

S B

1 1 2

JUDICIARY COMMITTEE REPORT

(7)
Date Referred: May 15, 1991

FURTHER REFERRALS:

Date of Committee Action: 5-19-91

The JUDICIARY Committee considered:

CSSB 112(JUD)

CS FOR SENATE BILL NO. 112 (JUDICIARY)

ANATOMICAL GIFTS

"An Act relating to anatomical gifts."

RECOMMENDATIONS: [] the same title
 be replaced with _____ [] a new title

[] have attached amendments(s)

do pass

[] do not pass

[] no recommendations

[] individual recommendations

[] additional referral to the _____ Committee

ADOPTS: _____ letter of Intent

ATTACHES NEW FISCAL NOTE(s): (Dept)

APPROVES PREVIOUS: (Dept/Date)

[] fiscal impact _____

[] fiscal note(s) _____

[] zero fiscal note: _____

2 zero fiscal note(s) Hess 4-3-91
Pub Sat 3/6/91

SIGNING <u>DO</u> PASS	DP	OTHER RECOMMENDATIONS	DNP	NR	AM
<i>Wanda Rowley</i>	✓	<i>Terry Martin</i>		✓	
<i>Ed Kennedy</i>	✓				
<i>Mark Staley</i>	✓				
<i>Mike Miller</i>	✓				
		<i>J. Ellis</i>		✓	


 CHAIRMAN'S SIGNATURE

STATE OF ALASKA
 1991 LEGISLATIVE SESSION

Revision Date: _____ Department Affected: Public Safety
 Title: An Act relating to anatomical BRU: Alaska State Troopers
gifts. Component: Detachments
 Sponsor: Senator Fahrenkamp
 Requestor: Senate HESS

COMPONENT SERIAL NO.

	7	9	9
--	---	---	---

EXPENDITURES/REVENUES: (Thousands of Dollars) (Inflation not Included)

OPERATING	FY 92	FY 93	FY 94	FY 95	FY 96	FY 97
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES	Changes in <u>CSSB</u> (AD) have no fiscal impact. This fiscal note is appropriate.			Changes in <u>CSSB112</u> (HES) have no fiscal impact. This fiscal note is appropriate.		
EQUIPMENT						
LAND & STRUCTURES	Apri 13, 1991 <u>DBB</u> date			3-6-91 <u>HL</u> date		
GRANTS, CLAIMS	Comte Aide (initial)			Comte Aide (initial)		
MISCELLANEOUS						
TOTAL OPERATING	-0-	-0-	-0-	-0-	-0-	-0-

CAPITAL	-0-	-0-	-0-	-0-	-0-	-0-
---------	-----	-----	-----	-----	-----	-----

REVENUE	-0-	-0-	-0-	-0-	-0-	-0-
---------	-----	-----	-----	-----	-----	-----

FUNDING: (Thousands of Dollars)

GENERAL FUND						
FEDERAL FUNDS						
OTHER/PROG RCPT						
TOTAL	-0-	-0-	-0-	-0-	-0-	-0-

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year impact None

ANALYSIS: (Attach a separate page if necessary)

No fiscal impact on Alaska State Troopers.

Prepared by: Gavle A. Horetski Phone: 465-4322
 Division: Commissioner's Office Date: 3/5/91
 Approved by Commissioner: Richard L. Burton Richard L. Burton
 Agency: Department of Public Safety Date: 3/5/91

COMM.

No. 2

STATE OF ALASKA
1991 LEGISLATIVE SESS

Bill Versio
Publish Da

Version: CSSB 112 (JUD)
(S) Publish Date: 4/3/91

REQUEST: FISCAL NOTE

Revision Date:		Agency Affect:	<u>Health & Social Services</u>
Title:	<u>Anatomical Gifts</u>	BRU:	<u>State Health Services</u>
Sponsor:	<u>Fahrenkamp</u>	Components:	<u>Public Health Administration</u>
Requester:	<u>Senate HESS</u>		

EXPENDITURES/REVENUES: (Thousands of Dollars)

OPERATING	FY 91	FY 92	FY 93	FY 94	FY 95	FY 96
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants, Claims						
Miscellaneous						
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0
CAPITAL	0.0	0.0	0.0	0.0	0.0	0.0
REVENUE	0.0	0.0	0.0	0.0	0.0	0.0

FUNDING: (Thousands of Dollars)

General Funds	0.0	0.0	0.0	0.0	0.0	0.0
Federal Funds						
Other						
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0

POSITIONS

Full-Time		0				
Part-Time		0				
Temporary		0				

ANALYSIS: (attach a separate page if necessary)

No fiscal impact.

Changes in CSSB 112 (JUD)
 have no fiscal impact. This
 fiscal note is appropriate.
 Apr 13 1991 date W.S. Saito
 Comte Aide (initial)

Prepared By: Alfred G. Zangri
 Division: PUBLIC HEALTH

Phone: 465-3090
 Date: 02/27/91

Approved By Commissioner: Theodore Mala, M.D., MPH
 Agency: HEALTH & SOCIAL SERVICES

Date: 3-5-91

Distribution (by preparer):
 Legislative Finance, Legislative Sponsor, Requestor,
 Office of Management & Budget, Impacted Agency(ies)

REQUEST: FISCAL NOTE

Revision Date: _____ Agency Affected: Health & Social Services
 Title: Anatomical Gifts BRU: State Health Services
 Sponsor: Fahrenkamp Components: Public Health Administration
 Requester: Senate HESS

EXPENDITURES/REVENUES: (Thousands of Dollars)

OPERATING	FY 91	FY 92	FY 93	FY 94	FY 95	FY 96
Personal Services						
Travel						
Contractual						
Supplies						
Equipment						
Land & Structures						
Grants, Claims						
Miscellaneous						
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0
CAPITAL	0.0	0.0	0.0	0.0	0.0	0.0
REVENUE	0.0	0.0	0.0	0.0	0.0	0.0

FUNDING: (Thousands of Dollars)

General Funds	0.0	0.0	0.0	0.0	0.0	0.0
Federal Funds						
Other						
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0

POSITIONS

Full-Time		0				
Part-Time		0				
Temporary		0				

ANALYSIS: (attach a separate page if necessary)

No fiscal impact.

