TESTIMONY OF THE COMMISSION TO PROMOTE UNIFORM LEGISLATION

ON H.B. No. 2139, H.D. 1

RELATING TO ANATOMICAL GIFTS.

BEFORE THE HOUSE COMMITTEE ON JUDICIARY

DATE: Friday, February 22, 2008, at 2:00 p.m.

Conference Room 325, State Capitol

PERSON TESTIFYING: ELIZABETH KENT

Commission to Promote Uniform Legislation

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E-MAIL to JUDtestimony@Capitol.hawaii.gov.

Chair Waters and Members of the House Committee on Judiciary:

My name is Elizabeth Kent and I am one of Hawaii's Uniform Law Commissioners. Hawaii's uniform law commissioners support the passage of House Bill No. 2139. This is a version of the Uniform Anatomical Gifts Act that includes some modifications that address concerns raised by the Organ Donor Center of Hawaii.

Despite significant technological improvements and numerous publicity campaigns over the past several decades, the substantial shortage for organs, tissues, and eyes for life-saving or life-improving transplants continues. This shortage persists despite efforts by the federal government and every state legislature to improve the system. Without changing the basic concept that an individual may execute a document of gift to donate organs, this bill would further improve the system for allocating organs to transplant recipients.

This bill revises and updates the original Uniform Anatomical Gift Act that Hawaii enacted twenty years ago. The scope of the bill is limited to donations from deceased donors as a result of gifts made before or after their deaths.

Similar bills updating the earlier version of the Uniform Anatomical Gift Act have been adopted in approximately 20 states (including California, Utah, and Virginia). This newer version of the Uniform Anatomical Gift Act was endorsed by numerous professional organizations, including the American Academy of Ophthalmology; American Association of Tissue Banks; American Medical Association; and the Association of Organ Procurement Organizations. Attached is a brief summary of the Revised Uniform Anatomical Gift Act for your information.

We urge your support of this bill.



SUMMARY

Uniform Anatomical Gift Act (2006)

Every hour another person dies waiting for an organ transplant. Despite significant technological improvements and numerous publicity campaigns over the past several decades, the substantial shortage for organs, tissues and eyes for life-saving or life-improving transplants continues. This shortage persists despite efforts by the federal government and every state legislature to improve the system. The Uniform Law Commission (ULC) continues to be a leader in developing the law in the organ transplant arena, and it has promulgated the **Uniform Anatomical Gift Act** (2006) (UAGA) to further improve the system for allocating organs to transplant recipients.

The original Uniform Anatomical Gift Act was promulgated in 1968, shortly after Dr. Christian Barnard's successful transplant of a heart in November 1967. It was promptly and uniformly enacted in every jurisdiction. The 1968 UAGA created the power, not yet recognized at common law, to donate organs, eyes and tissue, in an immediate gift to a known donee or to any donee that might need an organ to survive. In 1987, the ULC revised the 1968 UAGA to address changes in circumstances and in practice. Only 26 states enacted the 1987 UAGA, resulting in non-uniformity between those states and the states that retained the 1968 version. Subsequent changes in each state over the years have resulted in even less uniformity. In addition, neither the 1968 nor the 1987 UAGA recognizes the system of organ procurement that has developed partly under federal law. The 2006 UAGA is an effort to resolve any perceived inconsistencies thereby adding to the efficiency of the current system.

The scope of the 2006 UAGA is limited to donations from deceased donors as a result of gifts made before or after their deaths. Organ donation is a purely voluntary decision that must be clearly conveyed before an individual's organs are available for transplant.

The current mechanism for donating organs is a document of gift that an individual executes before death. The 2006 Act further simplifies the document of gift and accommodates the forms commonly found on the backs of driver's licenses in the United States. It also strengthens the power of an individual not to donate his or her parts by permitting the individual to sign a refusal that also bars others from making a gift of the individual's parts after the individual's death. Importantly, the 2006 UAGA strengthens prior language barring others from attempting to override an individual's decision to make or refuse to make an anatomical gift.

