

WITHDRAWAL SHEET

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Collection: Domestic Policy Council, Carol Rasco
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Date: 5/1/04

DOCUMENT NO. & TYPE	SUBJECT/TITLE	DATE	RESTRICTION
1. Form	HHS Fax cover sheet re: organ transplant, 1p	6/22/93	P6/B6
2. Memo w/attchmnt.	To Carol Rasco from Kevin Thurm re: organ transplant, 4p	n.d.	P6/B6

RESTRICTIONS

P1 National security classified information [(a)(1) of the PRA].
P2 Relating to 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].
PRM Personal records misfile defined in accordance with 44 USC 2201 (3).

B1 National security classified information [(b)(1) of the FOIA].
B2 Release could disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA].
B3 Release would violate a Federal statute [(b)(3) of the FOIA].
B4 Release would disclose trade secrets or confidential commercial financial information [(b)(4) of the FOIA].
B6 Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA].
B7 Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA].
B8 Release would disclose information concerning the regulation of financial institutions [(b)(9) of the FOIA].
B9 Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA].

THE WHITE HOUSE

WASHINGTON

Should we connect him w/
(?) F/H/S - Org. Transplantation

Christine - Status (?)

Div. of Transplantation
Judy

LIGHTLE, BEEBE, RANEY, BELL AND HUDGINS

ATTORNEYS AT LAW
211 WEST ARCH AVENUE
SEARCY, ARKANSAS 72143-5331
501 - 268-4111

MIKE BEEBE
DONALD R. RANEY
A. WATSON BELL
ROBERT HUDGINS

J. E. LIGHTLE, SR. (1932-45)
J. E. LIGHTLE, JR. (1936-88)

July 19, 1993

JUL 21 1993

Ms. Carol Rasco, President
DOMESTIC POLICY ADVISOR
White House
Washington, D.C. 20500

Dear Carol:

I want to express to you my personal thanks and appreciation for arranging for me to see Christine Heenan when I was in Washington last week to discuss issues with respect to organ transplantation. I must tell you that I was quite impressed with Christine. Her grasp of the complex and complicated issues involved with respect to the allocation and procurement of organs for transplantation was amazing. She was attentive, professional, and I felt a lot better about my cause after my meeting than before.

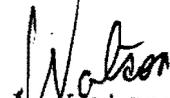
Your courtesy in arranging our meeting with Christine is greatly appreciated.

Please let me know if I can return the favor for you here in Arkansas.

My partner, Mike Beebe, sends his warmest and kindest personal regards.

Best personal regards.

Very truly yours,


A. Watson Bell

AWB/rc

Kevin Thorne -
Carol rec'd the same
letter ~~as~~ the Secty. from
Henrice Taylor -- where
she alleged discrimina-
tion of minorities in the
Nat'l Marrow Donor Program.
→ Where are we on this?
→ How should CHR respond?
left msg w/ Julia

Sent 7/30/93
(messenger) PR

JUL 27 RECD

faxed to LR
9:30 am by vll
(pv)

FAX**TOTAL PAGES INCLUDING COVER 10**

JUL 27 REC'D

DATE: July 26, 1993

TO: The Honorable Les Aspin, Secretary of Defense
 The Honorable Charles A. Bowsher, Comptroller General
 of the United States
 The Honorable Ron Brown, Secretary of Commerce
 Roger Herdman, M.D., Acting Director U.S. Congress
 Office of Technology Assessment
 Drs. Howard & Sylvia Johnson, JoAnne Katherine Johnson Foundation
 Ira Magaziner, Senior Policy Advisor to the President
 Carol Rasco, Domestic Policy Advisor, President's Task Force
 on Health Care
 The Honorable Janet Reno, Attorney General of the United States
 Senior Case Agent Federal Bureau of Investigation
 The Honorable Donna Shalala Secretary of Health & Human Services
 Fred B. Verinder, Deputy Assistant Director Criminal Investigative
 Division Federal Bureau of Investigation
 Antronette Yancey, MD., M.P.H.

NOTE

FROM: Henrice Taylor
 Former Assistant Director
 National Minority Recruitment
 National Marrow Donor Program
 Founder, Chairperson
 Citizens Action Committee for
 Minority Health & Educational Initiatives
 TEL. (800) 331-7966 FAX. (800) 331-7966 or (612) 922-4426
 Address: 3208 W. Lake Street #409 - Minneapolis, MN 55416

MESSAGE:

Please see attached correspondence, as described below, concerning the National Marrow Donor Program. Thank you.

1. Copy of July 22, 1993 correspondence to the Honorable John Dingell.
2. Copy of July 23, 1993 correspondence distributed to the full membership of the U.S. House and Senate.
3. Copy of 5 of 13 pages distributed to members of the House Energy and Commerce Committee.

Henrice Taylor

3208 West Lake Street Minneapolis, MN 55416 Tel 800 331-7966 Fax 800 331-7966 /612 922-4426

July 22, 1993

The Honorable John Dingell
 Chairman
 U. S. House of Representatives
 Committee on Energy and Commerce
 Rayburn House Office Building Rm. 2125
 Washington, DC 20515

Dear Congressman Dingell:

I am writing, once again, to request your assistance and support in addressing the discriminatory policies of the National Marrow Donor Program (NMDP) and the negative effect of these institutionally condoned practices on the survival of African, Asian, Hispanic and Native American transplant patients.

It is my understanding that the Committee on Energy and Commerce has requested that the NMDP respond to eleven questions, relating to concerns which have been raised regarding the "operation and effectiveness of the current program".

It is my belief that the enclosed correspondence may be helpful to you and to the members of your committee with respect to your review of the implementation of the provisions of section 379 of the Public Health Service Act scheduled for Tuesday July 27th.

This correspondence includes a letter of complaint directed to the NMDP from the Chairman of the "African Americans Uniting For Life" committee, based in Baltimore Maryland. It questions the "lack of commitment" of the NMDP to properly address minority recruitment needs and it is particularly critical of the recruitment goals for recruiting African Americans as indicated in the following quote "*When you consider the odds of African-Americans matching one another being one in a million or greater, your goal [i.e. 35,000 in two years] is grossly low*".

Also included is a set of recent correspondence, identifying similar concerns, which I directed to a new member of the NMDP Board of Directors, an African American physician.

As a point of information, not only is this African American physician a very recent addition to the Board, this is the first black physician and the first member of any minority group to be added in the past six years since the inception of the NMDP. The inclusion of this membership increased the total minority representation of the NMDP Board to a grand total of two.

This long term resistance to diversity among members of the NMDP Board is mirrored in the continuous resistance to increasing the ethnic diversity of the registry and is reflective of the lack of sensitivity and concern for the needs of minority patients and the minority community.

In closing I would like to again affirm my fifth or sixth request for an opportunity to provide further information to your committee so that you will have for review much of the same information that was provided to the Federal Bureau of Investigation.

While I have been and continue to be extremely critical, and rightly so, of the gross mismanagement of the minority recruitment and patient advocacy aspects of the NMDP and its unjust enrichment practices, there are other aspects of the Program that are worthy and deserving of support.

The Honorable John Dingell
 July 22, 1993
 Page 2

I believe that I can offer valuable insights and an important perspective that deserves to be heard. I was the first minority employee of the NMDP and prior to my involuntary separation, for objecting to discriminatory practices, served as the Assistant Director of National Minority Recruitment. I was also the co-coordinator of the "Save JoAnne" campaign.