Prepared By: Alfred G. Zangri
 Division: PUBLIC HEALTH

Phone: 465-3090
 Date: 02/27/91

Approved By Commissioner: Theodore Mala, M.D., MPH
 Agency: HEALTH & SOCIAL SERVICES

Date: 3-5-91

Distribution (by preparer):
 Legislative Finance, Legislative Sponsor, Requestor,
 Office of Management & Budget, Impacted Agency(ies)

FISCAL NOTE

STATE OF ALASKA
1991 LEGISLATIVE SESSION

BILL NO. SB 112

Revision Date: _____ Department Affected: Public Safety
Title: An Act relating to anatomical BRU: Alaska State Troopers
gifts. Component: Detachments

Sponsor: Senator Fahrenkamp
Requestor: Senate HESS

COMPONENT SERIAL NO. -

	7	9	9
--	---	---	---

EXPENDITURES/REVENUES: (Thousands of Dollars) (Inflation not Included)

OPERATING	FY 92	FY 93	FY 94	FY 95	FY 96	FY 97
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	-0-	-0-	-0-	-0-	-0-	-0-

CAPITAL	-0-	-0-	-0-	-0-	-0-	-0-
---------	-----	-----	-----	-----	-----	-----

REVENUE	-0-	-0-	-0-	-0-	-0-	-0-
---------	-----	-----	-----	-----	-----	-----

FUNDING: (Thousands of Dollars)

GENERAL FUND						
FEDERAL FUNDS						
OTHER/PROG RCPT						
TOTAL	-0-	-0-	-0-	-0-	-0-	-0-

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year impact None

ANALYSIS: (Attach a separate page if necessary)

No fiscal impact on Alaska State Troopers.

Prepared by: Gavle A. Horetski Phone: 465-4322
Division: Commissioner's Office Date: 3/5/91

Approved by Commissioner: Richard L. Burton Richard L. Burton
Agency: Department of Public Safety Date: 3/5/91

Distribution (by preparer): Legislative Finance, Legislative Sponsor, Requestor, OMB, & Impacted Agency(ies).

Alaska State Legislature

SENATOR BETTYE FAHRENKAMP
CHAIRMAN, LEGISLATIVE COUNCIL
CHAIRMAN, ADMINISTRATIVE REGULATION
REVIEW COMMITTEE
119 N. CUSHMAN STREET, SUITE 201
FAIRBANKS, ALASKA 99701
OFFICE (907) 452-4882
HOME (907) 456-2899



Senate

WHILE IN JUNEAU
P.O. BOX V
JUNEAU, ALASKA 99811
CAPITOL, ROOM 125
OFFICE (907) 465-3834
HOME (907) 780-6027

MEMORANDUM

TO: Representative Donley, Chair
House Judiciary Committee

FROM: Senator Bettye Fahrenkamp

DATE: May 10, 1991

SUBJECT: Senate Bill 112
"An act relating to anatomical gifts."

The intent of SB 112 is to ensure that hospitals comply with the wishes of the organ donor. Hospitals currently require the consent of the next of kin before they will accept an organ donation. If the next of kin refuse to honor an organ donor's wishes, hospitals and organ procurement centers may be withholding medical care from transplant recipients.

This bill requires that hospitals honor a donor's wishes, without the consent of any other individual. Also, that persons such as law enforcement or medical personnel, make a reasonable search for documentation that may show whether or not the person is a donor. Hospitals that are not equipped to accept an organ donation are required to contact a donor bank if a deceased person at the hospital has consented to an anatomical gift.

SB 112 is currently scheduled for a hearing in House Health, Education and Social Services Committee for May 16th at 8:00 a.m. with House Judiciary as the next committee of referral.

In the Senate, SB 112 has a unanimous "do pass" record. As there has been no opposition to the bill, there is a strong chance that it will be moved out of House (HESS) without a hitch.

Therefore, I urge you to consider scheduling SB 112 for May 17th <pending referral>. Thank you.

Alaska State Legislature



Senate

SENATOR BETTYE FAHRENKAMP
CHAIRMAN, LEGISLATIVE COUNCIL
CHAIRMAN, ADMINISTRATIVE REGULATION
REVIEW COMMITTEE
119 N. CUSHMAN STREET, SUITE 201
FAIRBANKS, ALASKA 99701
OFFICE (907) 452-4882
HOME (907) 456-2899

WHILE IN JUNEAU
P.O. BOX V
JUNEAU, ALASKA 99811
CAPITOL, ROOM 125
OFFICE (907) 465-3834
HOME (907) 780-6027

TO: Representative Donley, Chair
House Judiciary Committee

FROM: Senator Bettye Fahrenkamp

DATE: May 10, 1991

SUBJECT: Senate Bill 112
"An act relating to anatomical gifts."

A constituent of mine, upon renewing his driver's license this summer, decided to become an organ donor. He was then advised that hospital policy still required the consent of next of kin or they would not accept the donation.

By accepting next of kin's refusal to honor an organ donor's wishes, hospitals and organ procurement centers may be withholding medical care from transplant recipients. This would hold particularly true in the instance where a recipient is on hand and the next of kin cannot be reached to ask for consent. No one should interfere with an individual's right to make the final decision on organ donation.

BILL SUMMARY

- * Reinforces that an individual's decision to donate body organs does not require the consent or concurrence of any individual after the donor's death.
- * Requires that a reasonable search must be made for documentation that identifies the individual as a donor or as someone who has refused to make an anatomical gift. Failure to do so may result in administrative sanctions.
- * Law enforcement or medical personnel and hospitals located in areas where hospitals don't have the provisions to accept an organ donation, are exempt from being required to make a reasonable search for documentation. But the hospital is required to make an effort to contact a donor bank if they are aware that the individual is a donor.

