miami liver specialist calls Pittsburgh surgeon to say the organs are available in the New Orleans area.

5:15 p.m. Louisiana organ worker calls Miami to say that medical director declines to violate policy and rerun the list. The organs will be sent

to Atlanta, instead.

5:20 p.m. Miami liver specialist calls Pittsburgh to tell them they have been turned down. Pittsburgh doctors decline to call Atlanta to ask for priority.

Early evening. Miami officials get a call from Alabama saying that it, too, has suitable organs. The organs are committed to another patient, but would be sent to Miami if not used.

8-8:30 p.m. University of Pittsburgh is alerted that organs are available in western Pennsylvania.

10 p.m. Surgery team departs Pittsburgh hospital to harvest the organs. The drive takes about two hours.

JUNE 4:

1-1:30 a.m. Team calls Pittsburgh surgeons to tell them to take Jordan to the operating room and prepare her for transplant.

3:08 a.m. Jordan is taken to the operating room. She suffers cardiac arrest and is resuscitated. Her intestine is removed. She is placed on life support.

4:17 a.m. Jordan goes into cardiac arrest again and dies.

4:30-5 a.m. The team, already alerted to Jordan's death, arrives back in Pittsburgh with the organs. The liver is sent to another transplant patient in Philadelphia.

Louisiana officials disagree. They say that Jordan was not listed as a patient in Miami at the time the organs became available in Louisiana, meaning they would have to violate their policies in order to send the organs to Pittsburgh.

In fact, the most serious patient in Miami was a youngster listed as a "Status 2," serious, but not at the most critical level. Under the national guidelines, that patient was entitled to first crack at the organs. But as if to underscore the capriciousness of the process of deciding who gets what, Miami didn't have enough available surgeons to perform the operation, so they passed.

The liver specialist in Miami who took the call from Louisiana said she had entered Jordan's name on the computer database that same day, June 3. Perhaps the Louisiana list wasn't current, she said. Would they "rerun the list," she asked, by downloading the most current version to the state's computer?

Pittsburgh doctors angry

The decision by the Louisiana organ agency angered the doctors in Pittsburgh who saw Jordan's life slipping away. In an afternoon phone call with Zibari, Abu-Elmagd lost his patience.

"I said she will die in 24 hours," Abu-Elmagd recalled telling him. "I said if you think we are stealing the organs, that is not the case."

When Miami declined the organs because they didn't have enough surgeons available to complete the transplant needed there, the organs went to the next patient on the list, at Emory University Hospital in Atlanta. If the Pittsburgh surgeon wanted the organs, Zibari told him to call the Atlanta hospital and see if the surgeon there would be willing to give them up.

The child in Atlanta who got the liver was listed as a Status 8 patient, but Jacobbi said doctors told her the youngster was getting worse.

"They said their child was extremely sick as well. Those kids can change in a matter of hours or minutes," she said.

Abu-Elmagd chose not to call Atlanta. By then, another liver and small intestine set became available, this one in Alabama. However, this time, the organs were already committed to an-

other child. The Miami hospital was only being notified if it was needed as a backup. Ultimately, it wasn't. The other child got the organs and Jordan's doctors started their search all over again.

Chuck Patrick, director of the Alabama Organ Center, declined to discuss the case, so it's unclear if the child who got the transplant was in better condition than Jordan.

"I'm not going to get my organization in the middle of this war over where organs go," Patrick said.

The up-and-down ride wasn't over yet. Within hours, Pittsburgh got a call that suitable organs were available at a hospital in western Pennsylvania.

Abu-Elmagd hopped in a van and led a team to harvest the organs. Meanwhile, Jordan was getting worse. Her heart seized up and her blood pressure dropped. She was taken back to the emergency room and doctors opened her up. They cut out the rest of her intestine and kept her alive with fluids and medication.

For a brief time, Jordan seemed to improve, but then she suffered multiple cardiac arrests. Her body was never that strong to begin with and all the stress was simply too much for her to take.

Jordan died early in the morning of June 4. Abu-Elmagd was about an hour away from the Pittsburgh hospital with the organs on ice when he got the word.

"It came down to a matter of hours," he said. "If I could have gotten the organs a couple of hours earlier, she could have survived."

Rosebar said he didn't know all this was happening while he and Jordan's mother waited in the Pittsburgh hospital for word on their daughter's condition.

To him, state and regional boundaries are meaningless when it comes to deciding who should have first claim to a life-saving organ.

"I would have gone to Russia if I had to save her life," he said. "I would have done anything."

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET

ROUTE SLIP

TO: Distribution

Take necessary action ☐Approval signature ☐Comment ☐Prepare reply ☐Discuss with me ☐For your information ☐See remarks below ☐

FROM: Jeffrey Weinberg

DATE: October 20, 1998

REMARKS

FYI, here is the final Commerce letter to Senator Durbin on patent term restoration for certain ~~pipeline~~ drugs.

Distribution

Dan Mendelson
Chris Jennings
David Beier



GENERAL COUNSEL OF THE
UNITED STATES DEPARTMENT OF COMMERCE
Washington, D.C. 20230

OCT 20 1998

The Honorable Richard Durbin
United States Senate
Washington, DC 20510

Dear Senator Durbin:

This letter is in response to your October 15, 1998, request for clarification of the enclosed letter from Assistant Secretary Bruce A. Lehman. Your inquiry states that Mr. Lehman's letter implies that the Food and Drug Administration (FDA) has subjected companies to "extraordinary regulatory delays." Your inquiry also states that "extraordinary regulatory delays" would seem unfair in light of the safety issues that were addressed with respect to cancer causation and Claritin®.

Mr. Lehman intended in no way to suggest that the FDA subjected companies to inappropriate delays. Mr. Lehman's letter refers to "extraordinary regulatory delays" as a commonly used term to characterize the sometimes long length of time required for FDA approval, for reasons unrelated to FDA's efficiency. For example, the U.S. Patent and Trademark Office (PTO) uses the similar term of "unusual administrative delay" to describe the sometimes long internal process of issuing a patent.

In addition, I wish to clarify that there is no Administration position on establishing an administrative procedure within the PTO to review patent term restoration claims for "pipeline" drugs and other patented products that have been subjected to regulatory delays, external to the PTO. While the Administration has not taken a position on the substance of the policy involved, the Administration opposed inclusion of legislation on this subject in the "Omnibus bill" because there was not adequate time for consideration of such legislation.

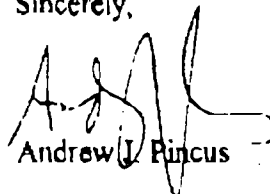
Mr. Lehman's October 13, 1998, letter merely restates his response to a question asked at the March 19, 1998, hearing of the House Judiciary Subcommittee on Courts and Intellectual Property. The original response was given without the presentation of specific legislative language. While the Administration has no position on patent term restoration legislation that is now before Congress, we remain willing to work in an open and fair manner with all parties -- consumers, manufacturers, Members of Congress and others -- to determine whether any policy interventions may be warranted.

The Honorable Richard Durbin

Page 2

It is my hope that this letter clarifies any issues of your concern. If I can provide further assistance, please do not hesitate to contact me.

Sincerely,



Andrew J. Rincus

Enclosure

cc: The Honorable Ed Bryant
House of Representatives
Washington, DC 20515-4207

The Honorable Bruce Lehman
Assistant Secretary of Commerce and
Commissioner of Patents and Trademarks
U.S. Department of Commerce
Washington, DC 20231



UNITED STATES DEPARTMENT OF COMMERCE
Patent and Trademark Office
ASSISTANT SECRETARY AND COMMISSIONER
OF PATENTS AND TRADEMARKS
Washington, D.C. 20231

OCT 13 1998

The Honorable Ed Bryant
House of Representatives
Washington, D.C. 20515-4207

Dear Representative Bryant:

You have asked me to confirm the views I expressed to you during the House Judiciary Subcommittee on Courts and Intellectual Property hearing on March 19, 1998, concerning an administrative process to review patent term restoration claims.

As I stated in response to the question you posed to me on March 19th, I believe that it would be an excellent idea to establish an administrative procedure within the Patent and Trademark Office to review patent term restoration claims for "pipeline" drugs and other patented products that have been subjected to extraordinary regulatory delays, external to the Patent and Trademark Office.

Please let me know if I can be of any further assistance to you or if I can provide you with any additional information.

Sincerely,

Bruce A. Lehman

Assistant Secretary of Commerce and
Commissioner of Patents and Trademarks

LOUIS STOKES

11TH DISTRICT, OHIO

MEMBER,

COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEES:

RANKING MEMBER,

VA/HUD/INDEPENDENT AGENCIES

MEMBER,

LABOR/HHS/EDUCATION

Congress of the United States
House of Representatives
Washington, DC 20515-3511

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SUITE 204
SHAKER HEIGHTS, OH 44122
(216) 522-4900

August 25, 1998

The Honorable Albert Gore
Vice President
United States of America
Office of The Vice President
Old Executive Office Building
Washington, D.C. 20501

Dear Vice President Gore:

While I am encouraged by the Department of Health and Human Services' efforts to implement the Administration's National Organ and Tissue Donation Initiative, I am concerned that the effort does not effectively incorporate key minority-based organizations in the planning and implementation phases of this national strategy, one such organization is the National Minority Organ Tissue Transplantation Education Program (MOTTEP).

MOTTEP was the first national minority organ and tissue initiative in the United States. Since 1993, MOTTEP has been supported by the National Institutes of Health (NIH) and has been charged with responsibilities for changing donation behavior in five minority populations: African Americans, Latinos/Hispanics, Asian, Pacific Islanders, Alaskan Natives, and Native Americans. UNOS data identifies significant improvements in minority organ donation rates, partially related to MOTTEP's efforts.

