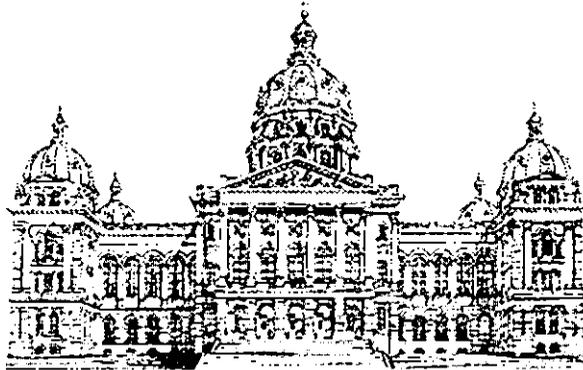


FINAL REPORT

**ANATOMICAL GIFT REFERRAL
STUDY COMMITTEE**



Presented to the
LEGISLATIVE COUNCIL
and the
IOWA GENERAL ASSEMBLY
January 1998

Prepared by the
LEGISLATIVE SERVICE BUREAU



Legislative
Service
Bureau

FINAL REPORT

Anatomical Gift Referral Study Committee

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MEMBERS

Senator Lyle Zieman,
Co-chairperson
Senator Nancy Boettger
Senator Mary Neuhauser

Representative Gary Blodgett,
Co-chairperson
Representative Jack Drake
Representative Rebecca Reynolds-Knight

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AUTHORIZATION AND APPOINTMENT

The Anatomical Gift Referral Interim Study Committee was created by the Legislative Council, was authorized by the Council for one meeting date during the 1997 interim, and was provided a charge of reviewing Iowa's system for organ donation and procurement, including the compliance of hospitals and other health organizations in making referrals to organ procurement organizations.



Anatomical Gift Referral Study Committee

1. Presentations.

The following presentations were made to the Committee at its November 17, 1997, meeting:

Iowa Statewide Organ Procurement Organization.

◆ **Historical Perspective.** Mr. C.W. "Bill" Hutchins, President, Charles W. Hutchins and Associates, and consultant to the Iowa Statewide Organ Procurement Organization (ISOPO), presented an historical perspective of legislative actions related to organ donation in Iowa and also shared the personal experience of his wife JoAnn, who is the recipient of a lung transplant. Mr. Hutchins described the following legislative efforts: requiring organ donation to be part of the driver's education classes in Iowa schools; updating chapter 142C of the Code of Iowa, the Uniform Anatomical Gift Act; authorizing the medical examiner to release and remove body parts to make a gift if the body is under the control of the medical examiner; creating the Anatomical Gift Public Awareness and Transplantation Fund to provide funding for public awareness efforts and for the costs associated with transplants under certain circumstances; requiring the Department of Transportation to include a question regarding consent for organ donation in information for drivers applying for a license by mail; and allowing county treasurers to retain 5 percent of the proceeds in donations made annually for organ donation as an incentive to encourage this effort.

◆ **Iowa Implementations.** Ms. Suzanne Conrad, RN, MS, Executive Director, Iowa Statewide Organ Procurement Organization (ISOPO), described organ and tissue donations in Iowa. She noted that the federal Health Care Financing Administration (HCFA) certifies organ procurement organizations under the Medicare program and that the organ procurement organization must meet certain performance standards to continue to be certified. Ms. Conrad noted that in Iowa's most recent HCFA review, the ISOPO met the criteria for certification. Ms. Conrad also noted that because performance is based upon death record reviews of referrals, the ISOPO has developed new strategies to increase referrals. In the past, the ISOPO relied upon existing hospital personnel to identify donors and to talk with families about donations. The new strategy is a hospital development and marketing plan to work with administrators, doctors, nurses, and other hospital personnel to determine what works best in obtaining early referrals. Ms. Conrad discussed the issue of routine and mandated referrals. In 1995, the hospitals and the organ and tissue procurement entities agreed to continue voluntary routine referrals. Even though the process has been slow in improving referrals, the voluntary referral effort appears to be working. Ms. Conrad indicated that in the future the ISOPO will continue to encourage early referral and to work with the Association of Iowa Hospitals and Health Systems and the Iowa Medical Society. She stressed that time is necessary in fully implementing routine referral. She recommended enacting legislation to change the 80 percent compliance with referral requirement for hospitals to receive

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grants from the Anatomical Gift Public Awareness Fund to a lower percentage, increasing public awareness that the Fund exists to receive donations, and appointing a state spokesperson, such as is used in Illinois where the Secretary of State is the spokesperson, for organ and tissue donation.