Page 2
April 18, 1991

FISCAL IMPACT: Zero fiscal notes from HESS and Dept. of Public Safety.

PREVIOUS COMMITTEE ACTION:

HESS: DO PASS Sturgulewski, Cotten and Menard.
JUDICIARY: DO PASS Halford, Collins, Adams and Frank.
SENATE FLOOR: UNANIMOUS DO PASS

DEPARTMENT POSITION: Supported by the Department of Public Safety.

ABOUT THE BILL:

Currently hospitals require the consent of the next of kin before accepting an organ donation. SB 112 requires that hospitals and organ procurement centers comply with the wishes of the individual to make a gift upon their death and not require the consent of any other person. Hospitals that are not equipped to accept a donation are required to make a reasonable effort to contact a donor bank if the individual is an organ donor.

As Joel Swerdlow of the Annenberg Washington Program wrote in Matching Needs, Saving Lives, "By letting donors themselves decide, we protect two basic values: First, we protect our right to decide, which is already granted by law. Second, we can save lives: when health-care institutions accept the next of kin's refusal to honor an organ donor's wishes, they may be withholding medical care from transplant candidates."

I urge your early scheduling and favorable consideration of this measure. I would be happy to answer any questions you may have and provide further information upon request.

HOUSE COMMITTEE REPORT

(7)
 Date Referred: April 17, 1991 FURTHER REFERRALS: Judiciary

Date of Committee Action: 5-15-91

The HEALTH, EDUCATION AND SOCIAL SERVICES Committee considered: CSSB 112(JUD)

CS FOR SENATE BILL NO. 112 (JUDICIARY) ANATOMICAL GIFTS

"An Act relating to anatomical gifts."

RECOMMENDATIONS:
 be replaced with CSSB 112 (JUD) the same title
 a new title

- have attached amendments(s)
- do pass
- do not pass
- no recommendations
- individual recommendations
- additional referral to the _____ Committee

ADOPTS: _____ letter of Intent

ATTACHES NEW FISCAL NOTE(s): (Dept) APPROVES PREVIOUS: (Dept/Date)

fiscal impact _____ fiscal note(s) _____

zero fiscal note _____ (x2) zero fiscal note(s) DPS 3/6/91
DNSS 4/3/91

SIGNING DO PASS	DP	OTHER RECOMMENDATIONS	DNP	NR	AM
<i>Choni Davis</i>	✓				
<i>William E. ...</i>	✓	(CARNEY)			
<i>James ...</i>	✓	(LINCOLN)			
<i>John ...</i>	✓	(GONZALEZ)			
<i>Betty Davis</i>	✓	(DAVIS)			

[Signature]
 CO-CHAIRMAN'S SIGNATURE (LINCOLN)

Alaska State Legislature

SENATOR BETTYE FAHRENKAMP
CHAIRMAN, LEGISLATIVE COUNCIL
CHAIRMAN, ADMINISTRATIVE REGULATION
REVIEW COMMITTEE
119 N. CUSHMAN STREET, SUITE 201
FAIRBANKS, ALASKA 99701
OFFICE (907) 452-4882
HOME (907) 456-2899



Senate

WHILE IN JUNEAU
P.O. BOX V
JUNEAU, ALASKA 99811
CAPITOL, ROOM 125
OFFICE (907) 465-3834
HOME (907) 780-6027

TO: Representative Georgianna Lincoln
Representative Pat Carney
Co-chairs, House Health, Education
and Social Services Committee

FROM: Senator Bettye Fahrenkamp

DATE: April 18, 1991

SUBJECT: Senate Bill 112
"An act relating to anatomical gifts."

A constituent of mine, upon renewing his driver's license this summer, decided to become an organ donor. He was then advised that hospital policy still required the consent of next of kin or they would not accept the donation.

By accepting next of kin's refusal to honor an organ donor's wishes, hospitals and organ procurement centers may be withholding medical care from transplant recipients. This would hold particularly true in the instance where a recipient is on hand and the next of kin cannot be reached to ask for consent. No one should interfere with an individual's right to make the final decision on organ donation.

BILL SUMMARY

- * Reinforces that an individual's decision to donate body organs does not require the consent or concurrence of any individual after the donor's death.
- * Requires that a reasonable search must be made for documentation that identifies the individual as a donor or as someone who has refused to make an anatomical gift. Failure to do so may result in administrative sanctions.
- * Law enforcement or medical personnel and hospitals located in areas where hospitals don't have the provisions to accept an organ donation, are exempt from being required to make a reasonable search for documentation. But the hospital is required to make an effort to contact a donor bank if they are aware that the individual is a donor.

Sponsor stmt

Page 2
April 18, 1991

FISCAL IMPACT: Zero fiscal notes from HESS and Dept. of Public Safety.

PREVIOUS COMMITTEE ACTION:

HESS: DO PASS Sturgulewski, Cotten and Menard.
JUDICIARY: DO PASS Halford, Collins, Adams and Frank.
SENATE FLOOR: UNANIMOUS DO PASS

DEPARTMENT POSITION: Supported by the Department of Public Safety.

ABOUT THE BILL:

Currently hospitals require the consent of the next of kin before accepting an organ donation. SB 112 requires that hospitals and organ procurement centers comply with the wishes of the individual to make a gift upon their death and not require the consent of any other person. Hospitals that are not equipped to accept a donation are required to make a reasonable effort to contact a donor bank if the individual is an organ donor.

As Joel Swerdlow of the Annenberg Washington Program wrote in Matching Needs, Saving Lives, "By letting donors themselves decide, we protect two basic values: First, we protect our right to decide, which is already granted by law. Second, we can save lives: when health-care institutions accept the next of kin's refusal to honor an organ donor's wishes, they may be withholding medical care from transplant candidates."