I am very concerned about the exclusion of the minority perspective in the active planning and implementation of the initiative as it is evolving. I understand that on numerous occasions minority-based organizations including MOTTEP have not been included in opportunities for public recognition, in spite of their major contributions and ongoing support of organ and tissue donations activities.

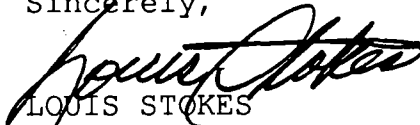
To facilitate the implementation of the initiative, I am requesting that the Administration directly involve Dr. Clive Callender, Founder and Principal Investigator of MOTTEP, and

The Honorable Albert Gore
August 25, 1998
Page 2

other key minority organizations as it moves forward in shaping the minority component of the Initiative. As I am very interested in your plans for developing viable partnerships and collaborations, I would like to meet with you at your earliest convenience to discuss these plans. My staff will be contacting you to arrange this meeting.

Please know that I look forward to working with you on this very important public health matter.

Sincerely,



LOUIS STOKES
Member of Congress

LS/st



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILEDATE March 19, 1999

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

Dewrahn Adler
(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): 2

COMMENTS:

If this language is o.k.
with Chris and you, I'd like to send
it out to the AFL-CIO and UAW tonight.
We also could approach the NEA.
I'm also working on securing a
partnership with a major credit card company

Thanks.

Lisa

John J. Sweeney, President
AFL-CIO
815 16th Street, N.W.
Washington, D.C. 20006

DRAFT

Dear Mr. Sweeney:

As a follow up to the February 5 letter UAW President Stephen P. Yokich sent to you regarding UAW/Saturn's National Donor Day, I would like to offer the AFL-CIO the opportunity to participate in an event proposed by the Administration to showcase organizations that have joined the Administration's National Organ and Tissue Donation Initiative and taken the lead in encouraging people to choose organ and tissue donation. The event would take place on or before National Organ and Tissue Donor Awareness Week, April 18-24. With the AFL-CIO's distinguished community service record and commitment to blood collection and other forms of life-saving donations, you could serve as a model for others by educating your members now on the need for organ and tissue donation and by participating in next year's National Donor Day (February 12). I invite the AFL-CIO to join us in this critical effort and to use this opportunity to announce your commitment to moving forward on an initiative to promote donation.

Organ and tissue transplantation has given the gift of life and better health to hundreds of thousands of individuals. Still, an average of 11 people die every day waiting for an organ transplant because the number of donated organs falls critically short of the need. At present, 62,000 men, women, and children are waiting for a healthy organ to replace a failing kidney, heart, liver, lung, or pancreas. About 20,000 individuals received an organ transplant in 1997. Thousands of critically-ill individuals could be saved every year if more organs were donated.

Launched in December 1997 by Vice President Al Gore and Health and Human Services (HHS) Secretary Donna E. Shalala, the National Organ and Tissue Donation Initiative aims to substantially increase organ and tissue donation by inspiring more individuals and families to say yes when asked to donate, increasing referral and identification of potential donors to maximize opportunities for donation, and learning more about what works best to promote donation. HHS continues to build partnerships with public and private organizations to support these goals.

As a voice for labor, your participation in this initiative would bring hope to the thousands of individuals and their families waiting for the gift of life. I look forward to hearing from you regarding our request. Please do not hesitate to contact me at (202) 690-6133.

Sincerely,

Lisa A. Gilmore
Special Assistant to the Deputy Secretary
Co-Chair, National Organ and Tissue Donation Initiative

cc: Stephen P. Yokich, President, UAW



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILEDATE March 15, 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

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): 12

COMMENTS:

For your information, attached is today's USA Today article on the upcoming public IOM meeting on organ allocation on April 15. Also attached is additional background information, including schedule, of the April 14 First Family Pledge event. Please note: my voicemail is not at present but you can call at (202) 690-6133. Thanks. Lisa

Wall St. Jnl.; 3-15-99

HMO Industry Kicks Off a Campaign To Raise Its Medicare Reimbursements

By LAURIE MCGINLEY

Staff Reporter of THE WALL STREET JOURNAL

WASHINGTON — The HMO industry, which is being pummeled in the patients-rights debate, wants to change the subject to one it hopes will pay both political and financial dividends: Medicare.

In a bid to bolster government reimbursements for Medicare HMOs, the American Association of Health Plans is kicking off a national effort to recruit senior citizens to plead its case with decisionmakers here.

The group, which represents health-maintenance organizations and other managed-care plans, is warning the elderly that reduced government payments could lead additional HMOs to scale back

extra benefits or drop out of Medicare entirely.

The association, targeting as many as 20 major HMO markets over the next several months, will hold news conferences, focus groups and rallies aimed at building long-term support among the elderly. "This is not just a technical argument but a political campaign," says AAHP President Karen Ignagni. "We're taking our message to the people affected, and they're responding."

The group trotted out its slogan—"Close the Medicare Fairness Gap"—a few weeks ago when it released a new industry-financed study. The study showed that by 2004, most seniors will live in areas where the government will spend at least \$1,500 less per person annually for HMO coverage than for traditional Medicare coverage.

For years, the government paid HMOs 95% of the amount it spent in a particular region to provide fee-for-service Medicare. But the 1997 budget law lowered that percentage and took other steps to curb payments to plans. Industry critics say the reductions are justified, given that several studies have concluded that HMOs have been overpaid for years.

"HMOs are serving younger and healthier beneficiaries and they shouldn't receive payments as though they are serving the older, sicker beneficiaries" in the

traditional program, says Ron Pollack, executive director of Families USA, a liberal health-care advocacy group.

HMOs "want to have it both ways," says Marilyn Moon of the Urban Institute, a Washington think tank. "For years, they claimed they'd be less expensive and more efficient than traditional Medicare. Now, when their feet are being held to the fire on this, they aren't happy about it."

But Kenneth Abramowitz, a health-care analyst for Sanford C. Bernstein & Co., a New York brokerage firm, disagrees, saying that the current policy is "bad economics, bad for beneficiaries and unfair to the health plans." He says the government should set policies that encourage seniors to join HMOs, because over time the health plans will be able to deliver more services at lower cost.

The industry may be making some progress. In a recent letter to the Senate Budget Committee, GOP Sen. William Roth, chairman of the Senate Finance Committee, said he wanted to explore "the issue of spending parity" between HMOs and the fee-for-service program.

But getting a spending-parity plan approved by Congress could be difficult. Lawmakers would have to cut spending in other areas, and they are already concerned about a Clinton administration proposal to cut Medicare hospital payments.

Nevertheless, AAHP officials say Medicare is a far better issue for the industry than patients rights — the effort to impose consumer protection rules on HMOs for the under-65 population. "Medicare lets us say not just what we're against, but what we're for," says Mark Merritt, AAHP vice president.

'USA Today; 3-15-99'

State, federal officials battle over donor organs

By Richard Willing
USA TODAY

WASHINGTON — A federal task force is refereeing a growing dispute between states that want organ transplants done locally and federal officials who want to make donated organs more available nationwide.

A task force organized by the Institute of Medicine, a non-profit advisory group, will meet April 15 in Washington to develop recommendations for Congress. The 16-member group of doctors, surgical nurses, public health specialists and medical ethicists completed two days of preliminary meetings last Friday.

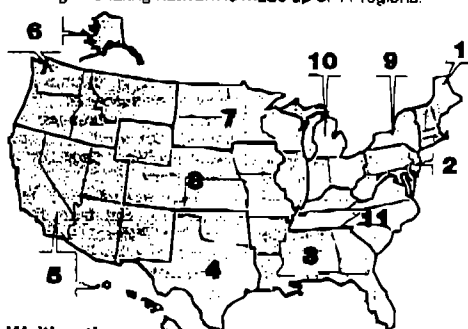
"We're just getting going, but it's clear from the response we've gotten already that this is an important issue that has touched many people," says Dan Quinn, an Institute of Medicine spokesman.

The controversy was sparked by a federal regulation proposed last year that would give priority in transplants to the sickest patients regardless of where they lived. Under the current system, organs are offered first to patients who live nearest to where the organs are recovered, then to patients in other parts of the country.

That, critics say, creates un-

Wait for liver transplants varies

The organ-sharing network is made up of 11 regions.



Waiting times

Number of days waiting for a liver transplant, by region.

fair disparities in waiting times for vital organs. One recent study found that the median wait for liver transplant patients in the Baltimore area was 439 days, but only 147 days in nearby Washington, D.C.

Organs must be rationed be-

cause demand far exceeds supply. About 19,500 major organs, including hearts, lungs, livers, kidneys, intestines and pancreases, have been transplanted in each of the past three years. More than 65,000 patients are listed on a national register of

transplant candidates.

Some states reacted negatively to the proposed rule. Louisiana, Wisconsin, South Carolina, Oklahoma and Florida have laws that would keep local organs from being shipped interstate. Similar legislation is pending in Texas and Arizona.

Because of the controversy, Congress ordered the Institute of Medicine study and delayed the effective date of the federal rule until at least Oct. 1.

Richard Ieyoub, Louisiana's attorney general, already has filed a challenge to the proposed rule in federal court.

"It's unconstitutional for... a federal agency to simply override our states' laws," says Ieyoub, who donated a kidney to his brother in 1977. "And medically it's a bad idea. It would cause delay and lessen success if you're shipping organs all over the country."

But proponents of making organs available nationwide say the present system is unfair and bad medicine. "Organs are a national resource," says G. Bruce Weir, president of the Transplant Recipients International Organization and the recipient of a heart transplant in 1988. "Your life shouldn't depend on where you live."

Claude Earl Fox, administrator of the federal Health Re-

sources and Services Administration, says a national system would "make sure that the people who need (organs), the most get them."