National Perspective on Organ Donation and Referral.

◆ **Overview.** Dr. Lawrence Hunsicker, President, United Network for Organ Sharing (UNOS), provided information regarding the national perspective on organ donation and referral. Dr. Hunsicker stated that transplantation is an increasingly successful medical procedure with excellent long-term outcomes. He noted that one of the consequences of the success of transplants is that the demand is increasing, while the supply is not, with a resultant increase also in the time on a waiting list. Currently, in the United States there are approximately 56,000 people waiting for an organ transplant, and this does not include those who have died waiting for an organ transplant procedure. Dr. Hunsicker noted that in Iowa, the waiting time is approximately 1.5 years, with the national average being 3.5 years. Dr. Hunsicker emphasized that donations are conducted in a humane manner and that donations are shared within a region and do not necessarily only remain in Iowa.

◆ **Recommendations for Increasing Donations.** Dr. Hunsicker provided recommendations for increasing the various sources of donations. For living donors, he suggested eliminating the disincentives for donation such as lost wages and other costs associated with donation; allowing for donating to a pool so that the donor's organ can be used and the donor might be able to receive an organ through the pool; and increasing the number of altruistic donors. For cadaveric donors with brain death, Dr. Hunsicker recommended improving the referral rate, improving the consent rate, and working with families who are considering removing life support so that it can be done in a manner conducive to preserving the organs. Dr. Hunsicker commented on the danger of financial incentives interfering with donation potential if payment through a managed care entity is limited so that under the rules of the managed care entity, life support would be removed earlier, thereby losing the opportunity of donation. Dr. Hunsicker suggested that in order to improve the referral and consent rates, the public needs to be provided with more educational information. Some options might include information distributed with tax refunds, information provided with car registration by mail, information on display at the Department of Transportation driver's license renewal stations, and information included in the curriculum in driver's education classes available to both students and their parents.

◆ **Iowa Status.** Dr. Hunsicker noted that the Association of Iowa Hospitals and Health Systems and the Iowa Medical Society are making progress regarding voluntary routine referral, but there is still much to be done. He suggested that the state must increase public awareness of the issue and emphasize that it is an issue that affects virtually everyone.



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Association of Iowa Hospitals and Health Systems.

Mr. Kirk Norris, Senior Vice President and Legal Counsel, Association of Iowa Hospitals and Health Systems, described the perspective of his association relative to organ donation. He noted that the Association had opposed the Senate study bill which would have mandated referrals, based upon the fact that hospitals were already required under federal and state law to have policies and protocols in place relating to organ and tissue donation. Mr. Norris noted that the premise for ISOPO's proposal for mandatory referral was a slight decrease in referrals which could have subjected the organization to decertification. However, since subsequent to that decrease ISOPO was reviewed, met the necessary criteria, and was recertified, the premise became a moot point. Mr. Norris noted that his association is concerned with maximizing organ donation and will continue to work toward that goal. He noted that hospitals will continue to provide support and encouragement to the organ procurement organizations through in-person meetings, mailings, and other sources to increase awareness and referrals. He also stressed that public education and family discussion have as much of an impact as a mandatory referral system would have. Mr. Norris stated that hospitals have varying degrees of success in making referrals, that mandating referrals and increasing paperwork may not achieve this objective, and that using hospitals with high referral rates as models might prove beneficial.

Iowa Medical Society.

Ms. Jeanine Freeman, Vice President of Public Policy and Advocacy, Iowa Medical Society (IMS), presented the Society's position regarding anatomical gift donation and referral. She stated that the current position of the Society is to support cooperative efforts in organ transplantation, including efforts to coordinate national organ procurement and to increase awareness and knowledge of both the public and the medical community about organ donation. She noted that the American Medical Association's position is one which supports mandated choice, but not presumed consent. She shared that the IMS and the Association of Iowa Hospitals and Health Systems have been working together to develop an alternative approach to the mandatory referral legislation proposed in 1995, but have not yet arrived at one. The Iowa Medical Society is supportive of efforts to encourage organ donation and of the work of the Study Committee as a step in reexamining the issue of donation, and places emphasis on the use of cooperative and coordinated initiatives on the part of affected and interested organizations in enhancing organ donation.

Anatomical Gift Public Awareness Advisory Committee.