You may recall that my niece's campaign was the first significant effort to recruit African Americans into the registry. This Washington, DC based community recruitment effort, though heavily edited and censored, was profiled in a book length article entitled "Window of Hope" in the July 1992 edition of the Readers Digest and featured as the cover lead story in foreign editions distributed via 28 million copies in 17 different languages worldwide.

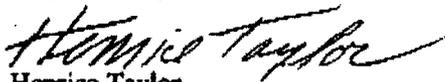
In correspondence of April 20th to the Attorney General, the Honorable Janet Reno, I expressed that *"a competently managed program, operating with even a modicum of the resources that have been made available through federal funds to the NMDP, should be able to reverse"* the almost certain death sentence facing minority patients.

I would appreciate an opportunity to share this information with you and the members of your committee. During both my tenure with the NMDP, and this past year as founder of the Citizens Action Committee for Minority Health and Educational Initiatives, I developed a comprehensive "Minority Marrow Donor Recruitment Plan". It is expedient and economical, and if implemented has the potential of saving tens of thousands of lives.

I hope that in considering my request that you will bear in mind that one end result of the "Save JoAnne" campaign was the recruitment of over 6,000 prospective minority donors for the nation's registries, in less than eight weeks, compared with only 300 minority donors recruited in three years by the NMDP. This feat was accomplished prior to the availability of congressional funding for minority tissue typing and despite significant resistance from the NMDP and its former recruitment arm, the "LifeSavers Foundation", to prevent the recruitment of African American donors.

Your comments to this correspondence and my request would be most appreciated. Thank you.

Respectfully yours,



Henrice Taylor
 Former Asst. Director National Minority Recruitment
 National Marrow Donor Program
 Founder, Chairperson
 Citizens Action Committee for
 Minority Health & Educational Initiatives

cc: Judy Braslow, Department of Health & Human Services
 Hon. Ron Brown
 Congressional Black Caucus
 Drs. Howard & Sylvia Johnson, JoAnne Katherine Johnson Foundation
 Ira Magaziner, Senior Policy Advisor to the President
 Hon. Sam Nunn, Chairman U.S. Senate Armed Services Committee
 National Marrow Donor Program, Board of Directors
 Hon. Janet Reno, Attorney General of the United States
 Hon. Donna Shalala Secretary of Health & Human Services
 U. S. House of Representatives Committee on Energy and Commerce

Henrice Taylor

3208 West Lake Street Minneapolis, MN 55416 Tel 800 331-7966 Fax 800 331-7966 /612 922-4426

July 23, 1993

Dear Legislator:

On Tuesday, July 27th the U.S. House of Representatives Committee on Energy and Commerce is scheduled to review the implementation of the provisions of section 379 of the Public Health Service Act with respect to the National Marrow Donor Program, and concerns which have been raised, regarding the "operation and effectiveness of the current program".

Background information is provided in the enclosed copy of correspondence directed April 20th to the Attorney General, the Honorable Janet Reno; May 27th to the Government Accounting Office and July 22nd to the Honorable John Dingell.

The issues discussed concern the fraudulent activities of the National Marrow Donor Program (NMDP) and the failure of its contractual overseers, the National Heart Lung and Blood Institute (NHLBI), the National Institutes of Health (NIH), and ultimately the Department of Health & Human Services, to acknowledge and act upon overwhelming evidence of the deliberate derailment and curtailment of minority recruitment initiatives and patient advocacy and protection programs. Also discussed is the possible misuse and or misallocation of tens of millions of dollars provided to the NMDP by the Department of Defense.

The above allegations include, but are by no means limited to, the attempted sabotage of the "Save JoAnne" African American marrow donor recruitment campaign for my niece, the late JoAnne Katherine Johnson, of Silver Spring, Maryland from December of 1989 through February of 1990. A description of this Washington DC based community recruitment effort, though heavily edited and censored, is profiled in a book length article entitled "Window of Hope" in the July 1992 edition of the Readers Digest and featured as the cover lead story in foreign editions distributed via 28 million copies in 17 different languages worldwide. A copy of the U.S. edition of the Digest is enclosed.

As noted in the correspondence referenced above, copies of a report will soon be available which demonstrates, through correspondence records of the NMDP and the NHLBI, the development and continuation of an institutionally ingrained policy of racial and economic discrimination by the NMDP, and the failure of the NHLBI to properly oversee the NMDP transplantation system.

This report, a sample of which is enclosed, also demonstrates illegal contract award policies, and unjust enrichment practices, which prevented both minority and non-minority institutions from participating in a multi-billion dollar federally funded health-care program, and which contributed directly to the almost certain death sentence facing the overwhelming majority of ethnic and racial minority patients awaiting a match.

I hope that these allegations, which ultimately affect transplant patients and their families throughout the world, will be viewed as being of sufficient importance and concern to investigate and report upon in an open forum.

While I and many others have been and continue to be extremely critical, and rightly so, of the gross mismanagement of the minority recruitment and patient advocacy aspects of the NMDP and its unjust enrichment practices there are other aspects of the Program that are admirable and commendable.

Legislator
 July 23, 1993
 Page 2

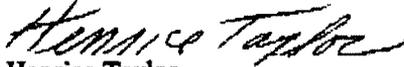
Many people in the NMDP transplantation system have devoted years of hard work to improving transplantation services. There are measures that can be instituted to reform the gross insufficiencies, inadequacies in the current system while still supporting those aspects and areas that are worthy and deserving of support.

Patients, their families, and community groups throughout the United States, should be provided with **sufficient time, notice and opportunity** to come forward to relate their experiences with the NMDP and/or its transplantation system and to suggest methods for reform.

It has been estimated that 40% of the patients who need a transplant, and who rely on state medicaid programs, or who may not be able to afford out of state transportation, **cannot even access** a system paid for with federal funds. This situation exists simply because their state may not have an "NMDP approved" transplant center and therefore they are denied access to potential donors in the file of the National Registry.

Additional documentation is available upon request, as are copies of the referenced correspondence enclosures and a representative sampling or listings of materials submitted to the Federal Bureau of Investigation.

Respectfully yours,



Henrice Taylor
 Former Asst. Director National Minority Recruitment
 National Marrow Donor Program
 Founder, Chairperson
 Citizens Action Committee for
 Minority Health & Educational Initiatives

cc: The Honorable Les Aspin, Secretary of Defense
 The Honorable Charles A. Bowsher, Comptroller General of the United States
 The Honorable Ron Brown, Secretary of Commerce
 Roger Herdman, M.D., Acting Director U.S. Congress Office of Technology Assessment
 Drs. Howard & Sylvia Johnson, JoAnne Katherine Johnson Foundation
 Ira Magaziner, Senior Domestic Policy Advisor to the President
 Carol Rasco, Domestic Policy Advisor, President's Task Force on Health Care
 The Honorable Janet Reno, Attorney General of the United States
 Senior Case Agent Federal Bureau of Investigation
 The Honorable Donna Shalala Secretary of Health & Human Services
 Fred B. Verinder, Deputy Assistant Director Criminal Investigative Division
 Federal Bureau of Investigation

FAX

TOTAL PAGES INCLUDING COVER **16**

DATE: March 11, 1993

TO: D. Ann Murphy
 Investigator
 Congressional Subcommittee on Oversight & Investigation
 2323 Rayburn
 Washington, D.C. 20515
 TEL. (202) 225-4441 FAX. (202) 225-2899

FROM: Henrice Taylor
 Former Assistant Director
 National Minority Recruitment
 National Marrow Donor Program
 3208 W. Lake #409 Minneapolis MN 55416
 TEL. (800) 331-7966 FAX. (612) 922-4426

MESSAGE:

Dear Ms. Murphy:

I am attaching for your review correspondence regarding the discriminatory policies of the Minnesota based National Marrow Donor Program (NMDP). The issues discussed concern the negative impact of those policies on the survival of African American transplant patients and contract award policies which have prevented minority institutions and minority businesses from participating in a multi-million dollar government funded marrow donor health-care project.