I urge your early scheduling and favorable consideration of this measure. I would be happy to answer any questions you may have and provide further information upon request.

BILL NO: SB 112

DATE: 3/5/91

TITLE: An Act relating to anatomical gifts.

CONTACT: Gayle A. Horetski
Deputy Commissioner
465-4322

DEPARTMENT OF
PUBLIC SAFETY

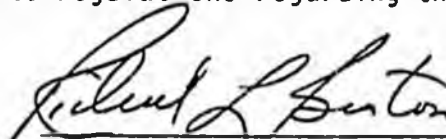
SB 112 modifies the existing anatomical gift statute in the following ways:

1. Unless a gift is revoked before death by the donor, the gift becomes irrevocable and does not require the consent or concurrence of any person after the donor's death.
2. Requires hospital administrators and employees to make a reasonable search for a document or other information, identifying the deceased as a donor, or as a person who has refused to make an anatomical gift.
3. Requires law enforcement officers to make a "reasonable search" for a document of gift or other information identifying the bearer as a donor, or as a person who has refused to make an anatomical gift, and to inform hospital personnel of the intended gift.
4. The bill establishes that failure of either hospital administrators or police officers to make a reasonable search may subject the administrator or police office to "appropriate administrative sanctions".

The Department of Public Safety interprets the requirement that law enforcement personnel at the scene of a death make a "reasonable search" for an anatomical gift document to mean that the officer must take an extra moment or two to search the person of the deceased for documents proclaiming him or her as a donor.

The Department of Public Safety supports this bill, as it has the laudable goal of encouraging Alaskans to donate their organs, upon their death, to other persons in dire need of those organs.

The Department proposes one change in the bill. In Section 3, at page 2, line 13, the word "administrative" should be changed to "disciplinary", and a period should be placed after "sanctions", ending the sentence. Line 14 should be omitted entirely. Disciplinary actions against State Troopers are taken under authority of the Department's Operating Procedures Manual (OPM), state personnel rules, bargaining unit contracts, and other applicable provisions. The Department of Public Safety does not have separate regulations regarding this subject.



Richard L. Burton
Commissioner

This article appeared in the March 13, 1991, edition of the Wall Street Journal.

MEDICINE

Trying to Cure Shortage of Organ Donors

By GLENN RUFFENACH

Staff Reporter of THE WALL STREET JOURNAL

A rapidly growing gap between the number of people waiting for organ transplants and the supply of organs has educators and researchers searching for ways to increase organ donations.

Some studies suggest that the timing of a physician's or nurse's request to surviving family members can raise consent rates substantially. Other proposals call for some type of federal tax benefit to a donor's estate or assistance with funeral expenses. A physician writing in today's *Journal of the American Medical Association* broaches the once-heretical notion of paying families outright—say, \$1,000—for an organ donation.

Though physicians, medical ethicists and patients differ, sometimes sharply, over the effectiveness of these strategies, there is little dispute about the need for added measures to procure organs.

More people are being recommended for transplants, reflecting soaring success rates for these operations, but organ donations "haven't kept up with demand," says Wanda Bond, a spokeswoman for the United Network for Organ Sharing, a national clearinghouse that maintains the waiting list for organs and matches organs with recipients.

The number of people in the U.S. waiting for a kidney, heart, liver, pancreas, lung, or heart and lung has jumped about 40% in the past two years. Moreover, 2,206 people died in 1990 while awaiting a transplant, 26% more than in 1988.

Altruism — the motivating force on which patients and physicians have long depended for donations—"just doesn't look like it's doing too much" to meet the grow-

Waiting for Transplants

The number of people in the U.S., as of March 4, awaiting a:

Kidney	18,163
Heart	1,984
Liver	1,344
Pancreas	516
Lung	394
Heart/Lung	182

Source: United Network for Organ Sharing

ing demand, says Ms. Bond.

The shortages have even sparked debate over which patients are most "worthy" to receive organs. A second article in the current *Journal of the American Medical Association* proposes that patients who develop liver disease through no fault of their own should have a higher priority for receiving a liver transplant than those whose disease results from failure to obtain treatment for alcoholism.

Public-opinion polls traditionally indicate that a large majority of Americans would be willing to donate their organs. But a study in five states in 1988 and 1989 by the Center for Biomedical Ethics at the University of Minnesota found that only 25% to 30% of families actually gave their consent to remove an organ from a family member who had died.

Respondents to polls often "want to impress [the questioner] with their altruism," says Arthur Caplan, the center's director. But when people are actually confronted with death and the thought of removing organs from a loved one, other issues crowd

in. "People think [a patient] might not get aggressive care because of the transplant system's 'pursuit of parts,'" Mr. Caplan says. "Or they're angry about stories they've heard about people buying their way into a transplant, or they think the body will be mutilated."

In addition, physicians and nurses who approach families about organ donation often botch it. Margaret Verble, president of a consulting company in Lexington, Ky., that has held workshops for hospitals on the subject, recalls one physician who asked a new widow: "You don't want to give away any of your husband's parts, do you?" Requests for organs, she says, "have been screwed up every way you can possibly imagine."

A partial remedy for that problem may come from a study completed last year by the Kentucky Organ Donor Affiliates, the state's organ-procurement agency, based in Louisville. Researchers found that if a request for organ donation isn't made at the same moment that a family learns of a relative's death, the family is much more likely to agree to donate.

R. Neal Garrison, medical director of the state agency and professor of surgery at the University of Louisville, says the pause "allows the family to accept the fact of death. Then they can start dealing with other options, including the possibility that some good could come from this."

The study found that when an organ request was made separately from a notification of death, 65% of families agreed to donate. When the two were made at the same time, only 18% agreed to the request.