Dr. Ronald Eckoff, Iowa Department of Public Health, provided an update of the Anatomical Gift Public Awareness and Transplantation Fund and the Advisory Committee. Dr. Eckoff noted that the Fund has been active since January 1997 and that there is currently approximately \$48,000 in the Fund. There are three categories of grants within the grant program: category 1, which provides grants to

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state agencies and nonprofit entities with an interest in anatomical gift public awareness and transplantation; category 2, which provides grants to hospitals for reimbursement of costs directly related to the development of in-hospital anatomical gift public awareness projects, anatomical gift referral protocols, and associated administrative expenses, with the condition that the hospital demonstrate an 80 percent compliance with anatomical gift request protocols for the previous calendar year; and category 3, which provides grants to hospitals which perform transplants, for payment of costs associated with the transplant with the same 80 percent compliance requirement as that for category 2 grants. Dr. Eckoff noted that the deadline for receipt of category 1 grants has recently passed and that these grants will be made by the end of January 1998. The deadline for receipt of category 2 proposals is March 1998, at which time those proposals will be reviewed and grants made. For category 3 grants, the Committee has met with three transplant coordinators and has developed a draft for making these grants. Dr. Eckoff noted that the 80 percent requirement, as suggested by the experts, may be too high for hospitals to meet. He also noted that there have been efforts to increase donations to the Fund through communications with county treasurers and the Department of Transportation.

2. Committee Discussion.

Committee discussion centered on the following key points:

- ◆ The medical community should be provided with more training in organ donation referral, and standards should be developed so that potential donations are not lost.
- ◆ Separation of the roles of hospital personnel is important so that the person approaching the family regarding donation is the appropriate person to make the inquiry. The organ procurement organization has personnel who are available to travel to provide the appropriate personnel for inquiry.
- ◆ Resistance to donation can be overcome if the common purpose is to help the living.
- ◆ At this time legislation for mandatory referral does not appear to be necessary.

3. Recommendation.

The Committee recommended that a bill be developed to require that the Iowa Department of Public Health, in conjunction with the Iowa Statewide Organ Procurement Organization, submit an annual report to the General Assembly on or before January 1 each year regarding organ donation rates and voluntary compliance efforts by physicians, hospitals, and other health systems organizations. The report shall contain an evaluation of the success of organ procurement efforts in the state,



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including statistics regarding organ and tissue donation activity as of September 30 of the preceding year, efforts by the Iowa Statewide Organ Procurement Organization and related parties to increase organ and tissue donation and consent rates, voluntary compliance efforts by physicians, hospitals, and health systems organizations and the results of those efforts, annual contribution levels to the Anatomical Gift Public Awareness and Transplantation Fund, efforts and ideas for increasing public awareness of the option of organ and tissue donation, and any additional information deemed relevant by the Department in assessing the status and progress of organ and tissue donation efforts in the state of Iowa. Additionally, the bill would amend Iowa Code section 142C.15 to modify the threshold protocol compliance rate of 80 percent in order for hospitals to qualify for Anatomical Gift Public Awareness and Transplantation Fund grants. The bill would implement a new compliance requirement that a hospital have achieved a rate in the top 50 percent of compliance with protocols compared with other hospitals to be considered eligible for a grant. The bill draft (LSB 3348IC) is attached and will be submitted to the Seventy-seventh General Assembly, 1998 Session, for consideration as a study bill.

4. Materials Filed With the Legislative Service Bureau.

- ◆ *Organ Transplantation and Donation in the United States*, Committee Presentation, submitted by Dr. Lawrence Hunsicker.
- ◆ *Iowa Statewide Organ Procurement Organization Third Quarter Activity Report*, and *Committee Presentation Outline*, submitted by Ms. Suzanne Conrad.
- ◆ *Association of Iowa Hospitals and Health Systems Presentation*, submitted by Mr. Kirk Norris.

3189ic

SENATE/HOUSE FILE _____
BY (PROPOSED ANATOMICAL GIFT
STUDY COMMITTEE BILL)

Passed Senate, Date _____ Passed House, Date _____
Vote: Ayes _____ Nays _____ Vote: Ayes _____ Nays _____
Approved _____

A BILL FOR

1 An Act relating to anatomical gifts by modifying certain
2 qualification requirements for hospital reimbursement grants
3 and requiring submission of an annual donation and compliance
4 report.

5 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

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1 Section 1. Section 142C.15, subsection 4, paragraphs b and
2 c, Code 1997, are amended to read as follows:

3 b. Not more than thirty percent of the moneys in the fund
4 annually may be expended in the form of grants to hospitals
5 for reimbursement for costs directly related to the
6 development of in-hospital anatomical gift public awareness
7 projects, anatomical gift referral protocols, and associated
8 administrative expenses. As a condition of receiving a grant,
9 a hospital shall demonstrate, through documentation, that the
10 hospital, during the previous calendar year, properly complied
11 with in-hospital anatomical gift request protocols for at
12 ~~least-eighty-percent-of~~ all deaths occurring in the hospital
13 at a percentage rate which places the hospital in the upper
14 fifty percent of all protocol compliance rates for hospitals
15 submitting documentation for cost reimbursement under this
16 section.