If an individual does not prepare a document of gift, organs may still be donated by those close to the individual. Another achievement of the 2006 UAGA is that it allows certain individuals to make an anatomical gift for another individual during that individual's lifetime. Health-care agents under a health-care power of attorney and, under certain circumstances, parents or a guardian, have this power. The donor must be incapacitated and the permission giver has to be the individual in charge of making health-care decisions during the donor's life. Second, the 2006 UAGA adds several new classes of persons to the list of those who may make an anatomical gift for another individual after that individual's death. The adoption of clear rules and procedures, combined with the definition of "reasonably available," provide clarity to the decision-making process. If more than one member of a class is reasonably available, the donation is made only if a majority of members support the donation. Minors, if eligible under other law to apply for a driver's license, are empowered to be a donor. These seemingly minor changes will provide more opportunities for donation than currently exist today.

The 2006 UAGA encourages and establishes standards for donor registries and better enables procurement organizations to gain access to documents of gift in donor registries, medical records, and records of a state motor vehicle department. This access will make it much easier for procurement organizations to quickly determine whether an individual is a donor. And, under Section 8 of the 2006 UAGA, which strengthens the language regarding the finality of a donor's anatomical gift, there is no reason to seek consent from the donor's family because the family has no legal right to revoke the gift. The practice of procurement organizations seeking affirmation even when the donor has clearly made a gift results in unnecessary delays in procuring organs and the occasional reversal of the donor's wishes. One exception is if the donor is a minor and the parents wish to revoke the gift. The 2006 UAGA acknowledges that the decision to donate organs, tissues and eyes is highly personal and deserves respect from the law.

The tension between a health-care directive requesting the withholding or withdrawal of life-support systems and a donor's wish to make an anatomical gift is resolved by permitting, prior to the removal of life-support systems, the administration of measures necessary to ensure the medical suitability of the donor's organs.

The 2006 UAGA provides that a general direction in a power of attorney or health-care directive that the patient does not wish to have life prolonged by the administration of life-support systems should not be construed as a refusal to donate. The 2006 UAGA provides numerous default rules for interpreting a document of gift if it lacks specificity regarding the persons to receive the gift or the purposes of the gift. One important rule, not present in the prior acts, is the prioritization of transplantation or therapy over research or education, when a document of gift sets forth all four purposes but fails to establish a priority.

Another improvement that the 2006 UAGA achieves is the clarification and expansion of rules relating to cooperation and coordination between procurement organizations on the one hand and coroners and medical examiners on the other. Unlike prior law, the 2006 UAGA prohibits coroners and medical examiners from making anatomical gifts except in the rare instance when the coroner or medical examiner is the person with the authority to dispose of the decedent's body. The 2006 UAGA complies with the policy guidelines articulated by the National Association of Medical Examiners.

The 2006 UAGA also addresses widely reported abuses involving the intentional falsification of a document of gift or refusal, to obtain a financial gain by selling a decedent's parts to a research institution. A person who falsifies a document of gift for such a purpose is guilty of a felony. Alternatively, the 2006 UAGA provides that a person acting in accordance with the act or with the applicable anatomical gift law of another state, or that attempts to do so in good faith, is not liable for his or her actions in a civil action, criminal prosecution or administrative proceeding.

Finally, the last section provides for repeal of the prior UAGA, whether it is the 1968 or 1987 version. Many states, however, have related laws on anatomical gifts that should be retained, such as donor awareness programs, Transplant Councils, and licensing provisions for procurement organizations and health care providers. However, it is highly desirable that the core provisions of the 2006 UAGA be uniform among the states. Little time is available to prepare, transport across state lines, and transplant life-saving organs, let alone to assess and comply with significant variations in state law.

The anatomical gift law of the states is no longer uniform, and diversity of law is an impediment to transplantation. Harmonious law through every state's enactment of the 2006 UAGA will help save and improve lives. It should be enacted in every state as quickly as possible.