I have written at least seven or eight times to Congressman Dingell, and carbon copied his office regarding this issue, but as yet I have not received a response.

It is most disappointing that the very people who can provide documentation and background information on the illegal activities of this federally funded program are continually ignored and not allowed an opportunity to be heard.

Under separate cover I am enclosing over 167 pages of material that I have written on this issue, on a continuous basis since April of 1992. I have mailed in excess of 1700 information packets to organizations, legislators and government officials pleading for a complete investigation of the NMDP. My efforts however, while forcing increased scrutiny of NMDP practices and contributing to major personnel changes within the NMDP hierarchy, have received not even a modicum of assistance with the notable exception of the Federal Bureau of Investigation.

It is my understanding that government funded health-care fraud is of great concern to Congressman Dingell and I hope that you will assist by personally bringing this information to his attention.

I hope that I can look forward to receiving a written response in the very near future. Thank you.

Sincerely,



Henrice Taylor

cc: Jack Cloherry, WRC TV
 Drs. Howard & Sylvia Johnson, JoAnne Katherine Johnson Foundation
 Dr. Donna Shalala, Secretary of Health & Human Services

MEMORANDUM

DATE: July 26, 1993

TO: Members of the U. S. House of Representatives
Committee on Energy and Commerce
c/o Legislative Asst. for Health
U. S. House of Representatives
Washington, D. C.

FROM: Henrice Taylor
Former Assistant Director
National Minority Recruitment
National Marrow Donor Program
Founder, Chairperson.
Citizens Action Committee for
Minority Health & Educational Initiatives

REGARDING: **DISCRIMINATORY POLICIES
OF THE
NATIONAL MARROW DONOR PROGRAM**

Please see attached correspondence, described below, concerning the National Marrow Donor Program (NMDP) referenced in a letter of July 22, 1993 to the Honorable John Dingell. Copies of this letter are being distributed to the full membership of the House and Senate. Thank you.

1. March 11, 1993 fax correspondence to Congressional Subcommittee on Oversight and Investigations. (See page 1)
2. June 28th correspondence to the NMDP from African Americans Uniting For Life. (See pages 2-4)
3. June 16th correspondence to a new member of the NMDP Board of Directors, an African American physician. (See pages 5-8)
4. Five page attachment to above, board of directors correspondence, of suggested questions for the NHLBI liaison to the NMDP. (See pages 9-13)

"AFRICAN AMERICANS UNITING FOR LIFE"



A Minority Marrow Donor Recruitment Campaign in the Baltimore Metropolitan Area

PAGE 2

A Special Initiative of the National Marrow Donor Program

American Red Cross Blood Services & Johns Hopkins Hospital
&
Uniting for Life, Inc.

ADVISORY COMMITTEE

Honorable William Donald Schaefer
Honorable Kurt L. Schawbe

June 28, 1993

- Walter G. Amprey, Ph.D.
- James Buchanan, M.D., MPH
- Hayden G. Brown, M.D.
- John W. Burnett, Ph.D.
- Cecil and Wilton C. Calhoun
- Stephen S. Carson, M.D.
- Ms. Carolyn W. Calvin
- Mr. Charles S. Dutton
- Ms. Hilda Ford
- Honorable Vera F. Hall
- Mr. Francis Hrabowski III
- Honorable Jesse Jackson
- Mr. Roger Lyons
- Honorable Jacqueline McLenn
- Honorable Kwesi Ninsin
- Reverend Lina M. Nims
- Honorable Warren J. Mitchell
- Paul M. Nye, M.D.
- Pastor Ronald F. Prunzio
- Pastor Howard P. Rawlings
- Honorable Iris G. Reem
- Honorable H. Richard, NJ, Ph.D.
- Honorable Richardson
- Honorable L. Robinson
- Honorable J. Sebastian
- Honorable Douglas B. Sands
- Honorable Stuart O. Simon
- Honorable Rochelle Spector
- Ms. Larry Stewart
- Honorable Carl Stokes
- Pastor Melvin B. Taggle
- Minister V.R. Zanzwani, Jr., USN (ret.)

The National Marrow Donor Program
3433 Broadway Street, N.E. Suite 400
Minneapolis, MN 55413

Attention: Mr. Jack Packer
Assistant Director of Minority Recruitment

Dear Mr. Packer:

Thank you for your letter of May 26, 1993 (photocopy attached). I do believe, however, that your response to Mr. Koenrich's memorandum concerning Ms. Rodgers should have been addressed directly to Ms. Demetria Rodgers. In response to the rest of your letter, I offer the following comments.

We share the mission of recruiting more minorities into the national registry, especially the recruitment of African-Americans. It is clear statistically this is where the greatest need for recruitment exist! Yet, the N.M.D.P.'s presentation of May 4 shows just how much difference does exist between the N.M.D.P. and the Uniting for Life, Inc. committee. One organization is the congressionally authorized entity and the other is primarily made-up of business people and other professionals who represent a broad cross section of the community who volunteer their very valuable time to help save lives.

These people have stood by me during the most trying time in my life, in support of my daughter Tria's quest for a marrow donor. The volunteers of this committee personally understand what a family goes through and the sense of urgency that exist for a victim of these devastating blood diseases.

PLANNING COMMITTEE

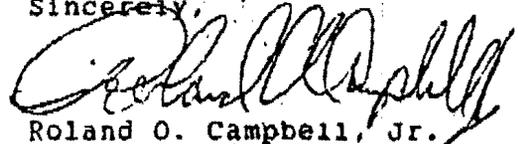
- Hackshaw, Ph.D.
- Hester Dixon
- Mr. Roland D. Campbell, Jr.
- Mr. Booker T. Carter, Jr.
- Mr. Robert Fulton Dandiel, Esq.
- Ms. Pat Dodd
- Ms. Pauline M. Harris
- Ms. Deborah Jo Jones
- Ms. Yvonne A. Jones
- Ms. Toni Leonard
- Mr. Thomas Hrabowski
- Ms. Martine McLaurin
- Mr. Geoffrey Nelson
- Mr. Omarion Rodgers
- Mr. David L. Smith
- Mr. Walter J. Skyles
- Mr. Joseph M. Stewart
- Ms. Virginia Wilson

PAGE 4

The Chicago kick-off can only be interpreted as posturing to impress your Board of Directors who were meeting there. What a waste of an opportunity to truly promote the National Campaign and benefit from the momentum of the Baltimore and D.C. committees in a major media market.

The commitment to the legacies of Demetria "Tria" Campbell and Jo Ann Johnson will remain! It is unfortunate that personalities and a lack of communication stand in the way of saving lives.