Under the present system, he says, vital time can be lost while available organs are matched with local candidates. The process would move more quickly, he says, if the sickest candidate were taken first.

The state-federal flap is also about preserving local transplant centers. Nearly 275 American hospitals now perform organ transplants. That number seems likely to shrink if a national organ transplant system is started.

"The movement would be toward (centralizing transplants) in a few facilities in big cities where there are a lot of donors," says Vermont Gov. Howard Dean, a Democrat and a medical doctor. "It would greatly disadvantage the majority of states."

Randolph Smoak, an Orangeburg, S.C., surgeon who is chairman of the American Medical Association's board of trustees, says the solution lies in increasing the supply of available organs.

"In a country with the numbers of deaths we have annually, it ought to be entirely possible," he says.

March 9, 1999



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

Dear Secretary Shalala:

On April 14th, more than 200 transplant kids, aged 2 to 10, from all across the country will be gathering in Washington to attend the First Family Pledge Congress on Organ and Tissue Donation in Senate Hart 902.

During the Congress, these kids – who were given a second chance at life through the successful transplantation of hearts, lungs, kidneys, pancreases, livers, tissue and eyes – will be presenting awards to more than 200 Members of the U.S. Congress who have taken the First Family Pledge in support of organ and tissue donation.

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.

In view of your long commitment to organ and tissue donation, we would like to invite you to deliver welcoming remarks to the kids – and leaders of medical centers and organ procurement organizations from around the country – who will be attending this historic event.

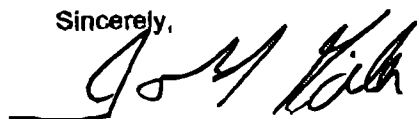
We also are inviting Vice President Albert Gore and Mrs. Elizabeth Dole to deliver welcoming remarks to emphasize the bipartisan nature of this important cause.

The First Family Pledge Congress is sponsored by the American Society of Transplant Surgeons, the American Red Cross, and the North American Transplant Coordinators Organization. It also has the support of the Association of Organ Procurement Organizations, the Coalition on Donation and the American Society of Transplantation, as well as numerous state and local members of the transplant community.

We very much hope you might be able to participate in this event on April 14th.

Thank you for your consideration.

Sincerely,



Joshua Miller, M.D.
President
American Society of Transplant Surgeons

AMERICAN SOCIETY OF TRANSPLANT SURGEONS

1729 H Street NW, Suite 400 • Washington, D.C. 20006 • 1-800-848-8836

www.familypledge.org

 American
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Tissue Services

First Family Pledge on Organ & Tissue Donation

Congress Schedule

8:30 am	Registration	
9:30	Congress opens.	Dr. Joshua Miller, President ASTS
9:35	VIP welcoming remarks and Pledge signings.	TBA
10:00	Introduction of First Family Pledge Congress followed by Parade of States (entrance and introduction of delegates).	Reg and Maggie Green, Honorary co-chairs
10:40	Invocation	Religious leader TBA
10:45	Pledge of Allegiance	TBA
10:50	National Anthem	Entertainer TBA
10:55	Two delegates – selected to be “Speaker of House” and “President of Senate” – convene First Family Pledge Congress. “Co- sponsors” introduce Resolution of Thanks. Four delegates – representing kidney/pancreas recipients, Liver recipients, heart/lung/intestine recipients, and tissue/eye recipients – Make floor statements in support of resolution.	
11:15	Roll call of states. One delegate from each state, DC and Puerto Rico announces state vote for Resolution of Thanks	
11:35	Presentation of Resolution of Thanks to a Member of U.S. Senate with request that it be conveyed to Senators. Member accepts and promises to bring delegation back for afternoon presentation.	TBA
11:45	Presentation of Resolution of Thanks to a Member of U.S. House with request that it be conveyed to Representatives. Member accepts and promises to bring delegation back for afternoon	TBA

	presentation.	
11:55	Delegates exit in reverse Parade of States. Morning session is adjourned.	Dr. Miller
12:15 pm	Special luncheon for delegates	
2:00 pm	Afternoon session convened	Steve Bullock
2:05	VIP welcoming remarks and Pledge signing.	TBA
2:17	"Speaker" and "President" ask if Congress is prepared to present Resolution of Thanks to Members of U.S. Congress from West and Northwest. "Whip" announces that Members of U.S. Senate and House of Representatives from West and Northwest are present.	
2:20	Members of U.S. Senate and House of Representatives rise and accept Plaques from Delegates as names are called out.	Reg and Maggie Green
2:30	A U.S. Senator or Representative from the West or Northwest formally thanks kids on behalf of Members of Congress from that region. Delegates and Members of U.S. Congress pose for group photo, then depart.	TBA
2:50	Presentation of Plaque to Members of U.S. Senate and House of Representatives from Southwest and Midwest.	Reg and Maggie Green
3:00	A U.S. Senator or Representative from the Southwest or Midwest formally thanks kids on behalf of Members of Congress from that region. Delegates and Members of U.S. Congress pose for group photo, then depart.	TBA
3:20	Presentation of Plaque to Members of U.S. Senate and House of Representatives from Southeast.	Reg and Maggie Green
3:30	A U.S. Senator or Representative from the Southeast formally thanks kids on behalf of Members of Congress from that region. Delegates and Members of U.S. Congress pose for group photo, then depart.	TBA
3:50	Presentation of Plaque to Members of U.S.	Reg and Maggie

	Senate and House of Representatives from MidAtlantic and Northeast	Green
4:10	A U.S. Senator or Representative from the MidAtlantic or Northeast formally thanks kids on behalf of Members of Congress from that region. Delegates and Members of U.S. Congress pose for group photo, then depart	TBA
4:30	Closing remarks	Dr. Joshua Miller
6:30 pm	Congressional reception	



Thank You, Congressional Leaders



On behalf of the 200 transplant kids from all 50 states who will be attending the First Family Pledge Congress on Organ and Tissue Donation on April 14th, the American Society of Transplant Surgeons and the American Red Cross would like to thank 100 Members of Congress who are leading the way in giving this historic event their strong support.

The First Family Pledge Congress will bring children ages 2 to 10 -- who are alive today as a result of the miracle of transplantation -- to the Capitol to honor all Members of Congress who have made a leadership commitment to help us address the growing national crisis posed by a shortage of donors.

We are hopeful that the First Family Pledge Congress will demonstrate to all Americans that the leaders of our country, Members of Congress, overwhelmingly believe that a commitment to donation and providing a new chance at life for thousands of additional men, women, and children is the right thing to do.

U.S. Senators

Senator Christopher "Kit" S. Bond - R, Missouri
 Senator John B. Breaux - D, Louisiana
 Senator Richard H. Bryan - D, Nevada
 Senator Jim Bunning - R, Kentucky
 Senator Conrad Burns - R, Montana
 Senator John A. Chafee - D, South Dakota
 Senator Mike DeWine - R, Ohio
 Senator Christopher Dodd - D, Connecticut
 Senator Byron Dorgan - D, North Dakota

Senator Richard J. Durbin - D, Illinois
 Senator Dianne Feinstein - D, California
 Senator Bill Frist - R, Tennessee
 Senator Jesse Helms - R, North Carolina
 Senator Edward M. Kennedy - D, Massachusetts
 Senator John F. Kerry - D, Massachusetts
 Senator Mary L. Landhear - D, Louisiana
 Senator Frank R. Lautenberg - D, New Jersey
 Senator Carl Levin - D, Michigan

Senator Blanche Lincoln - D, Arkansas
 Senator Mitch McConnell - R, Kentucky
 Senator Harry Reid - D, Nevada
 Senator John D. Rockefeller IV - D, West Virginia
 Senator Rick Santorum - R, Pennsylvania
 Senator Robert C. Torricelli - D, New Jersey
 Senator George V. Voinovich - R, Ohio

U.S. Representatives

Representative Jim Banta - R, Texas
 Representative Xavier Becerra - D, California
 Representative Howard E. Berman - D, California
 Representative Marion Berry - D, Arkansas
 Representative Brian R. Bilray - R, California
 Representative Earl Blumenauer - D, Oregon
 Representative Henry Bonilla - R, Texas
 Representative Mary Bono - R, California
 Representative George E. Brown Jr. - D, California
 Representative Shedd Brown - D, Ohio
 Representative Ken Calvert - R, California
 Representative Tom Campbell - R, California
 Representative Charles T. Canady - R, Florida
 Representative Sukhy Chaudhry - R, Georgia
 Representative E. Clayman - D, North Carolina
 Representative Tom L. Coburn, M.D. - R, Oklahoma
 Representative Michael Cook - R, Utah
 Representative Nathan Deal - R, Georgia
 Representative Rosa DeLauro - D, Connecticut
 Representative Lloyd Doggett - D, Texas
 Representative Bob Filner - D, California
 Representative Harold E. Ford Jr. - D, Tennessee
 Representative Bob Franks - R, New Jersey
 Representative Jim Gibbons - R, Nevada
 Representative Kay Granger - R, Texas
 Representative Gene Green - D, Texas

Representative Jim Greenwood - R, Pennsylvania
 Representative Ralph M. Hall - D, Texas
 Representative James V. Hansen - R, Utah
 Representative Wally Kerkorian - R, California
 Representative Rick Hill - R, Montana
 Representative David L. Hobson - R, Ohio
 Representative John M. Hontela - R, Indiana
 Representative Asa Hutchinson - R, Arkansas
 Representative Nancy L. Johnson - R, Connecticut
 Representative Nancy Kaptur - D, Ohio
 Representative John R. Kasich - R, Ohio
 Representative Patrick J. Kennedy - D, Rhode Island
 Representative Ron Kind - D, Wisconsin
 Representative Roy L. Lohr - R, Illinois
 Representative Nick Lampson - D, Texas
 Representative Tom Latham - R, Iowa
 Representative Steven C. LaTourette - R, Ohio
 Representative Jerry Lewis - R, California
 Representative Frank D. Lucas - R, Oklahoma
 Representative James H. Maloney - D, Connecticut
 Representative James P. McGovern - D, Massachusetts
 Representative Scott McInnis - R, Colorado
 Representative George Miller - D, California
 Representative Joe Moakley - D, Massachusetts
 Representative Constance A. Mink - R, Maryland
 Representative Sonny Morrell - R, North Carolina