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To:

Chair Tommy Waters

Vice-Chair Blake K. Oshiro

Members of the Committee on Judiciary

From: Rachael S. Wong, MPH

Executive Director

Date & Time of Hearing:

2:00 PM, Friday, February 22, 2008

State Capitol, Room 325

Testimony in support of HB2139 Relating to Anatomical Gifts

Kōkua Mau, our statewide hospice and palliative organization, supports HB2139, HD1. One of our core mission activities is to improve the quality of life for people living in Hawai'i by promoting excellence in advance care planning. The new language in Section 327U proposed by the Organ Donor Center of Hawaii adequately addresses our previous concerns about how advance directives and end-of-life care decisions will be made regarding potential donors.

Kōkua Mau supports all efforts to improve the quality of care for individuals and their families at the end of life, and this includes the reduction of confusion and unnecessary grief at the bedside of a loved one. We appreciate working with the local organ and tissue donation community to provide quality end-of-life care for individuals (including donors) and families in Hawai'i through the improvement of policy and clinical practice.

Sincerely,

Executive Director



February 20, 2008

Representative Tommy Waters, Chair Representative Blake K. Oshiro, Vice-Chair Committee on Judiciary Hawaii State Capitol Conference Room 325 Honolulu, Hawaii 96813

RE: H.B. No. 2139 - Enacts the Revised Uniform Anatomical Act

Dear Chairman Waters and Vice-Chair Oshiro and members of the State House Judiciary Committee,

I am Glen Hayashida, CEO, National Kidney Foundation of Hawaii (NKFH) and member of the Hawaii Coalition on Donation. Thank you for the opportunity to give testimony in support of HB 2139 with the proposed amendment to Section 327 – U as submitted by the Organ Donor Center of Hawaii.

The original Uniform Act was adopted in 1968, to provide standard methods to make organ, eye, and tissue donations after death for the purposes of transplantation, therapy, research, or education. In 1987, some 26 states adopted a new version of UAGA; however, because the other states did not adopt the changes, the Act was no longer considered uniform. The National Commissioners on Uniform State Laws developed the proposed UAGA in an effort to resolve any inconsistencies between the states, the eby making the system more effective.

The 2006 Uniform Anatomical Gift Act (2006) attempts to resolve many issue that have been concerns under current law.

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- Insures that individual choice regarding organ donation will be respected by barring persons from amending or revoking the anatomical bill;
- Allows for an individual to refuse to make an anatomical gift;
- Facilitates cooperation between coroners and medical examiners;
- Permits emancipated minors and minors eligible to apply for driver's licenses to make an anatomical gift. If an emancipated minor does before the age of 18; the parent or guardian would be permitted to revoke the gift;
- Expands those who are permitted to make an anatomical gift on behalf of others; and
- Expands methods for making an anatomical gift, i.e. donor registries, state identification cards, donor cards, and driver's licenses, and also allows for oral gifts.

However, it must be pointed out that there is tension between a health-care directive requesting the withholding or withdrawal of life-support systems and a donor's wish to make an anatomical gift. UAGA resolves this tension by permitting, prior to the removal of life-support systems, the administration of measures necessary to ensure the medical suitability of the donor's organs. The 2006 UAGA provides that a general direction in a power of attorney or health-care directive that the patient does not wish to have life pholonged by the administration of life-support systems should not be construed as a refunctionate.

The Revised UAGA (2006) poses challenges to the Patient Self Defermination Act (PSDA) embodied in advance health care directives and individual expression about the use of life support systems at the end-of-life. The

P.O. Box 10009 • Honolulu, iH-96414 Phone: (808) 737-1719 • Fax: (808) 737-1733 • www.sangatelite rawaii.org challenges are predicated on the UAGA revising the default choice to presumption of donation intent and the use of life support systems to ensure medical suitability of organs for transplantation. The default choice is given preference over the expressed intent in an individual's advance health care directive to withhold and/or withdraw life support systems at the end-of-life.

Due to this and other similar objections, meetings have been held to address this issue. Acceptable language has been developed as an amendment submitted by the Organ Donor Center of Hawaii. With this change in language to Section 327 – U, we support HB 2139 because this bill will save lives.