Sincerely,



Roland O. Campbell, Jr.
Chairman
Uniting for Life, Inc.

cc. Dr. Craig Howe
Ms. Kathy Denton
Mr. Jeff Koenrich
All U.F.L. Committee Members

Ms. Kathy Welte
Mr. Bob Pinderhughes
Mr. Howard Johnson
Ms. Kim Rudd, Burrell Co.

PAGE 3

The commitment of time and energy from the Uniting for Life Committee has yielded many successes. We have in the Greater Baltimore area increased awareness of the need for minority participation in the national registry beyond measure. We have increased the registry's volunteer base in Baltimore City alone from less than 200 African-Americans in September 1992 to nearly 1300. Nearly 30 of these new local volunteer donors have been called back for second stage typing; a phenomenal accomplishment!

We have also positively impacted nationally on the awareness of this great need. All of this was accomplished without any real support from the N.M.D.P., not even so much as a congratulations. In fact, in our area, we have accomplished more in a few months than the N.M.D.P. has since it was established in 1987.

The N.M.D.P. presentation of May 4 obviously lacked any real commitment to increase the African-American volunteer base significantly. The proposed goal to increase the African-American participation by 35,000 in two years is a target that should be achieved by maintaining current momentum. A low target was established. It seems solely because it could be achieved and it would look better to hit this low mark than to reach for the much more needed goal and not hit the mark. When you consider the odds of African-Americans matching one another being one in a million or greater, your goal is grossly low.

We asked some very simple questions with regard to the proposal for the 11 city "National Campaign". We were especially interested in what new support for the donor centers would be committed i.e. for advertising, promotion and staff support. What you interpreted as being combative, argumentative and hostile we interpreted as frustration. We could not get simple answers to very simple questions.

We are frustrated with all the paranoia in the N.M.D.P. about the U.F.L. committee. Our performance and success to date is something that should be welcomed by the N.M.D.P. Instead, we are described as radical, argumentative, combative and hostile. I take these comments as being insensitive and insulting to our volunteer committee! We are deeply concerned about the efforts being made to educate the public, to promote the need for minority participation and to develop and support recruitment groups throughout the nation.

We feel, we have been a model for committee development and yet we are not consulted. The N.M.D.P. has had its "kick-off" for the National Campaign in Chicago where a viable committee does not even exist! Our Governor, Mayor, Congressman, Superintendent of Schools, local corporations as well as many other dignitaries have publicly endorsed and embraced our recruitment initiative.

THIS FORM MARKS THE FILE LOCATION OF ITEM NUMBER 1
LISTED IN THE WITHDRAWAL SHEET AT THE FRONT OF THIS FOLDER.

EDWARD L. WRIGHT
(1903-1977)
ROBERT S. LINDSEY
(1913-1991)
RONALD A. MAY
ISAAC A. SCOTT, JR.
JAMES M. MOODY
JOHN G. LILE
GORDON S. RATHER, JR.
TERRY L. MATHEWS
DAVID M. POWELL
ROGER A. GLASGOW
C. DOUGLAS BUFORD, JR.
PATRICK J. GOSS
ALSTON JENNINGS, JR.
JOHN R. TISDALE
KATHLYN GRAVES
M. SAMUEL JONES III
JOHN WILLIAM SPIVEY III
LEE J. MULDROW
WENDELL L. GRIFFEN
N. M. NORTON, JR.
EDGAR J. TYLER
CHARLES C. PRICE
CHARLES T. COLEMAN
JAMES J. GLOVER
EDWIN L. LOWTHER, JR.
BEVERLY BASSETT SCHAFFER
CHARLES L. SCHLUMBERGER
SAMMYE L. TAYLOR

WRIGHT, LINDSEY & JENNINGS

ATTORNEYS AT LAW

2200 WORTHEN BANK BUILDING
200 WEST CAPITOL AVENUE
LITTLE ROCK, ARKANSAS 72201-3699

(501) 371-0808

FAX (501) 376-9442

OF COUNSEL
ALSTON JENNINGS
GEORGE E. LUSK, JR.

October 7, 1993

WALTER E. MAY
ANNA HIRAI GIBSON
GREGORY T. JONES
H. KEITH MORRISON
BETTINA E. BROWNSTEIN
WALTER McSPADDEN
ROGER D. ROWE
NANCY BELLHOUSE MAY
JOHN D. DAVIS
JUDY SIMMONS HENRY
KIMBERLY WOOD TUCKER
MARK L. PRYOR
RAY F. COX, JR.
HARRY S. HURST, JR.
TROY A. PRICE
PATRICIA SIEVERS LEWALLEN
JAMES M. MOODY, JR.
KATHRYN A. PRYOR
J. MARK DAVIS
KEVIN W. KENNEDY
KAREN J. GARNETT
M. TODD WOOD
R. GREGORY ACLIN
FRED M. PERKINS III
WILLIAM STUART JACKSON
MICHAEL D. BARNES
STEPHEN R. LANCASTER
FRED ANDREW WOOD
JUDY M. ROBINSON

file
Re: Allocation of Donated Organs for Transplants

Ms. Carol H. Rasco
Assistant to the President
for Domestic Policy
THE WHITE HOUSE
West Wing
1600 Pennsylvania Avenue
Washington, D.C. 20500

VIA UPS OVERNIGHT

OCT - 8 REC'D

Dear Carol:

I hope that you had a good visit to Little Rock and were able to spend a good deal of time with Hamp. I saw Terry not long ago and he told me that Hamp was still making good progress after his surgery.

I wanted to take a few minutes of your time to give you a brief update concerning the issues relating to allocation of donated organs on behalf of the University of Pittsburgh Medical Center. Since the Medical Center began voicing its concern about the adverse effects on patients of the new system for allocation of donated organs, other groups and transplant centers have stepped forward to voice the same or similar concerns. Most importantly, I believe, the two national patient groups (National Transplant Action and Transplant Recipients International Organization, both headquartered in Washington, D.C.) have spoken up with similar concerns. In addition, six of the largest transplant centers around the country and one small center which specializes mainly in heart transplant (Sentara Norfolk Hospital) have spoken up in favor of a nationwide allocation system for donated organs.

Ms. Carol Rasco
October 7, 1993
Page 2

The patient organizations, six transplant centers and some organ procurement organizations from around the country have joined together to form a coalition on the issue of allocation of organs. That coalition is beginning two initiatives. The first focuses on the Congress. The transplant centers in the coalition (other than Sentara Hospital) are among the seven largest liver transplant programs in the country. The surgeons who head those programs have incorporated some of their thoughts, suggestions and relevant data in a letter to Congressman Waxman for consideration by Congress in the pending re-authorization of the National Organ Transplant Act. I enclose a copy of that letter dated September 15, 1993. I apologize for the quality of this copy, but it is the best that I have been able to receive. I found some of the information and observations of these surgeons to be very thought provoking.

The coalition has also prepared and submitted to Congressman Waxman, Senator Kennedy and other senators and congressmen, a short position paper and proposed legislative language relating to organ allocation for their consideration in the pending re-authorization of the National Organ Transplantation Act. I also enclose a copy of that position paper for you.