Representative Robert W. Ney - R, Ohio
 Representative Michael G. Oxley - R, Ohio
 Representative Frank Pallone, Jr. - D, New Jersey
 Representative Ron Paul - R, Texas
 Representative Rob Portman - R, Ohio
 Representative Deborah Pryor - R, Ohio
 Representative Lynn M. Rivers - D, Michigan
 Representative Ileana Ros-Lehtinen - R, Florida
 Representative Thomas C. Sawyer - D, Ohio
 Representative Jim Saxton - R, New Jersey
 Representative Brad Sherman - D, California
 Representative John M. Shimkus - R, Illinois
 Representative Michael K. Simpson - R, Idaho
 Representative Louise M. Slaughter - D, New York
 Representative McSwain - D, Arkansas
 Representative Fred Spencer - R, South Carolina
 Representative Peter Stark - D, California
 Representative Kent Stedman - D, Ohio
 Representative Bob Stump - R, Arizona
 Representative John S. Tanner - D, Tennessee
 Representative John F. Tierney - D, Massachusetts
 Representative Henry A. Waxman - D, California
 Representative Jerry Weller - R, Illinois
 Representative Gern Wooley - D, California

If you haven't already signed the First Family Pledge, please do so now so the transplant kids coming to the Capitol on April 14th from your state can honor you at the First Family Pledge Congress.

For additional information, please call (202) 293-4911 or visit the First Family Pledge website at <http://www.familypledge.org>.

AMERICAN SOCIETY OF TRANSPLANT SURGEONS



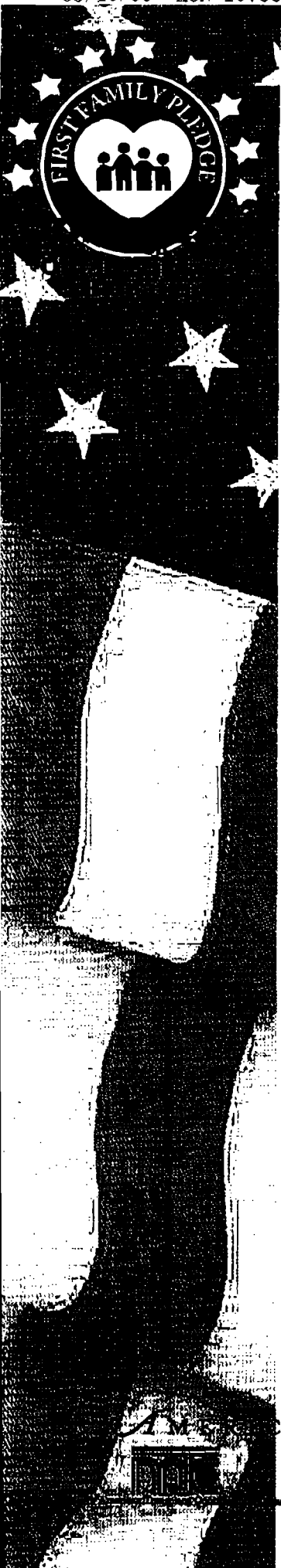
North American Transplant Coordinators' Organization



Tissue Services



American Organ Procurement Organization



ASTS FIRST FAMILY PLEDGE CAMPAIGN

Members of Congress who have signed The Pledge with their families
(as of March 5, 1999)

U.S. Senate

Senator Christopher S. Bond – R, Missouri
 Senator John Breaux – D, Louisiana
 Senator Richard H. Bryan – D, Nevada
 Senator Jim Bunning – R, Kentucky
 Senator Conrad Burns – R, Montana
 Senator Thomas A. Daschle – D, South Dakota
 Senator Mike DeWine – R, Ohio
 Senator Christopher J. Dodd – D, Connecticut
 Senator Byron L. Dorgan – D, North Dakota
 Senator Richard J. Durbin – D, Illinois
 Former Senator Lauch Faircloth – R, North Carolina
 Senator Russell Feingold – D, Wisconsin
 Senator Dianne Feinstein – D, California
 Senator William H. Frist – R, Tennessee
 Senator Jesse Helms – R, North Carolina
 Senator Daniel K. Inouye – D, Hawaii
 Senator Edward M. Kennedy – D, Massachusetts
 Senator John Kerry – D, Massachusetts
 Senator Mary Landrieu – D, Louisiana
 Senator Frank R. Lautenberg – D, New Jersey
 Senator Carl Levin – D, Michigan
 Senator Blanche L. Lincoln – D, Arkansas
 Senator Mitch McConnell – R, Kentucky
 Senator Harry Reid – D, Nevada
 Senator John Rockefeller – D, West Virginia
 Senator Rick Santorum – R, Pennsylvania
 Senator Robert Torricelli – D, New Jersey
 Senator George V. Voinovich – R, Ohio

U.S. House of Representatives

Representative Tom Allen – D, Maine
 Representative John Baldacci – D, Maine
 Representative Joe Barton – R, Texas
 Representative Xavier Becerra – D, California
 Representative Howard Berman – D, California
 Representative Marion Berry – D, Arkansas

Page 1 of 4

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www.familypledge.org

 American
 Red Cross
 Tissue Services

Representative Brian Bilbray – R, California
Representative Earl Blumenauer – D, Oregon
Representative Henry Bonilla – R, Texas
Representative Mary Bono – R, California
Representative George Brown, Jr. – D, California
Representative Sherrod Brown – D, Ohio
Representative Ken Calvert – R, California
Representative Tom Campbell – R, California
Representative Charles Canady – R, Florida
Representative Saxby Chambliss – R, Georgia
Former Representative Jon Christensen – R, Nebraska
Representative Eva M. Clayton – D, North Carolina
Representative Tom Coburn, M.D. – R, Oklahoma
Representative Merrill Cook – R, Utah
Representative Tom Davis – R, Virginia
Representative Nathan Deal – R, Georgia
Representative Rosa DeLauro – D, Connecticut
Representative Lloyd Doggett – D, Texas
Former Representative John Ensign – R, Nevada
Representative Bob Filner – D, California
Representative Harold E. Ford, Jr. – D, Tennessee
Representative Bob Franks – R, New Jersey
Former Representative Elizabeth Furse – D, Oregon
Representative George W. Gekas – R, Pennsylvania
Representative James A. Gibbons – R, Nevada
Representative Porter J. Goss – R, Florida
Representative Kay Granger – R, Texas
Representative Gene Green – D, Texas
Representative Jim Greenwood – R, Pennsylvania
Representative Ralph M. Hall – D, Texas
Representative James V. Hansen – R, Utah
Representative Wally Herger – R, California
Representative Rick Hill – R, Montana
Representative David L. Hobson – R, Ohio
Representative John N. Hostettler – R, Indiana
Representative Asa Hutchinson – R, Arkansas
Representative Nancy L. Johnson – R, Connecticut
Representative Marcy Kaptur – D, Ohio
Representative John R. Kasich – R, Ohio
Representative Patrick J. Kennedy – D, Rhode Island
Representative Ronald J. Kind – D, Wisconsin
Representative Dennis J. Kucinich – D, Ohio
Representative Ray LaHood – R, Illinois

Representative Nicholas V. Lampson – D, Texas
Representative Tom Latham – R, Iowa
Representative Steven C. LaTourette – R, Ohio
Representative Jerry Lewis – R, California
Representative John Lewis – D, Georgia
Representative Frank D. Lucas – R, Oklahoma
Representative James H. Maloney – D, Connecticut
Representative Carolyn McCarthy – D, New York
Representative James P. McGovern – D, Massachusetts
Representative Scott McInnis – R, Colorado
Representative George Miller – D, California
Representative Joseph Moakley – D, Massachusetts
Representative James P. Moran – D, Virginia
Representative Constance A. Morella – R, Maryland
Representative Sue Myrick – R, North Carolina
Representative Eleanor Holmes Norton – Delegate, District of Columbia
Representative Robert Ney – R, Ohio
Representative John W. Olver – D, Massachusetts
Representative Michael G. Oxley – R, Ohio
Representative Frank Pallone, Jr. – D, New Jersey
Representative Ron E. Paul – R, Texas
Representative Rob Portman – R, Ohio
Representative Deborah Pryce – R, Ohio
Representative Lynn N. Rivers – D, Michigan
Representative Ileana Ros-Lehtinen – R, Florida
Representative Thomas C. Sawyer – D, Ohio
Representative Jim Saxton – R, New Jersey
Representative Brad Sherman – D, California
Representative John M. Shimkus – R, Illinois
Representative Michael K. Simpson – R, Idaho
Representative Louise M. Slaughter – D, New York
Representative Vic Snyder – D, Arkansas
Representative Floyd Spence – R, South Carolina
Representative Pete Stark – D, California
Representative Ted Strickland – D, Ohio
Representative Bob Stump – R, Arizona
Representative Tom Tancredo – R, Colorado
Representative John S. Tanner – D, Tennessee
Representative W. J. "Billy" Tauzin – R, Louisiana
Representative John F. Tierney – D, Massachusetts
Representative Bruce F. Vento – D, Minnesota

Representative Henry A. Waxman – D, California
Representative Jerry Weller – R, Illinois
Representative Lynn Woolsey – D, California



Every family hopes that if one of its loved ones becomes seriously ill, medical science will be able to provide a miracle — and restore a husband or wife, son or daughter, brother or sister, mother or father, to a healthy and rewarding life.