ID: REP WATERS



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HOUSE OF REPRESENTATIVES THE TWENTY-FOURTH LEGISLATURE REGULAR SESSION OF 2008 COMMITTEE ON JUDICIARY

Friday, February 22, 2008 2:00 PM Room 325, State Capitol

Testimony in SUPPORT of HB2139, HD1

By

Stephen A. Kula, Ph.D., NHA Executive Director, Organ Donor Center of Hawaii

My name is Steve Kula; I am the Executive Director of the Organ Donor Center of Hawaii. I am here to give testimony in support of HB2139, HD1. This bill, if enacted, would make conforming changes to Chapter 327 Hawaii Revised Statutes. The Uniform Anatomical Gift Act ("UAGA") law among the various states is no longer uniform and harmonious, and the diversity of law is an impediment to transplantation. Recent technological innovations have increased the types of organs that can be transplanted, the demand for organs, and the range of individuals who can donate or receive an organ, thereby increasing the numbers of organs available each year and the number of transplantations that occur each year. Nonetheless, the number of deaths for lack of available organs also has increased.

Transplantation occurs across state boundaries and requires speed and efficiency. Thus, uniformity of state law is highly desirable. Furthermore, the decision to be a donor is a highly personal decision of great generosity and deserves the highest respect from the law. Because current state anatomical gift laws are out of harmony with both federal procurement and allocation policies and do not fully respect the autonomy interests of donors, there is a need to harmonize state law with federal policy as well as to improve the manner in which anatomical gifts can be made and respected.

Throughout the hearing process there has been discussion and controversy on and about Section 327-T of the Bill. The Organ Procurement and Transplant community, as well as other groups affiliated with organ recovery and transplant have gotten together and have agreed that this section needs to be revised and clarified. So we offer the attached proposed amendment to Section 327-T for your consideration.

We know that these changes to the UAGA can not fully supply the need for organs, but any change that could increase the supply of organs and thus save lives is an improvement.

ATTACHMENT

§327-T Effect of anatomical gift on advance health-care directive. (a) As used in this section: "Advance health-care directive" means a record signed or authorized by a prospective donor containing the prospective donor's direction concerning a health-care decision for the prospective donor or a power of attorney for health care.

"Declaration" means a record signed by a prospective donor specifying the circumstances under which a life support system may be withheld or withdrawn.

"Health-care decision" means any decision made regarding the health care of the prospective donor. (b) If a prospective donor has a declaration or advance health-care directive, and the terms of the declaration or directive and the express or implied terms of a potential anatomical gift are in conflict with regard to the administration of unless it expressly provides to the contrary, measures necessary to insure the medical suitability of an organ a part for transplantation or therapy may not be withheld or withdrawn from the prospective donor, the prospective donor's attending physician and prospective donor shall confer to resolve the conflict. If the prospective donor is incapable of resolving the conflict, an agent acting under the prospective donor's declaration or directive, or, if none or the agent is not reasonably available, another person authorized by law other than this [act] to make health-care decisions on behalf of the prospective donor, shall act for the donor to resolve the conflict. The conflict must be resolved as expeditiously as possible. Information relevant to the resolution of the conflict may be obtained from the appropriate procurement organization and any other person authorized to make an anatomical gift for the prospective donor under Section 327-H. Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn from the prospective donor if withholding or withdrawing the measures is not contraindicated by appropriate end-of-life care.

TESTIMONY IN SUPPORT OF HB 2139

I support HB 2139, relating to anatomical gifts, because this bill will revise and update the process for organ donations for transplantation. Moreover, this will help to establish Uniform Legislation on organ donation.

Edgar Fernandez Resident of Hawaii

TESTIMONY IN SUPPORT OF HB 2139

I support HB 2139, RELATING TO ANATOMICAL GIFTS, as this measure will help to establish a priority list of persons who are reasonably available who may make an anatomical gift of a deceases person's body or part and this bill will update the process for organ donations for transplantation.

Dr. Leolani Oyama Private Citizen and Resident of Hawaii