Perhaps the most radical proposals for increasing donations involve some type of

Please Turn to Page B1, Column 5

Shortage of Organs For Transplants Spurs Search for Remedies

Continued From Page B1

reimbursement. (The purchase or sale of human organs is currently a felony, under the National Organ Transplant Act of 1984.) In today's AMA Journal, Thomas Peters, a physician at the Jacksonville, Fla., Transplant Center, calls for a pilot program to determine whether payments of \$1,000 to families from procurement groups might increase the organ supply—without sparking a process of "organ brokerage or commercialization."

If a family is staunchly opposed to donation, writes Dr. Peters, \$1,000 "would not be so great a financial temptation to deter strongly held beliefs." Conversely, if a family is opposed to donation because of "superstition, reaction to the 'Establishment' or belief that the disadvantaged in society are again being exploited," \$1,000 might be enough to prompt a donation.

But while many people are starting to view reimbursement as "an option we have to pursue," says Ms. Bond at the United Network for Organ Sharing, resistance to the idea remains substantial.

Trust in the transplant system—not reimbursement—is what's needed, says Mr. Caplan in Minneapolis: "People won't be altruistic if they think their gifts are going to the rich."

A less-divisive possibility might be some form of federal assistance. Felix T. Rapaport, chairman of surgery and director of transplantation services at the State University of New York at Stony Brook, says Congress should subsidize burial costs of organ donors or offer an estate-tax abatement or grant. The key, he says, "is to make it a federally sponsored program that would be standard for all donors."

The management and staff of the space station welcome your cooperation to ensure the safety of all children and to comply with the wishes of parents.

This letter appeared in the February 27, 1991 edition of the Anchorage Times letters to the editor.

Gift of life from Anchorage

Dear Editor:

It is with a heart full of thanks that I write this letter. My granddaughter, Alishia, is recovering very rapidly from a kidney transplant. This 20-month-old child suffered from a kidney ailment from birth. The only way to provide her a normal life, or any life at all, was a transplant.

A call came at 3 a.m., Sunday morning, Dec. 30, saying a kidney was available in Anchorage. My

waiting for trains, but the normal reaction is to leave the automobile running. My engine idled about five minutes before I turned it off.

I wouldn't mind waiting if these trains were carrying supplies for our troops in the Middle East, but this train was hauling, among other things, scrap automobiles. I think trains with this kind of cargo can be rescheduled without disruption.

John Westover
Anchorage



son, Raymond Puzio, and his wife, Tonya, traveled with Alishia from their home in West Palm Beach, Fla., to Children's Hospital in Pittsburgh, Pa., for the operation.

The operation was completed shortly after the donated kidney arrived from Anchorage and it was very successful. Alishia has recovered quickly. She was released from the hospital in just two weeks. Recovery time is normally a month. She is back home in Florida now with a chance to live a long life thanks to people in Anchorage I don't even know, but would like to thank from the bottom of my heart.

My feelings are bittersweet. There is a great joy knowing my granddaughter will live, but I know it came at the cost of another life. We received no details about the donor or the donor's family. I almost lost my sweet granddaughter and can understand the sorrow of their loss. I want them to know that their loss was not in vain. I want them to take whatever solace they can in the fact that Alishia is alive as a result.

If members of the family read this letter and would like to get in touch with me, I encourage them to write me at 1035 Adams St., No. 2, New Castle, Pa. 16101. My telephone number is (412) 652-2859.

I have faith in God. I don't pretend to understand his will. Why should Alishia's life be spared through your loss? All I can do is offer thanks in my prayers and ask God to sooth your sorrow.

Chris Carran
New Castle, Pa.

Kindness of strangers

Dear Editor:

Wasilla Area Seniors would like to thank Staff Sgt. Paul Jordan and Mrs. Jordan of Elmendorf Air Force Base, Spc. Doug Embree and Mrs. Embree and Pfc. Rod Smith of Fort Richardson for providing first aid and comfort for one of our seniors who fell and suffered serious injury at the Fur Rondy ice sculptures.

These people are an example of the good neighbors we have at the military bases. We thank them and wish them every good fortune during their tours of duty in Alaska.

We also thank Kevin Brown of Anchorage for his aid in keeping our senior warm until the ambulance arrived. Human kindness is alive and well in Alaska.

Louise G. Harris
President, Wasilla Area Seniors

The Anchorage Times welcomes letters to the editor from readers on issues of the day. Letters must include signatures, addresses and telephone numbers that can be verified during daytime hours. Letters that cannot be verified and copies of letters sent to other papers will not be published. All letters should be as brief as possible and are subject to editing. Send to: Letters to the Editor, The Anchorage Times, 820 W. Fourth Ave., Anchorage, AK 99501.



MATCHING NEEDS, SAVING LIVES

BUILDING A COMPREHENSIVE
NETWORK FOR TRANSPLANTATION
AND BIOMEDICAL RESEARCH
A REPORT ON POLICY OPTIONS

BY JOEL L. SWEDLOW

THE ANNENBERG
WASHINGTON PROGRAM

Communications Policy Studies
Northwestern University

DEDICATION

About a year ago I read a newspaper story about how a 49-year-old woman in Wisconsin had saved the life of a six-year-old girl in Raleigh, N.C., who was dying of leukemia. The girl needed a bone marrow transplant and had no siblings whose antigens matched hers. But the woman in Wisconsin was a perfect match—a computer search that cost pennies brought the two of them together.

The story made me think of my brother, Paul H. Swerdlow. He was full of life and love, a Ph.D. in nuclear physics and a board-certified radiologist—a man with much to give. In late 1984 he lay dying of leukemia.

Paul's hope for life was that either our sister or I would be a match. Technicians took our blood. We all tried to keep busy with other things while we waited for the results. When the telephone rang, however, the lab reported that neither of us matched Paul. Seven months later, at the age of 42, he died.