Medical science has been able to do exactly that over the past decade for hundreds of thousands of families with loved ones suffering from diseases and injuries that affect the heart, kidney, pancreas, lungs, liver or tissues.

Transplantation of organs and tissue has become one of the most remarkable success stories in medicine, now giving tens of thousands of desperately ill Americans each year a new chance at life — and returning them to the love of their families.

But sadly, this medical miracle is not yet available to all in need. Waiting lists are growing more rapidly than the number of organs and tissues being donated.

Just as we would hope, in times of crisis, that the miracle of a gift that could save or greatly enhance the life of a loved one would be available to our family, we want to pledge to make this same miracle available to others.

Therefore, we hereby sign the *First Family Pledge*, agreeing to talk about the importance of organ and tissue donation with our loved ones, and pledge with them to make this gift available to other families, if medically acceptable, in the event of a family member's death.

And in hopes of encouraging other families to join us in this affirmation of love and life, we hereby add our names to the public roster of those taking the *First Family Pledge*. Pledge signers will be listed on the internet at www.familypledge.org as testament to the growing public support for donation. The pledge is not a legally binding document.

 SIGNED

 DATE

 SIGNED

 DATE

 SIGNED

 DATE

 SIGNED

 DATE


Tissue Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILEDATE March 21, 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

H.H. Humphrey Bldg., Room 814G
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): 5

COMMENTS:

follow-up
Draft letters to AFL-CIO,
UAW, and Coalition on Donation
(for Capital One Financial - the 3rd
largest credit card issuer in U.S.) for
Chris' approval. NEA is a long-shot
unless Chris can establish contact.
Thanks. Lisa

DRAFT

David Fleming
Executive Director
Coalition on Donation
1100 Boulders Parkway, Suite 500
Richmond, VA 23225-8770

Dear Mr. Fleming:

As we discussed last week, the Administration is proposing an event to showcase organizations that have joined the Administration's National Organ and Tissue Donation Initiative and taken the lead in encouraging people to choose organ and tissue donation. I would like your assistance in identifying major national organizations who would like to join us and the Coalition on Donation in this critical effort and to use this opportunity to announce their commitment to moving forward on an initiative to promote donation. The event would take place on or before National Organ and Tissue Donor Awareness Week, April 18-24.

Organ and tissue transplantation has given the gift of life and better health to hundreds of thousands of individuals. Still, an average of 11 people die every day waiting for an organ transplant because the number of donated organs falls critically short of the need. At present, 62,000 men, women, and children are waiting for a healthy organ to replace a failing kidney, heart, liver, lung, or pancreas. About 20,000 individuals received an organ transplant in 1997. Thousands of critically-ill individuals could be saved every year if more organs were donated.

Launched in December 1997 by Vice President Al Gore and Health and Human Services (HHS) Secretary Donna E. Shalala, the National Organ and Tissue Donation Initiative aims to substantially increase donation by inspiring more individuals and families to say yes when asked to donate, maximizing opportunities for donation, and learning more about what works best to promote donation. HHS continues to build partnerships with public and private organizations to support these goals.

I appreciate the ongoing support and leadership of the Coalition on Donation in this national life-saving partnership and hope we can join together to highlight the commitment of the Coalition and its organizational partners to the goals of the National Organ and Tissue Donation Initiative. I look forward to hearing from you soon regarding our request. Please do not hesitate to contact me at (202) 690-6133.

Sincerely,

Lisa A. Gilmore
Special Assistant to the Deputy Secretary
Co-Chair, National Organ and Tissue Donation Initiative

DRAFT

Mr. S. P. Yokich
Page 2
March 2, 1999

As one of the largest and most diverse unions in North America, your participation in this initiative would bring hope to the thousands of individuals and their families waiting for the gift of life. I look forward to hearing from you soon regarding our request. Please do not hesitate to contact me at (202) 690-6133.

Sincerely,

Lisa A. Gilmore
Special Assistant to the Deputy Secretary
Co-Chair, National Organ and Tissue Donation Initiative

cc: John J. Sweeney, President, AFL-CIO

DRAFT

Stephen P. Yokich, President
UAW
Solidarity House
8000 East Jefferson Avenue
Detroit, Michigan 48214

Dear Mr. Yokich:

I would like to begin by thanking you for your support of National Donor Day hosted by the UAW and Saturn. The U.S. Department of Health and Human Services (HHS) is a partner in this annual donation drive, and to kick off this year's effort, HHS Deputy Secretary Kevin Thurn hosted a National Donor Day Preview Event with the UAW, Saturn, and other coalition partners on February 11 in Washington, D.C. In light of your ongoing commitment to increasing life-saving donations, I would like to offer the UAW the opportunity to participate in an event proposed by the Administration to showcase organizations that have joined the Administration's National Organ and Tissue Donation Initiative and taken the lead in encouraging people to choose organ and tissue donation. The proposed event would take place on or before National Organ and Tissue Donor Awareness Week, April 18-24.

The UAW could serve as a model for others by educating your members on the need for organ and tissue donation. I invite the UAW to join us in this critical effort and to use this opportunity to announce your commitment to moving forward on an initiative to promote donation. To encourage the full involvement of labor in this effort, AFL-CIO President John J. Sweeney also has received an invitation to join this national life-saving partnership.

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DRAFT
(Revised)

John J. Sweeney, President
AFL-CIO
815 16th Street, N.W.
Washington, D.C. 20006

Dear Mr. Sweeney:

As a follow up to the February 5 letter UAW President Stephen P. Yokich sent to you regarding UAW/Saturn's National Donor Day, I would like to offer the AFL-CIO the opportunity to participate in an event proposed by the Administration to showcase organizations that have joined the Administration's National Organ and Tissue Donation Initiative and taken the lead in encouraging people to choose organ and tissue donation. The event would take place on or before National Organ and Tissue Donor Awareness Week, April 18-24. With the AFL-CIO's distinguished community service record and commitment to blood collection and other forms of life-saving donations, you could serve as a model for others by educating your members now on the need for organ and tissue donation and by participating in next year's National Donor Day (February 12). I invite the AFL-CIO to join us in this critical effort and to use this opportunity to announce your commitment to moving forward on an initiative to promote donation.

Organ and tissue transplantation has given the gift of life and better health to hundreds of thousands of individuals. Still, an average of 11 people die every day waiting for an organ transplant because the number of donated organs falls critically short of the need. At present, 62,000 men, women, and children are waiting for a healthy organ to replace a failing kidney, heart, liver, lung, or pancreas. About 20,000 individuals received an organ transplant in 1997. Thousands of critically-ill individuals could be saved every year if more organs were donated.

Launched in December 1997 by Vice President Al Gore and Health and Human Services (HHS) Secretary Donna E. Shalala, the National Organ and Tissue Donation Initiative aims to substantially increase donation by inspiring more individuals and families to say yes when asked to donate, maximizing opportunities for donation, and learning more about what works best to promote donation. HHS continues to build partnerships to support these goals.

As a leading voice for labor, your participation in this initiative would bring hope to the thousands of individuals and their families waiting for the gift of life. To encourage the full involvement of labor in this effort, UAW President Stephen P. Yokich also has received an invitation to join this national life-saving partnership. I look forward to hearing from you regarding our request. Please do not hesitate to contact me at (202) 690-6133.

Sincerely,

Lisa A. Gilmore, Special Assistant to the Deputy Secretary
Co-Chair, National Organ and Tissue Donation Initiative

cc: Stephen P. Yokich, President, UAW



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILEDATE March 21, 1999

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

Ms. Deborah Adler
(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
gilmore@os.dhhs.gov

RECIPIENT'S FAX NUMBER (202) 456-5557NUMBER OF PAGES TO SEND (INCLUDING COVER SHEET): 2

COMMENTS:

One more thought regarding the
proposed organ donation event.
Thanks again for your efforts
on this!

Lisa

MAR 21 1999

NOTE TO DEVORAH ADLERFrom: Lisa A. Gilmore *L. A. Gilmore*

Subject: Proposed Administration Organ Donation Event

I didn't want to interrupt you again but wanted to mention another benefit to conducting this event during the week of March 29 - April 2. In addition to being the first event leading into the National Organ and Tissue Donor Awareness Week (NOTDAW) activities, including the April 14 American Society of Transplant Surgeons' First Family Pledge Congress with Mrs. Dole, we can create a video news release from the Administration's event and send it out to 60-100 organ procurement organizations, local coalitions on donation, and other partners to use in their promotional activities for NOTDAW. The Coalition on Donation is well organized to ensure the success of such an effort. In addition, we can reinforce the Administration's recent announcements when we promote the National Donor Recognition Ceremony on April 18 with Surgeon General Dr. David Satcher.

Thanks again.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILEDATE February 9, 1999

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

Ms. Deborah Adler
DPC
(202) 456-5560

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
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(202) 690-6133
Fax (202) 690-7765
lgilmore@os.dhhs.gov

RECIPIENT'S FAX NUMBER (202) 456-5557NUMBER OF PAGES TO SEND (INCLUDING COVER SHEET): 11

COMMENTS:

For President's Radio
address this week if
approved. Thank you for
expediting this request?
Lisa



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

MEMORANDUM

FEB -9 1999

To: Devorah Adler
Domestic Policy Council

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

Subject: National Donor Day Submission for President's Radio Address, February 13, 1999

As we discussed, this memorandum is to request that President Clinton use a brief portion of this week's radio address to inform Americans that they can save lives by participating in National Donor Day (Saturday, February 13). Former NFL-player Walter Payton's dramatic announcement last week of his need for a liver transplant adds poignancy and urgency to what is already the nation's largest one-day "gift of life" donation drive. Through a partnership with Saturn Corporation, the United Auto Workers, the U.S. Department of Health and Human Services (HHS), and ten leading non-profit organizations, nearly 400 Saturn retailers nationwide are opening their doors to the public and providing opportunities for individuals to donate blood, be tissue typed to join the National Marrow Donor Program Registry, sign an organ and tissue donor card, and learn more about donations of platelets and umbilical cord blood. For the nearest participating Saturn facility, individuals can call a toll-free number - (800) 553-6670. A National Donor Day fact sheet and press release are attached.