In addition to correspondence to and meeting with members of Congress concerning allocation of donated organs and the pending re-authorization of NOTA, the coalition and some of its members have provided some of this information to and have had conversations with Dr. Brian Biles and others at HHS. I believe a small delegation from the coalition is scheduled to meet with Dr. Biles next week to discuss the regulations on organ allocation which are being formulated and reviewed by HHS. The members of the coalition have very significant and real concerns about the present content of the regulations being drafted. Notwithstanding the call by the patient organizations and the growing number of more experienced transplant centers for an allocation system which is based on patient needs and patient choices, the regulations submitted by the United Network for Organ Sharing to HHS for approval provided for a transplant center oriented approach and only secondarily considered patient needs and patient choices. At some of the lower levels of HHS, these suggestions by UNOS still seem to be accepted without question. Obviously, the coalition hopes that its meeting with Dr. Biles will help him and other senior staff at HHS understand the real and significant need for a patient centered allocation system. I hope to talk with you about this shortly.

I know that I have rambled on longer than I anticipated in this letter, and I appreciate your patience. Although it may not be evident on its face, I believe the positions put forth by the coalition and the University of Pittsburgh related to allocation of donated organs for transplant support the basic policies of the President's health care reform program. First, the proposed allocation system supports and is based on patient choice. For example, if a Little Rock patient was the most medically appropriate recipient for a donated liver, a liver donated in Los Angeles would be allocated to that patient whether that patient chose to be transplanted

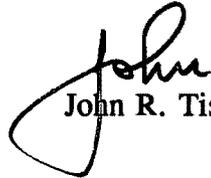
Ms. Carol Rasco
October 7, 1993
Page 3

in Little Rock or at the Mayo Clinic. Second, the proposed system should reduce medical costs associated with treatment of patients before and after transplants. By transplanting the most "medically appropriate patient" without regard to geographic location, the University of Pittsburgh believes that the patients undergoing the most intensive (and most costly) medical treatment while awaiting transplant can be transplanted first, thus reducing the total costs for treatment of these patients. Finally, the University of Pittsburgh believes that the quality of care given to transplant patients will be better if those patients are transplanted at centers which have the most appropriate treatment program for that patient rather than at a center which, based solely on geographic location, might have a better chance to obtain an available organ. I enclose an analysis of organ transplant issues and health care reform prepared by Lazar Palnick.

Thanks for all of your work and support for the President. I trust things are going well for you and Mary Margaret and that she has adjusted to her new school.

Cordially yours,

WRIGHT, LINDSEY & JENNINGS


John R. Tisdale

JRT/blm
K:blm1414.027

September 15, 1993

Congressman
Henry Waxman
2408 Rayburn
House Office Building
Washington, D.D. 20515

Dear Congressman Waxman:

Over the last ten years, the field of liver transplantation has experienced incredible advances, much of this made possible by the efforts of your Committee. However, with increased success has come increased demand for donor organs, the supply of which has become extremely precarious. As a result, surgeons and physicians involved full time in liver transplantation have become alarmed at the increased numbers of deaths among despairing patients waiting for their chance at receiving a donor liver. In response to what we view to be a crisis in organ availability further aggravated by inequities arising from geographical, parochial organ allocation policies currently in force, several of us have communicated with you as well as with other members of Congress and the Health Care Financing Authority (HCFA). More recently, a group of concerned transplant surgeons met to review Congressman Waxman's Committee proposal for the reauthorization of the Transplant Act. Our group respectfully submits for the consideration of you and your Committee what, in our opinion, are the most critical issues facing the field of liver transplantation.

In 1992, 3059 liver transplants were performed at 96 institutions. We represent the seven U.S. institutions that perform more than 100 transplants per year. Collectively, our centers provided 42% (1288) of all liver transplants performed in this country in 1992. Furthermore, of the 446 children (<15 years) who received liver transplants in 1992, 41% (185) underwent the procedure at our institutions. Just as importantly, our centers collectively represent 38% (1041/2739) of all patients currently awaiting liver transplantation in the United States. Although each of our programs serves as a referral center for broad geographic regions independent of state borders and the current UNOS definitions of "regions," each center has also established a national reputation that results in patient referrals from across the nation. We have joined our voices in an effort to set before the Committee on Labor and Human Relations the overriding principles discussed below, principles which we believe are widely supported both by individuals with a full time commitment to liver transplantation and by patients and their advocates.

Liver transplantation is perhaps the most complex procedure in surgery. However, the successful delivery of liver transplantation as a service to patients dying of liver failure requires more than a skilled surgeon. Established centers such as ours have developed comprehensive,

multidisciplinary programs of care that treat patients from the moment they arrive for evaluation of their liver disease. The commitment extends through the period of surgery and postoperative care, and continues for the lifetime of the patient. The successful delivery of this level of comprehensive life-long care has been dependent on the development of expertise among an extremely wide range of personnel that see liver transplantation as a full time commitment.

The recognized success of liver transplantation in restoring people with fatal liver disease to full and productive lives has resulted in a revolutionary change in the treatment of liver disease. Before 1980, the probability of patient survival after liver transplantation at one of the handful of centers worldwide was in the range of 20-40%. Under such circumstances, physicians responsible for the care of patients with liver disease rarely considered transplantation a viable option. However, with the remarkable improvements in survival to the 80-90% range during the last decade, liver transplantation has become the treatment of choice for a wide variety of lethal disorders of the liver.

The demand for donor organs now far exceeds the limited supply and many patients unfortunately die while awaiting livers. Because the organs are so scarce, it is important that they be deemed a national resource and be allocated in the most equitable manner possible. We believe that this is a problem of importance to the entire nation. For these reasons, we feel that deliberations by the Committee on Labor and Human Relations on the Transplant Act should be guided by the following two basic principles.

- 1. Candidates for liver transplantation should have equitable access to organs, regardless of geographical location.**

We believe that a patient should have the right to choose wherever he/she wants to be transplanted. And wherever that choice leads him/her, the patient should be comfortable knowing that the choice will not affect the possibility to receive a lifesaving liver. We believe that a patient's choice of transplant program may be based on a variety of issues, but should not be influenced by any real or perceived differences in the access of programs to donor organs. Organ availability should be uniform throughout the system.

The issue of equitable organ distribution can be solved only by eliminating the local "priority of use" principle currently in operation and by nullifying the current regional barriers to equitable access. In 1992 the median waiting time for a liver transplant varied from 18 days to 236 days in the different organ procurement organizations throughout the country. The creation of a single national waiting list for all patients awaiting liver transplantation is one alternative. The disadvantages of this approach include: 1) increased expenses associated with transportation of organs over the entire country; 2) lengthened organ preservation times that may be associated with less satisfactory organ function or even organ failure after transplantation; and 3) lack of some form of local or regional reward for the effectiveness of organ procurement efforts that result in increased organ supply. The most important advantage of a single national list is that it ensures fair access for every patient.

A second option is to create two or three large regions of roughly equal population. The advantages of the development of several large regions, each with a single shared candidate list are: 1) increased fairness over the current system in terms of access to donor organs; 2) greater efficiency in organ transportation compared to a single national list; and 3) cost savings with consolidation of organ procurement agencies. The disadvantages of this option include: 1) slightly increased transport expenses compared to the current scheme; and 2) the potential for some increase in organ preservation times compared to the current system.