Paul lived in Boston. In just that area, according to medical experts, there were about 100 people who might have saved him. In all of America, as many as 25,000 people might have saved my brother's life—if society had set up the necessary communications system. It could have been so simple, but ultimately it was impossible. And, as this report shows, the need goes far beyond my brother's particular illness.

My brother lived in the world of medicine and

science; my work involves politics and public policy. "We should write something together," he often said. "The people in your world have to better understand the great advances in mine."

During the past six months I've visited in Paul's world. I've interviewed hundreds of health care providers, read medical journals and transcripts of congressional hearings, and attended conventions of transplant specialists. Although I was sometimes the only nonmedical person at the meetings, few participants seemed surprised to see me. The transplantation community knows the outside world will eventually pay more attention. Some expect the attention to come in the form of scandal, bred by the lack of regulation in tissue recovery and the huge dollar flow in the processing and distribution of organs and tissues. Others expect that the public will some day demand to know why more sick and injured people don't benefit from transplants.

I repeatedly heard one message from professionals who work long hours, receive little recognition and make miracles: To accept the status quo, given today's capabilities, is inexcusable.

This report is dedicated to all the people who would have helped my brother if given the chance; to all who now suffer for lack of a transplant; and to those who will make possible the happy endings yet to come.

JOEL L. SWERDLOW

CONTENTS

DEDICATION	3
FROM THE DIRECTOR	6
INTRODUCTION	7
EXECUTIVE SUMMARY	8
LIFESAVING CONNECTIONS	10
THE SITUATION TODAY: SHORTAGES	13
OPTIONS: TO INCREASE DONATION	16
THE SITUATION TODAY: RECOVERY AND DISTRIBUTION	21
OPTIONS: TO COORDINATE RECOVERY AND DISTRIBUTION	28
THE NEXT STEPS	31
COMMENTARIES	36
By Richard L. Fuller and Thomas J. Moore, Eye Bank Association of America; William E. Grizzle, University of Alabama at Birmingham; Dale Hatfield, communications consultant; Nancy Holland, American Council on Transplantation; William V. Miller, American Red Cross; John M. Newmann, health policy consultant; Luke Skelley, American Association of Organ Procurement Organizations; Rodney A. Smolia, law professor, College of William and Mary; William W. Tomford, American Association of Tissue Banks; Pamela Weinberg, National Marrow Donor Program; Steven S. Wildman, communications professor, Northwestern University.	
APPENDIX	
Laws and Regulations Relating to the Procurement and Use of Human Organs and Tissues	
By Fred H. Cate, Debevoise & Plimpton	46
ACKNOWLEDGMENTS	61
ENDNOTES	63

INTRODUCTION

This report is worthy of attention for its fresh, comprehensive look at the issues in the critical field of human organ and tissue transplantation, and, in particular, for its emphasis on improving communications within the field and coordination of efforts to increase organ and tissue availability.

The shortage of organs and tissues is often the factor that most severely limits physicians' ability to treat patients who need a transplant. The patients' life-or-death situation and the present scarcity of available organs demand the most efficient use of present resources and intensification of efforts to increase supply.

We are making progress in increasing supply through such measures as state required-request laws for organ donation, the Uniform Anatomical Gift Act and federal requirements that hospitals develop written protocols for identification of potential organ donors. Despite these important steps, however, we are still unable to provide lifesaving organs to even a majority of individuals who need transplants.

Innovative means of increasing supply should be both encouraged and subjected to thoughtful scrutiny by patients, physicians and other health care personnel, ethicists, legal experts, hospital administrators and those involved in organ procurement and distribution. Improvements in supply are likely to be achieved by involving all parties concerned with improving patient care.

M. ROY SCHWARZ, M.D.
Assistant Executive Vice President,
Medical Education and Science
American Medical Association

propose a comprehensive National Human Organ and Tissue Policy. The task force would both initiate and coordinate demonstration projects in the medical community and propose legislation. It would consider and recommend plans for initiatives such as these, built on existing institutions:

- a comprehensive national computer-based communications network to coordinate the recovery and allocation of donated tissues as well as organs under consistent, equitable ground rules,
- a continuous, intensive public education campaign to promote donation and family discussion of donation options,
- experimentation with a statewide electronic donor registry and other mechanisms that would let donors themselves (instead of their next of kin) make the final decision to donate,
- training and incentives for hospital personnel to increase the recognition of potential donors and improve requests for donation,
- streamlined systems on the local level for more extensive recovery of donated organs and tissues,
- an expanded computer registry of living Americans who volunteer to donate lifesaving bone marrow,
- a 24-hour database of medical literature and a telephone hotline to make available the latest techniques and data to health care providers,
- a coordinated system of national databases, linked with all tissue and organ transplantation centers and procurement organizations, to collect data on treatment, cost and outcomes for evaluation,

- assessment of public attitudes about and the desirability of expanding "presumed-consent" laws, which would increase donation by declaring that everyone has given consent to donation unless they explicitly withhold it (registering their refusal with a national databank), and

- a medical consensus conference on the desirability of beginning kidney recovery from non-heart-beating donors, which would greatly increase the supply of the most frequently transplanted organ.

Many people still think of transplantation as a high-technology luxury. In fact, investing in the measures described above would save money for taxpayers and society as a whole, because transplantation is often less costly than alternative treatments.

More importantly, the lives saved and suffering ended give us tens of thousands of human reasons for action.

OPTIONS: TO INCREASE DONATION

In the Dan Smith scenario, Dan was able to donate because he and his wife had talked about donation long before his fatal accident and because hospital personnel were prepared to respond to his wish. These things seem simple, but they are not the norm in the United States today. As long as patients are waiting for organ transplants, the failure to recover a single suitable donated organ is tantamount to withholding medical care. A concerted effort is needed, including any or all of the following policy options, before we can expect more people to give or receive "the gift of life."