U.S. Surgeon General David Satcher has called donation a critical public health issue. Every day, more than 10,000 Americans receive blood transfusions, and about 11 Americans die waiting for an organ transplant due to the shortage of donated organs. Last year's inaugural National Donor Day event raised nearly 8,000 units of blood, added 1,000 potential donors to the National Marrow Donor Program Registry, and distributed tens of thousands of organ and tissue donor cards.

National Donor Day is an excellent example of the type of public-private partnership that is at the heart of the Administration's *National Organ and Tissue Donation Initiative*. In support of this event, HHS Deputy Secretary Kevin Thurm is hosting a preview event this Thursday in the HHS Humphrey Building's Great Hall. This preview event will include the first-time meeting of a marrow donor from Washington, D.C. and the eight-year-old boy from Newark, N.J. who received her marrow. Vice President Gore and Mrs. Gore have been invited to participate in this event. The invitation and the media advisory are attached.

Thank you for facilitating the consideration of this request. I can be reached at (202) 690-6133, directly at (202) 260-1370 (voice-mail), or by e-mail at lgilmore@os.dhhs.gov.

cc: Elizabeth Summy, HHS Deputy Chief of Staff
Dave Quick, Saturn/UAW
Attachments (4)



NATIONAL DONOR DAY 1999

FACT SHEET

- WHO** Eleven of America's leading community health donation organizations have joined forces to create the USA's largest one day donor event ever. National Donor Day is hosted by Saturn and its UAW partners at nearly 400 retailer sites nationwide:
- American Association of Blood Banks
 - American Red Cross
 - America's Blood Centers
 - Coalition on Donation
 - National Kidney Foundation
 - National Marrow Donor Program
 - National Minority Organ Tissue Transplant Education Program
 - Rotary International District 6760
 - The Bill & Beverly Young Fund of the Marrow Foundation
 - Transplant Recipients International Organization, Inc.
 - U.S. Department of Health and Human Services
- WHAT** The public is invited to attend and donate/pledge blood, sign an organ & tissue pledge card, be typed for the National Marrow Donor Registry, learn more about and celebrate the life-saving miracle of donation. Last year's inaugural Donor Day raised nearly 8,000 units of blood and 1,000 potential donors were added to the National Marrow Donor Registry. Sixty percent of the 1998 events had one or more organ transplant recipients in attendance.
- WHY** There are five ways every American can help -- the "Five Points of Life" -- which include blood, platelets, marrow, cord blood and organ & tissue. There are 10,000 life saving transfusions every day and blood shortages occur often during winter. Demand for organ & tissue transplantation is critical and this is especially true among minority populations. Nationwide, approximately ten transplant candidates die every day because a donor is not found in time.
- WHERE** Call the National Donor Day "hotline" at 800 553-6670 to find the nearest event.
- WHEN** Saturday of Valentine's Day weekend, February 13th, from 11:00a.m. - 5:00p.m.

www.saturn.com

NATIONAL DONOR DAY 1999 PARTICIPATING ORGRANIZATIONS

American Association of Blood Banks (AABB) member facilities are responsible for collecting virtually all of the nation's blood supply and transfusing more than 80 percent.

Contact: Bob Ensinger (301) 215-6557 web site: www.aabb.org

The American Red Cross is the nation's single largest blood supplier.

Contact: Mike Fulwider (703) 807-5275 web site: www.redcross.org

America's Blood Centers (ABC) is the nation's largest network of non-profit, independent community blood centers that collects about half of the U.S. blood supply.

Contact: Melissa McMillan (202) 393-5725 web site: www.americasblood.org

The Coalition on Donation is a non-profit alliance of 48 national members and 50 local coalitions dedicated to increasing organ and tissue donation.

Contact: John Dean (804) 327-1445 web site: www.shareyourlife.org

The National Kidney Foundation is the world's largest organization promoting organ and tissue donation.

Contact: Ellie Schlam (212) 889-2210 web site: www.kidney.org

The National Marrow Donor Program (NMDP) facilitates unrelated marrow transplants for patients with life-threatening blood diseases by recruiting donors, maintaining a registry of more than three million volunteer donors and offering patient services.

Contact: Andrea Carter (612) 627-8182 web site: www.marrow.org

The National Minority Organ Tissue Transplant Education Program (MOTTEP) educates minority communities on the facts about organ/tissue transplantation, communities where the need is disproportionately great.

Contact: Rod Taylor (800) 393-2839 web site: www.mottep.org

Rotary International District 6760 of Tennessee is leading an effort to have Rotary International launch a long term initiative in support of donation.

Contact: Boyd Fulton (615) 373-4567

The Marrow Foundation secures support from private sources for the work of the National Marrow Donor Program. The **Bill & Beverly Young Fund** of the Marrow Foundation is providing resources to offset the cost of marrow typing at National Donor Day 1999 events.

Contact: Candace Steele (202) 638-6601

Transplant Recipients International Organization, Inc. (TRIO) works to improve the quality of life of transplant candidates, recipients, donors and their families.

Contact: Lisa Kory (202) 293-0980 web site: www.trioweb.org

The U.S. Department of Health and Human Services (HHS) is the federal government's principal agency for protecting the health of all Americans and for providing essential human services.

Contact: Charlotte Mehuron (301) 443-3376 web site: www.organdonor.gov

**NATIONAL DONOR DAY 1999****FOR IMMEDIATE RELEASE****Contact: Heidi Magyar
Saturn Corporation
248 528-6352****NATIONAL DONOR DAY 1999 DRIVES HELD AT
PARTICIPATING SATURN FACILITIES NATIONWIDE
Saturday, February 13, 1999****National Donor Day is a "Celebration of Life"****Last Year's Inaugural Event Raised Nearly 8,000 Units of Blood, Added 1,000
Potential Donors to the National Marrow Donor Program Registry and
Distributed Tens of Thousands of Organ & Tissue Donor Cards**

TROY, MICHIGAN (Jan. 25, 1999) -- Saturn and its United Auto Worker partners are joining America's leading non-profit donor organizations to encourage millions of Americans to visit any participating Saturn locations between 11:00 a.m. and 5:00 p.m. on Saturday, Feb. 13, 1999, to become part of National Donor Day.

The event is a "celebration of life" and families with a direct connection to donation and transplantation are invited to attend -- one goal of National Donor Day is to let all Americans know that transplantation has become mainstream medical practice that leads to normal and productive lives. An equally important goal is to inform the public of the five ways each of us can help give the "gift of life" so that others may live -- the "Five Points of Life" -- which are whole blood, platelets, umbilical cord blood, bone marrow, and organ and tissue donation.

Organ donor cards will be distributed at all participating Saturn sites, blood can be donated or pledged at all sites, and bone marrow typing also will be available at many Saturn facilities. Participating donor organizations will have informative materials, including information about cord blood donation, available at Saturn sites as well.

"Donation is a critical public health care issue and one immediate way millions of Americans can help save lives," states U.S. Surgeon General David Satcher. "The Department of Health and Human Services has again joined the National Donor Day partners in this most important awareness builder."

NATIONAL DONOR DAY 1999 RELEASE

Page 2

Saturn Chairman and President Cynthia Trudell states, "Saturn and its UAW partners are noted for their community service efforts. Our retailers tell us that last year's Donor Day was one of the most meaningful events in the history of the company. Most Saturn locations were visited by organ donor recipients and it helped us realize on a very personal level how important this cause is. Our web site has received hundreds of congratulatory messages of encouragement from donor recipients, persons awaiting donation and donor families. We have also learned of Saturn associates, and Saturn owners, who have first hand experience with life saving donation. It is our understanding that nationwide an average of over ten people die each day because a suitable donor is not found in time. We hope that by hosting National Donor Day, Saturn and our UAW partners working with donor organizations will make a difference."

NATIONAL DONOR DAY 1999 ORGANIZATIONS

American Association of Blood Banks
American Red Cross
America's Blood Centers
Coalition on Donation
National Kidney Foundation
National Marrow Donor Program
National Minority Organ & Tissue Transplant Education Program
Rotary International District 6760
Saturn Corporation
The Bill & Beverly Young Fund of the Marrow Foundation
Transplant Recipients International Organization, Inc.
United Auto Workers
U.S. Department of Health and Human Services

In addition to the above organizations, the Emergency Nurses Association is lending its support by sending Donor Day materials to ENA representatives at 3,000 hospitals nationwide. The "Five Points of Life" is a program of LifeSouth Community Blood Centers.

THE NEED

Approximately 10,000 life saving transfusions occur daily yet only about five percent of the eligible population of Americans give **blood** regularly. The winter months, including February, are often times of critical blood shortages and National Donor Day augments the blood supply during this period.

There are about 60,000 Americans, including children, awaiting **organ transplants** at any given moment and, sadly, approximately 10 die every day because a suitable donor is not found in time. Family consent is the major determining factor in donation and if Donor Day encourages millions of potential donors to make their wishes known to their families (in the words of the Coalition on Donation "Share your life. Share your decision."), the available donor pool would expand greatly. Transplantation leads to normal, productive lives. For example, a current university study has tracked the births of nearly 2,000 healthy babies by mothers who are transplant recipients.