2. Performance standards must be instituted for all liver transplant centers and procurement organizations.

Currently the quality of care and the probability of patient survival vary tremendously among the burgeoning number of transplant centers. Recent UNOS data reveal that at least 20 centers have survival statistics which are more than two standard deviations below the mean for the country. We believe that a center must demonstrate one year patient survival probabilities of 75% and two year survival of 70%. In order for prospective transplant recipients or their agents to make an informed choice of a transplant center, they must have access to updated, accurate survival data from transplant centers of interest to them. These data, in conjunction with competitive pricing, will also aid major insurance carriers in selection of centers of excellence that also result in important cost control.

In the UNOS Center-Specific Data Report published in the Fall of 1992, it was shown in the field of heart transplantation, which is less technical than liver transplant, the mortality rate of recipients at centers that performed fewer than nine heart transplants annually was 50% higher than at the centers which performed more than nine cases per year. The liver transplant data are still being reviewed. However, we do not believe centers should be chosen only on the basis of transplant volume since there are some small programs with excellent results. However, we advocate that all centers, regardless of size, should be held to the same survival requirements. There is a disturbing trend nationwide of transplanting patients who are less ill. In 1989, 60% of the transplants were done for patients that were classified in the two most urgent statuses, UNOS 3 and 4. Currently, it has fallen to 30% nationwide. This Consortium of 7 has a rate of about 45% which suggests that our large centers are transplanting more critically ill patients than the smaller ones.

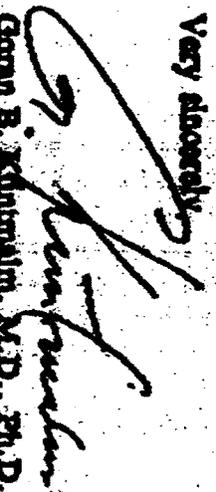
In a similar vein, organ procurement agencies must be held accountable for their activity and efficiency. There is widespread variability of efficiency among these agencies, evidenced by the widely varying rate of liver procurement. Liver procurement from organ donors varies from 36% to 92%. An increase of 10% in the national average rate of liver procurement efficiency would yield an additional 400 livers annually. This equates to an increase in the donor liver pool of 13%. We believe that the regional approach would lead to higher efficiency rates and utilization of all organs, not just the liver.

Information that is not currently available from UNOS includes the number of potential liver donors who are not referred to any transplant center because of local organ procurement practices or the number of organs that are not offered outside of regions because of regional variations in acceptance criteria for donor livers. The rate of interregional sharing of livers has

markedly decreased over the past few years. We believe that the elimination of current regional boundaries and the establishment of a few large regions, as mentioned previously, would dramatically increase OPO efficiency. This can be exemplified by the State of West Virginia. In the past the State had been served by Virginia Organ Procurement Agency until 1991, in which time organ procurements were obtained. In 1992, the Center for Organ Recovery Education assumed the direction of West Virginia, and saw an immediate increase of 155% for the calendar year of 1992. An increase in 1993 of approximately 30% in this State is also anticipated.

We appreciate the opportunity to submit our thoughts to you and to your Committee. We believe that we are championing sound principles that represent both the interests of the transplant community and, more importantly, the large constituency of patients that comes to us for care. The adoption of these principles will improve the public's perception of the transplant community, and thereby lead to an overall growth in organ donation. Performing 42% of all liver transplants in the U.S. in 1992, and representing 38% of all patients currently awaiting liver transplantation, we believe we have a serious responsibility. In the current organizational structure, the voices of the few who represent many patients are easily muffled. Thus, we are all the more grateful for your time and attention.

Very sincerely,


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NATIONAL TRANSPLANT ACTION**AD HOC COALITION ON ORGAN TRANSPLANTATION****STATEMENT OF CONCERN**

The individuals and associations listed below have formed an ad hoc coalition to express concerns regarding the Reauthorization of the National Organ Transplant Act and other major issues pertaining to organ transplantation. While the members of the coalition are pleased with the work done by the Committee on Energy and Commerce in its mark up of H.R. 2659, some important issues appear to need clarification.

In a second meeting held by the coalition on September 8, 1993, a consensus was reached on the allocation of extra-renal organs. It was agreed that the reauthorization should emphasize in an appropriate manner the original intent of the 1984 N.O.T.A. legislation which called for the establishment of an equitable and efficient distribution of donor organs on a national basis. As it stands now, this intent has not been carried out by the Organ Procurement and Transplantation Network (O.P.T.N.). The current system is manipulated by artificial geographic boundaries and ignores the medical needs of the patients. A medically needy patient may be passed over in the current allocation system, so that a less medically appropriate individual receives a donated organ.

The coalition decries such an inequity and urges Congress to correct it.

In deliberations during the mark-up of H.R. 2659, Committee members acknowledged this problem. Congressman Michael Bilirakis voiced his interest in introducing an amendment which would codify a more balanced allocation system. Other members of the Committee were very concerned that the Congress should not address such a matter that depends upon medical and scientific determinations. However, the Committee acknowledged that a problem existed and decided that they would take steps to address the issue - perhaps in its Committee Report.

The coalition urges the Senate Labor and Human Resources Committee to take a more proactive position on this issue. While it may not be appropriate to codify a detailed allocation system for extra-renal organs in the Reauthorization of the N.O.T.A., we urge that the Committee re-emphasize the original intent of the establishment of a national and equitable allocation system based upon patient needs. The allocation system should assure that available extra-renal organs go to the most medically appropriate patient and that any geographic

considerations be restricted to the viability of the available organ.

H.R. 2659 currently calls for a one-year study by the Secretary of Health and Human Services to address the viability of allocating organs without respect to defined geographic areas. The coalition members strongly recommend that this provision be eliminated. Such studies often take more time than is expected. Because human lives are at stake, the allocation system cannot wait for improvement while a lengthy study takes place. We advise more immediate action.

The coalition members strongly suggest that the Senate adopt the following legislative language. Furthermore, it recommends that the Reauthorization direct the Secretary to convene a group of experts to address the geographic issue immediately after passage of the Reauthorization Bill and during the period in which pertinent regulations are under development. Such a study group must be given full access to extensive statistics already available at the O.P.T.N. contractor: the United Network for Organ Sharing (U.N.O.S.). The group must complete its work and submit conclusions and recommendations to the Secretary within three months.

OTHER ISSUES:

Some coalition members expressed concerns over the lack of patients, patient family members, recipients, and donor family members in the governance of the O.P.T.N. All are pleased that H.R. 2659 calls for one-third of the O.P.T.N. Board be made up of the groups described above. But patients, patient family members, recipients, and donor family members should have a deeper representation on all O.P.T.N. committees and subcommittees.

Some coalition members suggested that since professional groups such as "N.A.T.C.O." and "A.O.P.O." each have the right to designate two representatives apiece to the O.P.T.N. Board, so should patient advocacy groups such as Transplant Recipients International Organization and National Transplant Action have a similar right to designate consumer representatives to the O.P.T.N. Board.

AD HOC COALITION ON ORGAN TRANSPLANTATION

PROPOSED LEGISLATIVE LANGUAGE

The Ad Hoc Coalition on Organ Transplantation recommends that the Senate Labor and Human Resources Committee adopt the following amendment as part of the Reauthorization of the National Organ Transplant Act.

Section 372 of the Public Health Service Act (42 U.S.C. Sec. 274) is amended by inserting the following after paragraph (2):

"(3) Criteria for allocating extra-renal organs required under paragraph (2)(B),

(A) shall be based upon the degree of medical appropriateness of the patient, and

(B) shall not be based upon geographic considerations, except to the extent necessary for the viability of the organ.