FULLY IMPLEMENT THE "REQUIRED-REQUEST" LAWS

In the mid- to late 1980s, public policymakers took what they hoped would be a major step to increase donation: federal regulations and "required-request" laws in 41 states and the District of Columbia obligate hospitals to ask next of kin whether they wish to donate the organs and tissues of a recently deceased family member.²³

In practice, however, state agencies make little effort (or have little authority) to enforce required-request laws, and many hospitals—including major transplant centers—have done nothing to implement them, according to hospital officials. Short-staffed hospitals frequently lack the resources to perform the time-consuming, demanding tasks necessary to acquire donated tissue and organs.

The first task is for physicians to identify medically eligible donors and alert the appropriate hospital personnel. This is not so likely to be done as

one might expect. A recent sample of 195 physicians and nurses found that only 35 percent "correctly identified the legal and medical criteria for determining" brain-death.²⁴ The leader of one of the nation's most successful organ procurement organizations says the hospitals in his area often do not call when they have potential donors because they do not properly identify them. "We sit around and wait far more than we should," he says.

Second; a hospital or organ procurement worker must approach the family to request donation—a delicate task. When the health-care worker assigned to request donation doesn't want to do so or doesn't know how, says University of Minnesota ethicist Arthur Caplan, "the consent rate is . . . zero."²⁵ In some states, furthermore, the required-request laws do not apply to tissue donation and do nothing to encourage donation of human material for medical research.²⁶

It is too soon to know how well required-request laws work. Caplan, their principal proponent, remains optimistic that "the supply of organs and tissues will significantly increase once all protocols are in place and people are more comfortable with required request."²⁷ However, evidence about the effects of the laws is conflicting. Tissue bank officials indicate that tissue donations have increased perhaps by as much as 300 percent.²⁸ The Eye Bank Association of America reports only a 4 percent increase in 1985.²⁹ A recent UNOS study reveals a marked upturn trend for the 15-month period ending in December 1988,³⁰ although some transplant surgeons question this finding.

Experience indicates that donations surge in hospitals where trained professionals have adequate time to communicate with donor families.³¹ At the

same time, reports from some localities, including a statewide Ohio survey, show no change in the donation rate after passage of required-request laws.⁴² Whatever the success of required-request laws, experts agree that there is little reason to believe that these laws alone will produce an adequate supply.

INCENTIVES AND TRAINING TO PROMOTE REQUIRED-REQUEST

Requesting donations is a difficult, labor-intensive task that demands sensitivity and special skills. Yet it often falls upon hospital personnel who are already overworked and underpaid. Thus, money for training and incentives is needed: public/private-sector mechanisms could pay for training of personnel to implement required-request. Hospitals could be motivated by more consistent enforcement of existing required-request statutes and by linking their accreditation or tax-exempt status to effective donor-recruitment efforts.

When the House of Representatives was considering transplantation legislation in 1984, then-Congressman Albert Gore predicted that the bill would inspire "educational and training programs in every hospital and medical community throughout this country in order to greatly increase the rate of organ donation."⁴³ But no organization received the mandate or the money necessary to conduct such an effective nationwide training program. Training has been sporadic, and varies significantly from hospital to hospital.

BUILD A CONTINUING PUBLIC EDUCATION CAMPAIGN

Despite extraordinary dedication of the OPOs and voluntary organizations, current efforts to spread the word about donation have been underfunded.⁴⁴ For various reasons the health community has not yet fully enlisted the communications media in this cause as effectively as it has put out messages about smoking, seat belts, drunk driving, illegal drugs and AIDS.

By not volunteering to donate their own or their relatives' organs and tissues, too many people opt to permit avoidable suffering and death without knowing they are making the choice.

Today, the major effort to educate the donation decision-maker occurs immediately after the death of a relative, when a health-care worker sits down with the grieving next of kin. It is not the ideal time for either one. A concerted public education program would at least lay the groundwork for such sensitive discussions.

Teaching people about donation when they are in a learning setting can be very effective; therefore, donor-awareness programs could well be expanded in schools, churches, synagogues and civic organizations. Other mechanisms, some already in use, are also appropriate—among them, public service advertisements and dramatizations of the donation theme in popular television programs.⁴⁵

Other health-related campaigns have shown that sustained effort can change behavior, particularly when the message taps into preexisting public support. According to public opinion polls, transplantation has such support. If campaigns are to promote complex changes in behavior, however, they must be continuous. Sporadic campaigns yield sporadic results.

The ideal campaign would encourage people to consider universal donation—all tissues and organs for medical research as well as transplantation. As a complement to in-depth efforts, it would also offer a 24-hour "800" Human Organ and Tissue (HOT) hotline, similar to the service the OPTN now operates (dial 800-24-DONOR), that anyone could call to ask questions.

In-depth research on Americans' current knowledge and attitudes about donation would help in fine-tuning the donor-options message, perhaps building on the familiar "Give the Gift of Life" theme now employed. Surveys and anecdotal evidence suggest, for instance, that many fear that organ and tissue donation disfigures the body before burial and in the afterlife. (Polls show that a vast majority of the American people believes in an afterlife.⁴⁶) Outreach could reassure people that the major religions in this country encourage donation and could clarify the poorly understood concept of brain-death.

LET DONORS DECIDE FOR THEMSELVES

Federal and state laws give adults the right to decide whether to donate their tissues and organs.

Indeed, many people carry signed consent forms or fill in pledges on their drivers licenses. Many assume that their wishes will be automatically respected, but often they are wrong. Hospitals contend that family values must be protected and fear negative publicity and legal challenges by displeased survivors. Therefore, they almost always let the next of kin make the final decision, regardless of the wishes of the deceased.

ONLY ABOUT 5% OF ELIGIBLE
ADULTS DONATE BLOOD. IF
THE SAME PERCENTAGE
DONATED TISSUE, THE
NATION'S TISSUE NEEDS
COULD BE MET.