NATIONAL DONOR DAY 1999 RELEASE

Page 3

THE NEED (Continued)

Thousands of Americans, including children, need a bone **marrow** transplant each year yet are unable to find a suitable match. Marrow typing of a potential donor requires only a very small sample of blood. Patients who need bone marrow transplants are actually in need of new stem cells, which produce the body's blood cells. To date, bone marrow has been the most prominent source of stem cells. New research proves that **umbilical cord blood** is also an effective source of stem cells. Cord blood banks are developing around the country.

Demand for transplants among **minority populations** is disproportionately high, while traditional minority representation among donor pools is not meeting the need. As a result of these two divergent trends, there is a greatly heightened need for donor awareness within minority communities.

LOCAL EVENTS

National Donor Day will be held at nearly 400 Saturn sites nationwide from 11:00 a.m. to 5:00 p.m. on Saturday, Feb. 13, 1999. Media **inquires** should call Heidi Magyar of Saturn Corporate Communications at (248) 528-6351. For the public, Saturn has established a toll-free number to direct interested persons to the nearest Saturn facility -- (800) 553-6670. National Donor Day information is also available on the Saturn web site at www.saturn.com.

During inaugural National Donor Day 1998, many of the Saturn retailers worked with their local blood banks and other non-profit donor organization local chapters to create special community events and incentives. This year, the Washington-Baltimore region will focus on the special needs of the minority community. In Chicago, National Donor Day will tie into the opening of the Chicago Auto Show. Other special events will occur at hundreds of Saturn sites as Saturn retailers and their partners create events that best serve their local communities.

DONOR DAY ORGANIZATIONS

American Association of Blood Banks (AABB) member facilities are responsible for collecting virtually all of the nation's blood supply and transfusing more than 80 percent. More than 2,200 institutions and 8,500 individuals are members of AABB. The mission of AABB is to establish and promote the highest standard of care for patients and donors in all aspects of blood banking: transfusion medicine; hematopoietic, cellular and gene therapies; and tissue transplantation. AABB members are located in all 50 states and in 80 foreign countries.

Contact: Bob Ensinger web site: www.aabb.org
(301) 215-6557

NATIONAL DONOR DAY 1999 RELEASE

Page 4

The **American Red Cross** is the nation's single largest blood supplier. Nearly 6 million volunteer blood donations are made to the Red Cross each year, accounting for about half of the U.S. blood supply. The Red Cross provides tissue for nearly one-quarter of transplant surgeries plus operates the world's leading blood, plasma and tissue research laboratory.

Contact: Mike Fulwider web site: www.redcross.org
(703) 807-5275

America's Blood Centers (ABC) is the nation's largest network of non-profit, independent community blood centers that collects about half of the U.S. blood supply serving 12.5 million patients annually at 3,100 hospitals nationwide. ABC members serve more hospitals and hospital chains and provide more direct transfusions, clinical and diagnostic services than any other U.S. blood organization.

Contact: Melissa McMillan web site: www.americasblood.org
(202) 393-5725, ext. 21

The **Coalition on Donation** is a non-profit alliance of 48 national members and 50 local coalitions dedicated to increasing organ and tissue donation. Their common goal is to ensure that every individual in the U.S. understands the need for organ and tissue donation and accepts donation as a fundamental human responsibility. The Coalition utilizes a single, unified message -- "Share your life. Share your decision." -- within a strong network of national members and local coalitions to forge dynamic partnerships with major organizations, associations and government agencies to create a greater willingness to donate.

Contact: John Dean web site: www.shareyourlife.org
(804) 327-1445

The **National Kidney Foundation** is proud to be the world's largest organization promoting organ and tissue donation. Through its service, advocacy, educational and athletic programs the Foundation increases public awareness of the need, supports the health care professionals, living donors and donor families involved in the organ and tissue donation process and provides education and services to transplant recipients.

Contact: Ellie Schlam web site: www.kidney.org
(212) 889-2210

The **National Marrow Donor Program (NMDP)** facilitates unrelated marrow transplants for patients with life-threatening blood diseases by recruiting donors, maintaining a registry of more than three million volunteer donors and offering patient services -- while also conducting research to further the field of unrelated marrow transplantation.

Contact: Andrea Carter web site: www.marrow.org
(612) 627-8182

NATIONAL DONOR DAY 1999 RELEASE

Page 5

The **National Minority Organ & Tissue Transplant Education Program (MOTTEP)** is the first program of its kind in the country to educate minority communities on the facts about organ/tissue transplantation; empower minority communities to develop transplant education programs which allow them to become involved in addressing the shortage of donors; increase minority participation in organ/tissue transplant endeavors including signing organ donor cards; encourage and increase family discussions related to organ and tissue donation; and, increase the number of minorities who donate organs and tissues.

Contact: Rod Taylor web site: www.mottep.org
(800) 393-2839

Rotary International District 6760 of Tennessee, along with other districts in Florida, Washington and California is leading an effort to have Rotary International launch a long term initiative in support of donation. The initiative includes the establishment of a national registry of donor pledges for use by the medical community.

Contact: Boyd Fulton
(615) 373-4567

The **Marrow Foundation** secures support from private sources for the work of the National Marrow Donor Program. The **Bill & Beverly Young Fund** of the Marrow Foundation is providing resources to offset the cost of marrow typing at National Donor Day 1999 events, in support of adding additional potential marrow donor names to the NMDP Registry.

Contact: Candace Steele
(202) 638-6601

Transplant Recipients International Organization, Inc. (TRIO) is an independent, non-profit international organization, working to improve the quality of life of transplant candidates, recipients, donors and their families. TRIO provides a range of services to its community, including awareness, support, education and advocacy. TRIO's members serve as emissaries, educating the public to the benefits of transplantation and the need for increased donation.

Contact: Lisa Kory web site: www.trioweb.org
(202) 293-0980

The **U.S. Department of Health and Human Services (HHS)** is the federal government's principal agency for protecting the health of all Americans and for providing essential human services. In addition to promoting organ and tissue donation, HHS funds the operation of the Organ and Procurement and Transplantation Network through a contract with the United Network for Organ Sharing and the operation of the marrow program through a contract with the National Marrow Donor Program; provides financing and oversight to the organ procurement organizations and Medicare and Medicaid hospitals; funds outreach through the National Minority Organ & Tissue Transplant Education Program and other programs; conducts research to improve transplant outcomes; oversees human tissue products; and supports disease prevention and health promotion activities.

Contact: Charlotte Mehuron web site: www.organdonor.gov
(301) 443-3376

February 8, 1999

MEDIA ADVISORY

For Thursday, Feb. 11

HHS Hosts Kick Off of National Donor Day Supporting Organ, Tissue, Blood and Marrow Donation -- HHS Deputy Secretary Kevin Thurm, Rep. Philip Crane and partnering organizations including Saturn Corp. and the United Auto Workers will host an event supporting the second annual National Donor Day (Feb. 13).

Special focus is on increasing minority donors in the Washington, D.C.-Baltimore area.

** The event will include the first-time meeting of a marrow donor from Washington, D.C. and the 8-year-old boy from Newark, N.J., who received her marrow. **

In addition to the speakers program, stations will be set up for individuals to donate blood, be tissue typed to join the National Marrow Donor Program Registry, sign an organ and tissue donor card, and learn more about donations of platelets and umbilical cord blood. The need for all forms of donation is critical: Every day, more than 10,000 Americans receive blood transfusions, and about 11 Americans die waiting for an organ transplant due to the shortage of donated organs.

WHO: HHS Deputy Secretary Kevin Thurm
Deputy Surgeon General Kenneth P. Moritsugu, M.D.
Rep. Philip M. Crane (Illinois)

WHEN: Thursday, Feb. 11, 1999
10 a.m.

WHERE: Hubert H. Humphrey Building
The Great Hall
200 Independence Avenue, S.W.
Washington, D.C.

CONTACT: Kay Garvey or Charlotte Mehuron
HRSA Communications, (301) 443-3376

Note: Organ, tissue, blood, and marrow donors or recipients will be available for interviews after the speakers program.

###



NATIONAL DONOR DAY '99 – SATURDAY FEBRUARY 13

MEMO

DATE: February 8, 1999
TO: The Office of the Vice President
Sarah Bianchi
Sue Greenberg
Scheduling Office
FROM: Dave Quick @ 800 738-1817
RE: The Vice President's and/or Mrs. Gore's attendance at Thursday's event at the U.S. Department of Health & Human Services

cc Lisa Gilmore, HHS @ 202 690-6133

Last year was inaugural National Donor Day and the Vice President invited leaders to the White House following our Washington D.C. launch event. We invite the Vice President and/or Mrs. Gore to attend and speak at our event this Thursday at HHS. Confirmed speakers include Congressman Phil Crane, HHS Deputy Secretary Kevin Thum and ~~and~~ Deputy Surgeon General Dr. Kenneth Moritsugu. An eight year boy and his mother will be traveling to the event from Newark to meet for the first time ever the boy's unrelated marrow donor, a female lawyer who lives in Washington DC. The meeting is being facilitated through the National Marrow Donor Program. The Vice President and/or Mrs. Gore could facilitate the introduction at our speakers event.

This year National Donor Day will be featured in a full page advertisement in Friday's (February 12) *USA Today*. Walter Payton's dramatic announcement last week of his need for a liver transplant adds poignancy and urgency to what is already the nation's largest one-day "gift of life" donation drive. Our goal is to double last year's results which included 8,000 units of blood collected/pledged in hundreds of communities nationwide.