17 c. Not more than fifty percent of the moneys in the fund
18 annually may be expended in the form of grants to hospitals
19 which perform heart, lung, liver, pancreas, or kidney
20 transplants. As a condition of receiving a grant, a hospital
21 shall demonstrate, through documentation, that the hospital,
22 during the previous calendar year, properly complied with in-
23 hospital anatomical gift request protocols for ~~at-least-eighty~~
24 ~~percent-of~~ all deaths occurring in the hospital at a
25 percentage rate which places the hospital in the upper fifty
26 percent of all protocol compliance rates for hospitals
27 submitting documentation for cost reimbursement under this
28 section. The hospital shall submit an application on behalf
29 of a patient requiring a transplant in the amount of the costs
30 associated with the following, if funds are not available from
31 any other third-party payor:

- 32 (1) The costs of the organ transplantation procedure.
33 (2) The costs of post-transplantation drug or other
34 therapy.
35 (3) Other transplantation costs including but not limited

1 to food, lodging, and transportation.

2 Sec. 2. NEW SECTION. 142C.17 ANNUAL DONATION AND
3 COMPLIANCE REPORT.

4 The Iowa department of public health, in conjunction with
5 any statewide organ procurement organization in Iowa, shall
6 prepare and submit a report to the general assembly on or
7 before January 1 each year regarding organ donation rates and
8 voluntary compliance efforts with hospital organ and tissue
9 donation protocols by physicians, hospitals, and other health
10 systems organizations. The report shall contain the
11 following:

12 1. An evaluation of organ procurement efforts in the
13 state, including statistics regarding organ and tissue
14 donation activity as of September 30 of the preceding year.

15 2. Efforts by any statewide organ procurement organization
16 in Iowa, and related parties, to increase organ and tissue
17 donation and consent rates.

18 3. Voluntary compliance efforts with hospital organ and
19 tissue donation protocols by physicians, hospitals, and health
20 systems organizations and the results of those efforts.

21 4. Annual contribution levels to the anatomical gift
22 public awareness and transplantation fund created in section
23 142C.15, and any distributions made from the fund.

24 5. Efforts and ideas for increasing public awareness of
25 the option of organ and tissue donation.

26 6. Additional information deemed relevant by the
27 department in assessing the status and progress of organ and
28 tissue donation efforts in the state.

29 EXPLANATION

30 This bill requires the Iowa department of public health, in
31 conjunction with any statewide organ procurement organization,
32 to prepare and submit a report to the general assembly on or
33 before January 1 each year regarding organ donation rates and
34 voluntary compliance efforts with hospital organ and tissue
35 donation protocols by physicians, hospitals, and other health

1 systems organizations. The report is required to contain an
2 evaluation of organ procurement efforts in the state,
3 including statistics regarding organ and tissue donation
4 activity as of September 30 of the preceding year, efforts by
5 any statewide organ procurement organization and related
6 parties to increase organ and tissue donation and consent
7 rates, voluntary compliance efforts with hospital organ and
8 tissue donation protocols by physicians, hospitals, and health
9 systems organizations and the results of those efforts, annual
10 contribution levels to the anatomical gift public awareness
11 and transplantation fund created in Code section 142C.15 and
12 any distributions made from the fund, efforts and ideas for
13 increasing public awareness of the option of organ and tissue
14 donation, and any additional information which is determined
15 to be relevant by the department in assessing the status and
16 progress of organ and tissue donation efforts in the state of
17 Iowa.

18 The bill also provides for a change in the threshold
19 protocol compliance rate in order for hospitals to qualify for
20 anatomical gift public awareness and transplantation fund
21 reimbursement grants pursuant to Code section 142C.15,
22 subsection 4, paragraphs "b" and "c". Currently, hospitals
23 must submit documentation that they are observing organ and
24 tissue donation protocols for at least 80 percent of all
25 patient deaths in that hospital in order to receive grants
26 providing reimbursement for the development and administration
27 of organ donation procedures, and expenses related to
28 performing organ and tissue transplant operations. The bill
29 provides for a new compliance requirement that a hospital has
30 achieved a rate of compliance with organ donation procedure
31 protocols in the top 50 percent of all hospitals submitting
32 documentation to be considered eligible for a reimbursement
33 grant.

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