By letting donors themselves decide, we protect two basic values: First, we protect our right to decide, which is already granted by law. Second, we can save lives: when health-care institutions accept the next of kin's refusal to honor an organ donor's wishes, they may be withholding medical care from transplant candidates. This is particularly true in cases when a potential organ donor has just died, a recipient is at hand and the next of kin cannot be reached to be asked for consent.

Letting the donor decide would also clarify in the public mind who is making the decision and give donors a measure of personal satisfaction while they are still living.

Various kinds of legislation could put the decision back in donors' own hands. New laws could, for example, strengthen and more clearly define the protection against liability afforded hospital officials and physicians who act on the basis of signed donor cards. States could obligate hospitals and OPOs to recover organs and tissues for which there is a donor card and a demonstrated need. States could also more diligently enforce existing administrative penalties or allow civil liability to be im-

posed against institutions that fail to act on the basis of donor cards.

A DONOR REGISTRY

A communications option that would help return the donation decision to the donor is a computerized donor registry,⁴⁷ which medical personnel would consult shortly before or after the death of a person medically eligible to donate. With information from the registry, personnel could act promptly to recover organs and tissues during the brief period of time in which they are most useful for transplantation and research. For people who register as donors and then change their minds, the registry would permit easy updates.

In 1984, the Senate committee responsible for the National Organ Transplant Act reported its belief "that one important and appropriate new action to include in the national computer registry is to provide a centralized list of individuals who have voluntarily agreed to donate organs. . . ."

To avoid pitting the health care community against the family, donor registries (and nonelectronic alternatives such as consent forms and living wills) could include certification that the donor had discussed the decision with family members and, as appropriate, that the family had endorsed the decision. The registry could also bring in medical history data vital for screening for AIDS, hepatitis and other infectious diseases (and helpful in locating particular types of diseased tissues needed for research).

Great Britain briefly tested in-hospital donor registries with some success in the mid-1980s.⁴⁸ Twenty-one hospitals were connected in a system listing more than a quarter-million donors and volunteers. Britain is now considering a system that would allow people to sign up as donors through a computer network with terminals in every physician's office. This would have the dual advantage of placing the discussion of donation in the context of the patient-physician relationship and removing it from the family's time of grief.

Georgetown University bioethicist Robert Veatch suggests that the government could increase the percentage of Americans making the donation decision themselves, and encourage family discussion of the decision, by adding donation questions to income tax forms.⁴⁹ For example, the terms could

ask the taxpayer. "Do you wish to be an organ/tissue donor? With any limitations?" If a central registry were created, those who consented would have their names entered.

Opponents argue that donor registries are too expensive and difficult to keep up to date, that registries cannot guarantee confidentiality,³¹ and that reliance on a registry might inadvertently contradict family wishes. Furthermore, critics say, hospitals might still leave the actual decision to next of kin, disregarding a donor registry just as they now ignore notations on donor drivers' licenses.

A MEDICAL ARGUMENT FOR LETTING DONORS DECIDE

Changing medical practice may increase the number of cases when doctors must determine quickly whether they have consent for donation. Kidneys recovered as late as one hour after coronary death can be transplanted, if certain medical steps are taken.³² American transplant teams now almost always take kidneys only from brain-dead donors whose hearts are beating with support from ventilators, but recovering from non-heart-beating donors in addition would greatly increase the supply of kidneys—by far the most frequently transplanted organ. By the end of the century, says transplant surgeon David Anaise of the State University of New York at Stony Brook, livers and other organs may also be recovered from non-heart-beating donors.

Anaise estimates that the practice would increase the supply of kidneys tenfold if proper medical procedures are followed. It is, he says, "the only solution to the supply problem."³³

Although the practice arouses opposition from parts of the medical community, many surgeons agree that "non-heart-beating donors can be a reasonable approach to help alleviate the shortage of kidneys."³⁴ Animal studies and advances in drugs that inhibit tissue death also suggest the practice may be productive.³⁵

Each year, tens of thousands of Americans medically eligible to donate organs suffer coronary death from some form of heart attack or trauma.³⁶ Use of a donor registry, for rapid identification of those patients who have already consented to donate, would enable hospitals to coordinate rescue squads, emergency room personnel and organ recovery

teams to recover the kidneys without delay.

States could adopt laws making it unnecessary to seek permission from next of kin before taking medical steps to protect the transplantability of organs from the deceased, thereby keeping their options open for later donation.³⁷ (Hospitals already perform a number of routine nondeforming procedures on cadavers for which permission is not requested.³⁸)

EXAMINE THE DESIRABILITY OF EXPANDING PRESUMED-CONSENT

More than a dozen countries—including France, Israel and Italy—have adopted "presumed-consent" laws, under which everyone is designated a donor unless they register their refusal.³⁹ These laws may not have had much effect, however, because most physicians still seek family permission.

The prevailing view among U.S. health care professionals is that presumed consent would never attract public support. However, given the new capability of computer/communications systems to register declinations, presumed-consent laws may be consistent with our basic values.⁴⁰

Such a suggestion may seem startling, but limited presumed-consent laws are already on the books. Twenty-one states—double the number of only a few years ago—have such laws for corneas obtained from bodies under the jurisdiction of a medical examiner; unless the next of kin objects, the medical examiner may remove the corneas of the deceased during autopsy. Seventeen states have similar provisions for pituitary glands.⁴¹ Many states also have presumed-consent laws for unclaimed bodies. These laws could be expanded to provide tissues for research.

Presumed consent seems to be attracting support within the medical community for use in areas other than transplantation. Medical leaders, for example, are discussing mandatory autopsies and application of presumed consent to "intubation training" for physicians, which does not disfigure the body and is necessary for sound medical training.

In Britain, furthermore, there is reportedly substantial public support for laws under which doctors [can] remove organs from dead patients for transplant unless they had specifically refused before death.⁴²