☐ National Donor Day Washington D.C. Event Time & Place

Thursday, February 11, 1999
Blood Collection beginning at 9:00 a.m.
Speakers Program 10:00a.m - 10:30a.m.
Great Hall, U.S. Department of Health & Human Services
H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington D.C. 20201

Withdrawal/Redaction Marker

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. memo	Lisa Gilmore to Devorah Adler re: phone number (partial) (1 page)	12/18/1998	P6/b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20469

FOLDER TITLE:

Organ Donation [Folder 3]

2012-0463-S

rc804

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

MEMORANDUM

DEC 18 1998

To: Devorah Adler
Domestic Policy Council

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

Subject: Background for Radio Address on Organ Donation

As you requested, attached is an update on the Administration's National Organ and Tissue Donation Initiative. Major accomplishments over the past year include a new rule for hospital participation in Medicare and Medicaid that will help ensure that potential organ donors are identified and families are asked about donation; creation of a broad national partnership to encourage Americans to discuss donation with their families and agree to be organ and tissue donors; and a "best practices" conference to identify strategies that work in increasing donation and effective evaluation protocols for such interventions. Another major development is the significant increase in funding for organ donation activities for FY 1999 that will enable the federal government to mount its biggest effort ever to increase organ and tissue donation.

Also attached for your information is a press release on the hospital conditions of participation, a letter from the American Hospital Association in support of the hospital conditions, a cover letter to state hospital association executives, a fact sheet on the National Organ and Tissue Donation Initiative, and a December 17, 1998 *Washington Post* story on multi-organ transplant recipient 14-year-old Daniel Canal who recently returned home from the hospital after three multi-organ transplants in nine months.

Thank you for this opportunity to get out the Administration's message about the critical importance of saving lives by pledging to give the gift of life during this holiday season. If you have any questions, please contact me at work (202/690-6133) or at home (202/690-6133) or My direct line at work (for after hours and sometimes on weekends) is 202/260-1370.

Attachments (6)

NATIONAL ORGAN AND TISSUE DONATION INITIATIVE

Update as of December 18, 1998

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.)

NATIONAL ORGAN AND TISSUE DONATION INITIATIVE

One-Year Anniversary of the National Initiative Celebrates Creation of National Partnership

In response to this urgent need, on December 15, 1997, Vice President Al Gore and Health and Human Services (HHS) Secretary Donna E. Shalala launched the National Organ and Tissue Donation Initiative ("National Initiative"), a broad partnership of public, private, and volunteer organizations to encourage all Americans to discuss donation with their families and to agree to be organ and tissue donors. The National Initiative aims to substantially increase organ and tissue donation by inspiring more individuals and families to say yes when asked to donate, by maximizing opportunities for donation, and by learning more about what works to increase donation and transplantation through carefully designed research efforts.

* Administration Launches 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.

* New Final Rule Ensures that Families are Asked About Donation

Increasing the public's willingness to donate is critical, but it is only part of the solution. We are tragically and needlessly missing thousands of donation opportunities every year - sometimes because a family is reluctant to donate, but in many cases because a death was not identified as a potential donor - or because the family was never asked. One study by the Partnership for Organ Donation found that almost one-third of the families of potential donors are never approached about donation.

The National Initiative is making great strides in closing this gap. HHS's Health Care Financing Administration, or HCFA, has revised its conditions for participation in the Medicare program for all 5,200 short-stay hospitals in the United States. Under the rule, which took effect on August 21, hospitals are required to refer all deaths to organ procurement organizations (OPOs) to assure that OPOs have the opportunity to determine the suitability of every potential organ donor. Then, working with the hospital, the OPO can use appropriate discretion and sensitivity to approach the subject of donation with families. The rule also ensures that hospitals maintain or establish agreements with at least one tissue bank and one eye bank to preserve and distribute tissues and eyes. The rule was suggested by approaches that have been successful in other areas, for example, southeastern Pennsylvania experienced substantial increases in organ donation since a 1994 required referral law took effect.

On November 19, 1998, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) incorporated these conditions into its standards for the accreditation of hospitals. In addition, the American Hospital Association is educating its membership about the rule and working with its state hospital associations to disseminate guidelines on the new requirements.

The Association of Organ Procurement Organizations (AOPO), which represents the majority of OPOs, recently issued the following statement on the rule:

"HHS's Conditions of Participation Regulation, which requires hospitals to more closely work with their affiliated organ procurement organization (OPO) by reporting all deaths and imminent deaths to the OPO, has resulted in dramatic growth in the number of calls to each OPO. Most importantly more families are now receiving the opportunity to obtain some solace through organ and tissue donation. As was the case with the Pennsylvania law upon which this regulation is based, over time we anticipate resulting increases in both organ and tissue donation. The regulation has also dramatically increased immediate opportunities for professional education surrounding brain death and organ and tissue donation."



New Partners [HHS will know by Monday whether or not the AFL-CIO is an official partner in the National Initiative. The union has 17 million members.]

OTHER RECENT DEVELOPMENTS

Three-Time Multi-Organ Recipient 14-Year-Old Daniel Canal Comes Home from the Hospital

Daniel Canal, a Wheaton, Maryland teenager who underwent three multi-organ transplants, recently left the hospital and is recovering better than expected. Daniel was the focus of a debate over organ allocation and participated in a Washington rally in front of HHS urging reform of the organ allocation system. When Daniel faced his first surgery, Secretary Shalala issued a public statement expressing her good wishes for Daniel and his family.

New Organ and Tissue Donation Stamp Issued in August, 1998

On August 5, 1998 at the opening ceremonies of the National Kidney Foundation 1998 U.S. Transplant Games in Columbus, Ohio, the United States Postal Service dedicated and issued the new organ and tissue donation postage stamp. Secretary Shalala recorded a radio PSA to promote donation in conjunction with the issuance of the stamp. More recently, Secretary Shalala sent a letter to Postmaster General Henderson encouraging him to reissue the stamp at the new 33 cent rate which goes into effect on January 10, 1999. The stamp has proved to be very popular: all but 6.5 million of the 50 million stamps issued have been sold thus far.

Second Annual National Donor Day hosted by Saturn/UAW to be Held February 13, 1999

National Donor Day is sponsored by a partnership of America's leading health organizations, including HHS, American Red Cross, America's Blood Centers, National Kidney Foundation, and others, to increase organ and tissue, marrow, blood, apheresis, and cord blood donation. Last year, leaders of the participating organizations met with Vice President Gore for a photo-op two days before the Valentine's Day event. Vice President and Mrs. Gore have been asked to be spokespersons for the event this year. During National Donor Day 1998, held at nearly 400 Saturn locations nationwide, 8,000 units of blood were collected, 1,000 potential marrow donors were typed, and thousands of organ and tissue pledge cards were signed.

AMA Begins Organ and Tissue Donation Initiative/NMA Continues to Promote Donation

At the American Medical Association House of Delegates mid-year meeting held on December 6 - 9, 1998 in Honolulu, Hawaii, the American Medical Association began promoting its new initiative to increase organ and tissue donation. Vice President Gore announced the AMA's partnership at the launch of the National Organ and Tissue Donation Initiative last December. The initiative enjoys the support of the AMA House of Delegates which represents 95 percent of the country's practicing physicians. Many of the delegates signed organ donor cards at the meeting following a speech by former Texas Medical Association (TMA) President and liver transplant recipient Phil H. Berry, Jr., M.D. of Dallas, Texas. The theme for the AMA's initiative is based on the TMA's "Live and Then Give" organ donor campaign. Over the past year, the National Medical Association has been educating its membership about donation at its meetings and continues to encourage its physicians to talk with their patients about donation.



Rotary Districts Expanding Organ and Tissue Donation Efforts

Rotarians and Past District Governors from six Rotary International Districts are developing a comprehensive Donor Education Program to educate Rotarians about organ and tissue donation, including blood, bone marrow, and stem cell donation. The program is picking up support from other Rotary Districts. Program organizers hope to have the program endorsed by all Rotary Districts in North America and to enroll 1,000,000 members by the end of the year 2000.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Deputy Secretary

Washington, D.C. 20201

FACSIMILEDATE March 24, 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
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COMMENTS:

The attached proposed proclamation has been sent by HHS today to OMB for processing. I thought you might like a heads up on it.

Lisa

National Organ and Tissue Donor

DRAFT

Awareness Week, 1999

By the President of the United States of America

A Proclamation

The miracle of organ transplantation enables one human being to give another the gift of life. Generous Americans who have lost their loved ones, and altruistic living donors, have saved thousands of lives through gifts of organs and tissues. Americans are now working, caring for their families, and participating in community and social activities because they received these wonderful gifts. Children whose life expectancy was once nonexistent now have a future thanks to a new liver or healthy bone marrow, and cornea transplant recipients can see their loved ones. Yet the need for organs for transplantation continues to exceed the number donated. Too many Americans wait too long; some of them will die before an organ becomes available.

Today about 62,000 patients are on the national organ transplant waiting list. Every sixteen minutes a new name is added to the list. For everyone on the list, the continuance of life, or the quality of life, depends upon receiving a transplant.

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In 1997, Vice President Gore and Health and Human Services Secretary Donna E. Shalala launched the National Organ and Tissue Donation Initiative. The goals of this national public-private partnership are ongoing: to increase public awareness of the successes of transplantation and to educate our citizens to the urgent need for increased donation. All Americans should consider organ and tissue donation. They need to be aware that by completing and carrying a donor card, and especially by informing their family and friends of their wish to donate, they may someday give that gift of life to other Americans awaiting organs for transplantation.

Americans are a generous and caring people. Americans who have lost their loved ones tragically, and donated their organs, and living donors, have set an example that is an inspiration to us all.

NOW, THEREFORE, I, WILLIAM J. CLINTON, President of the United States of America, do hereby proclaim the week of April 18 through April 24, 1999, as National Organ and Tissue Donor Awareness Week.

I urge all health care professionals, educators, the media, public and private organizations concerned with organ donation and

DRAFT

transplantation, and all Americans to join me in supporting this humanitarian action.

IN WITNESS WHEREOF, I have hereunto set my hand this day of, in the year of our Lord nineteen hundred and ninety-nine, and of the Independence of the United States of America the two hundred and twenty-first.

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A/H/A