NOTE: The following alternative language has also been suggested by one of our coalition members.

Section 371 (b) of the Public Health Service Act (42 U.S.C. Sec. 273(b)) is amended:

in paragraph (2), subparagraph (B) by inserting before the comma at the end the following:

"which system shall be consistent with the criteria set out in Section 372(b), paragraph (2), subparagraph (B) (42 U.S.C. Sec. 274(b)(2)(B)),"

Section 372(b) of the Public Health Service Act (42 U.S.C. Sec. 274(b)) is amended:

in paragraph (2), subparagraph (B) by striking the comma at the end, replacing it with a period, and after the period inserting the following:

"For extra-renal organs the allocation criteria shall be based upon the degree of medical appropriateness of the patient and shall not be based upon geographic considerations, except as necessary for the viability of the organ or as practical when selecting between patients having comparable priority for an organ based upon the criteria of medical appropriateness."

NATIONAL TRANSPLANT ACTION**AD HOC COALITION ON ORGAN TRANSPLANTATION****ROSTER OF PARTICIPANTS**

The following individuals and organizations have participated in or supported the Ad Hoc Coalition on Organ Transplantation:

I. Patient Advocacy Organizations

National Transplant Action
Transplant Recipients International Organization

II. Organ Procurement Organizations

*Brian Broznick, Center for Organ Recovery and Education
*Bill Anderson, Lifenet Transplant Services

III. Transplant Centers

O. Howard Frazier, M.D., Texas Heart Institute
John Herre, M.D., Norfolk General Hospital Heart Transplant Program
Sentara Hospital Heart Transplant Program
Byers Shaw, M.D., University of Nebraska
Goran B.G. Klintmalm, M.D., Ph.D., Baylor University Medical Center
*Nancy Ascher, M.D. Ph.D., University of California at San Francisco Liver Transplant Program
*Dr. Emmet Keefe, M.D.; Dr. Carlos Esquivel, M.D., Ph.D., California Pacific Medical Center Liver Transplant Program
University of Pittsburgh Transplant Program

* Due to time constraints and the need to forward our recommendations to the Senate Committee on Labor and Human Resources in a timely manner, not all coalition members have had an opportunity to review and render an opinion on the coalition's proposed legislation.



University of Pittsburgh

UNIVERSITY OF PITTSBURGH MEDICAL CENTER
Office of the Vice President and Counsel

September 30, 1993

HEALTH CARE REFORM AND LIVER TRANSPLANT ALLOCATION POLICY

INTRODUCTION:

During his speech to the Joint Session of Congress on his plan for Health Care Reform, the President listed six principles which he described as the basics of his plan: Security, Savings, Simplicity, Quality, Choice and Responsibility. Just as these six principles show the need for Health Care Reform, generally, they also support the need for a change in the manner in which human livers are allocated for transplantation. The current allocation program clearly demonstrates all that is wrong with the present health care system. On the other hand, what is now being proposed as a new national transplant allocation policy, by a variety of proponents including Members of Congress and some members of the transplant community, meets all of the criteria of the President's Health Care Security Plan.

In 1984, the National Organ Transplant Act, declared that organs for transplantation were a national resource which should be allocated on a "national" basis. Prior to 1991, the legislation worked as envisioned with organs being allocated to the sickest patients first on a national priority basis. In 1991, the government contractor United Network for Organ Sharing ("UNOS") independently changed the allocation system to what is now the current system of organ allocation. The current system relies on geography (specifically the location of the organ donor) as the primary criterion for allocation. Organs must be offered first to all compatible patients locally, then regionally, and then nationally.

The proposed national liver allocation policy, similar in many respects to the pre-1991 policy, would eliminate artificial geographic restrictions in favor of a national list which ranks patients according to medical necessity.

This paper will briefly show how the proposed allocation proposal eliminates the old problems and complements the President's plan.

**PRINCIPLE NUMBER 1. SECURITY - GUARANTEEING
COMPREHENSIVE BENEFITS THAT CAN NEVER BE TAKEN AWAY.**

CURRENT ALLOCATION SYSTEM:

Under the current allocation system, which depends on geography and politics, the uncertainty of ever receiving an organ means that patients and loved ones cannot be assured the peace of mind that the allocation system is fair and that they will be treated in turn under traditional principles of "triage." The geographic-based system means that patients in a particular geographic locality who may not be very sick or who are not in jeopardy of losing their life could be and often are transplanted before a sicker patient who is on the other side of some artificial geographic border. The reality of the current system is that often times a sicker patient dies while a relatively healthy patient is transplanted first based purely on location.

Further, patients are forced to "shop around" for shorter waiting lists, sometimes at the expense of quality care. This geographic hunt means that the patients do not get the "security" of knowing that they are getting the best that medicine has to offer, but merely the place where they can get an organ faster, no matter what the quality of the services provided.

Additionally, the cost of a liver transplant is significant. For example, the average liver transplant costs approximately \$250,000. After a patient is transplanted and completes the initial recovery period, he or she requires

continued monitoring and medication with the attendant costs for life. Often, when a patient requires a transplant, he or she finds that the insurer will either not cover the treatment or cancel the policy at the first opportunity. Changing insurers is impossible as no carrier will undertake the risk of the cost of the transplant and continued care. Those who are not insured at all either die or are forced to seek donations from charity, be it from the government, public or the care-givers. The geographically based system multiplies problems for patients as they, their families, and their care-givers "shop" around the nation for not necessarily the best transplant center or highest quality medical care but the shortest organ waiting list and fight with insurance companies over coverage.

PROPOSED ALLOCATION SYSTEM:

A national list of transplant patients, regardless of location, who are waiting to receive livers would alleviate these insecurities identified above. First, patients could be secure in the knowledge that they will have the opportunity to receive a liver in a fair manner and therefore the peace of mind that they do not have to roam the country for a short list. Prospective recipients will not be forced to compete with each other but rather wait their turn. They will also have the security of knowing that they have selected the center and doctors who can provide the most appropriate care in a manner that treats them like individuals rather than as priority numbers. Finally, they will have the security of knowing that they need not conduct this frantic search for the shortest list and that when their turn for a transplant comes, they will be treated in a fair manner. A national list based on treating the sickest patients first would restore that sense of fairness so necessary for security.

With organ allocation being an area where the government has chosen to pre-empt the field, the responsibility to make sure that the system is fair for similarly situated patients is incumbent upon the leadership of the nation.

PRINCIPLE NUMBER 2. SAVINGS - CONTROLLING HEALTH CARE COSTS FOR CONSUMERS, BUSINESS AND OUR NATION.

CURRENT ALLOCATION SYSTEM:

The current system contributes to soaring health care costs. Very sick patients often linger and even die hoping to receive an organ at the last moment. These patients almost always are required to use our most expensive health care services such as intensive care units (\$5000 per day) and life support devices such as ventilators and maybe even mechanical organs or other assisting devices. When a compatible liver is allocated, not to a very sick patient in an ICU at a distant hospital, but to a less medically needy local patient, the ICU and other costs for the sicker patient continue to mount. Of course, traditional concepts of triage prevent wasting organs on those who are beyond help from a transplant, but as technology has advanced, this point has been extended longer and longer.

The cost of this current system can also be measured in increased loss of life years. Those who are sickest will certainly die if they are not given priority. Each of these very sick patients who is transplanted and saved, has a 100% gain in life years. Those who are least sick but receive a transplant may have only a minimal increase in life expectancy in comparison to their pre-transplant life expectancy.

In order to maximize their chances of getting the needed organ, many patients apply to be placed on several local or regional listings as they "shop around" for the shortest waiting lists. Each listing also requires a costly user fee.

The result is a multiplicity of fees for the same service in each location. In addition, because the patient is listed on several lists, each list is longer than necessary making it more costly to operate the system.

PROPOSED ALLOCATION SYSTEM:

Under the proposed system which eliminates geographical distinctions, patients will get the life-saving organs as their turn comes up for allocation based on medical necessity. Patients will select the centers that offer quality treatment at reasonable prices and costs. This, often means the location where their chances of survival is best.

Because there are enough livers available to treat the two categories of sicker patients first with enough remaining to treat two-thirds of the third of the categories, it is anticipated that you will shorten, or even eliminate, the expensive pre-transplant ICU time. Further, as discussed below, transplant centers, which cannot and should not be able to compete in the marketplace because of lower quality and cost considerations, will be eliminated. This will provide additional cost savings to the patients and payers, as those high quality centers which continue to develop the most cost efficient services will assume the increased volume and be able to operate even more cost-effectively and efficiently. Fees from the costs of multiple listings will be eliminated.

PRINCIPLE NUMBER 3. SIMPLICITY - REDUCING PAPERWORK AND SIMPLIFYING THE SYSTEM.

CURRENT ALLOCATION SYSTEM:

Under the current plan, the government's contractor for operating the procurement and transplantation network makes the allocation rules, keeps the waiting lists and operates the system. It has devised a complex system that allocates organs first based on the geographic location of the donor and second on

the length of time a patient has been waiting. Accordingly, separate lists for each organ now exists for each local area of the country, each region and then one for the entire nation which consists of a combination of the local and regional lists. The complexity is mind-boggling. Doctors and their staffs are spending more of their time either searching lists, filling out forms to apply for a multiplicity of lists or justifying the placement of their patients on a particular list than they do in the actual surgery and other patient care.

Patients are just as burdened. They are busy trying to understand the byzantine rules of the game, applying to lists at several locations hoping to find "the shortest list." Each is trying to get the jump on the other in this deadly "game."

Additionally, insurance companies also may have different coverage policies for these procedures, so problems related to the lack of coverage or pre-approval increase as the patient applies for benefits to be given at multiple locations where they become listed as a transplant candidate. It can be described as "your worst college registration nightmare with death as the penalty for failure to get the class you need to graduate."

PROPOSED ALLOCATION SYSTEM:

The proposed allocation system simplifies all this paperwork and makes the system understandable to the general public. It provides for one nationally centralized list for each type of organ or organ combination. Patients and doctors will know immediately where they stand because no matter where the patient happens to be, the organ needed to save his life will be made available based on medical appropriateness. Coverage will be universal and pre-approval for multiple listings will be moot.

PRINCIPLE NUMBER 4. QUALITY - IMPROVING THE QUALITY OF AMERICAN HEALTH CARE.

CURRENT ALLOCATION SYSTEM:

With the current allocation system favoring organ delivery to patients listed in small geographic localities first, there has been a growth of small transplant centers servicing each locality and performing only a small number of operations per year. The proliferation of transplant centers due to the current organ allocation policy has caused an erosion of the quality of services provided to the patients. In 1992, UNOS had approved 96 liver transplant centers. Thirty-seven of these programs formed less than 15 transplants in 1992, which seven programs performed 42% of all liver transplants. Because small transplant centers are favored in the allocation system, they receive organs to transplant less sick or relatively well patients, or patients who fail to meet the medical criteria at more experienced programs. This "boutique" practice serves to drive up the cost of providing the service due to the establishment of costly transplant facilities in many locations for only a few cases per year. Facilities for this type of practice are expensive, but due to lack of experience, quality of care suffers. The most complex cases, usually the sickest patients, cannot and will not be transplanted at these inadequate centers. The allocation system actually works against the time honored maxim that "practice makes perfect" which is then reflected in higher costs and lower survival rates for patients. Surgical and treatment skills at boutique centers are not enhanced as they would be with a higher volume and patients suffer lower survival rates under this system.

PROPOSED ALLOCATION SYSTEM:

Under the proposed allocation system, patients will be able to go to transplant centers with proven track records of high success. Those are the centers which have the volume necessary to provide the highest quality care most efficiently. They have the doctors and other health care professionals who are

very proficient in the surgery and other treatment. They have the facilities to handle quantity with quality. They have the know-how and resources to keep pre-transplant patients alive longer and to have a higher success rate for those who receive organs. Survival rates go up due to the transplant teams' proficiency and with the higher skill rates, even the most complex operations become more successful.

PRINCIPLE NUMBER 5. CHOICE - INCREASING CHOICES FOR CONSUMERS.

CURRENT ALLOCATION SYSTEM:

Because of the manner in which organs are allocated, Americans have restricted choices as to where they will receive their life-saving treatment. The current system requires them to try to figure out a "shell game" in which they go to the transplant center that gives them the best shot at finding that elusive donated organ. The current system forces patients to "shop" for the shortest list rather than the place that offers the quality, doctors, prices, convenience or other choices they might wish to have available.

Further under the current system, research into new and experimental techniques which can develop ways to save additional lives is stymied because allocation goes to smaller centers without either the patient base or proficiency for research protocols. As a result, advances in the field become less likely.

PROPOSED ALLOCATION SYSTEM:

With a system that eliminates geographic concerns and treats the most medically appropriate patients first, (the sickest patients in most cases) all the options become available to the patients and the doctors. Patients will have the choice of the highest quality care, the most qualified doctors, and state-of-art facilities, which will result in the most-cost effective care.

PRINCIPLE NUMBER 6. RESPONSIBILITY - MAKING EVERYONE RESPONSIBLE FOR HEALTH CARE.

CURRENT ALLOCATION SYSTEM:

The scarce national resource of human organs is not allocated on a fair basis. Because there are hundreds of local and regional lists for each organ or combination of organs, the responsibility for allocating them falls hardest on the patient and his or her doctor and their staff who must do all the leg work and justify the various lists upon which the patient is placed. Government, which by law was supposed to oversee the process to prevent abuses, has in effect shunned its responsibility in favor of the self interests of those who receive the contract to monitor the system.

PROPOSED ALLOCATION SYSTEM:

Under the proposed system, responsibility is placed back where it belongs in the hands of the people's representatives, the government. Individuals will remain responsible for keeping their end of the bargain. Doctors, hospitals and insurers cannot abuse the system as well. The maximum flexibility of the system to compete in a fair and appropriate manner to insure that the patient's needs are taken care of first would be protected.

CONCLUSION:

The President's Health Security Act and the proposed changes to the organ allocation policies and regulations complement each other. With changes to the liver allocation policies, the President's Health Security Act will be able to operate as it is designed. Without these changes, the purposes of health reform will be defeated by maintaining a system which operates in a manner contrary to its very principles. Because transplantation is one of the most expensive areas of medicine, the failure to change these policies to conform to the President's plan

will have an enormous effect on the success of the effort. Citizens will continue to face the same problems and confidence in the reforms will be destroyed. A national allocation system based on patients' needs and interests best serves them and the President as we move toward comprehensive health care reform.