TESTIMONY OF THE
COMMISSION TO PROMOTE UNIFORM LEGISLATION

ON H.B. No. 2139, H.D. 2
RELATING TO ANATOMICAL GIFTS.

BEFORE THE SENATE COMMITTEE ON JUDICIARY AND LABOR

DATE: Tuesday, March 25, 2008, at 9:45 a.m.
Conference Room 016, State Capitol

PERSON TESTIFYING: WRITTEN TESTIMONY ONLY
(For further information, please contact Elizabeth Kent of the Commission to Promote Uniform Legislation at 539-4237.)

C:/cpuleg.ANATOMICAL GIFTS.tes.3/25/08 E-MAIL to testimony@capitol.hawaii.gov.

Chair Taniguchi and Members of the Senate Committee on Judiciary and Labor:

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.

Uniform Law Commissioners
The National Conference of Commissioners on Uniform State Laws

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.

March 21, 2008

Senator Brian T. Taniguchi, Chair
Senator Clayton Hee, Vice-Chair
Committee on Judiciary and Labor
Hawaii State Capitol
Conference Room 016
Honolulu, Hawaii 96813

RE: H.B. No. 2139, HD2 – Enacts the Revised Uniform Anatomical Act

Dear Chairman Taniguchi and Vice-Chair Hee and members of the State Senate Judiciary and Labor 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, HD2.

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, thereby making the system more effective.

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

- 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.

These proposed changes will not only help clarify current language but help increase the number of anatomical gifts and save additional lives. We strongly support the passage of HB 2139. HD2.

Organ Donor Center
of Hawaii

1149 Bethel Street, Suite 801 • Honolulu, HI 96813

THE SENATE
THE TWENTY-FOURTH LEGISLATURE
REGULAR SESSION OF 2008
COMMITTEE ON JUDICIARY AND LABOR
Tuesday, March 25, 2008
9:45 AM Room 016, State Capitol

Comments in STRONG SUPPORT of HB2139, HD2

By

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

My name is Dr. Steve Kula; I am the Executive Director of the Organ Donor Center of Hawaii. I am here to give comments in **STRONG SUPPORT of HB2139, HD2**. 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.

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.

Thank you for your consideration.

THE QUEEN'S MEDICAL CENTER

1301 Punchbowl Street • Honolulu, Hawaii 96813 • Phone (808) 538-9011 • Fax: (808) 547-4646

SENATE COMMITTEE ON JUDICIARY AND LABOR
Senator Brian T. Taniguchi, Chair
Senator Clayton Hee, Vice Chair

Tuesday, March 25, 2008 – 9:45 a.m.
State Capitol, Conference Room 016
Deliver to: Room 219, 1 copy

Comments on HB 2139 HD2, Relating to Anatomical Gifts

Chair Taniguchi, Vice Chair Hee, and Members of the Committee:

The Queen's Medical Center offers the following comments and recommendations on House Bill 2139 HD2, which enacts the Revised Anatomical Gift Act. While we support the organ donation system and appreciate the benefits it provides to transplant recipients, we are concerned with sections §327-N (c) and §327-U 9(b) of HB 2139 HD2 and the potential unintended impact they may have on patients' rights to appropriate end-of-life care.

1. §327-N (c) Rights and duties of procurement organization and others.

   Proposed language in HB 2139 HD2 (emphasis added) provides that:

   "When a hospital refers an individual at or near death to a procurement organization, the organization may conduct any reasonable examination necessary. . . **During the examination period, measures necessary to ensure the medical suitability of the part may not be withdrawn unless the hospital or procurement organization knows that the individual expressed a contrary intent.** "

   Currently in Hawaii, patients who meet the criteria for prospective organ donation often have not completed health care-related declarations or advance health care directives. In addition, in cases involving incapacitated patients, the person may not have otherwise expressed his wishes concerning health care to anyone, the preferences may be ambiguous or there may be no readily available interested parties who have any personal knowledge of the patient's desires. Accordingly, physicians and hospital staff cannot clearly ascertain the prospective donor's intent.

   Therefore, it is of concern that, pursuant to §327-N (c), staff may not be permitted to withdraw life support measures, although medically indicated, in such situations where wishes are unknown because organ preservation, rather than the individual's best interest, becomes paramount. Such an imposition on the long-held tenets of the physician-patient relationship and the essentially therapeutic mission of the hospital can create an insurmountable burden for the attending physician and hospital staff who see their duty to use best medical judgment as solely for the benefit of the patient, not a prospective organ recipient. This is compounded by the fact that such life support measures may be considered highly intrusive and uncomfortable for the terminally ill individual.

In addition, hospitals and attending physicians are required to comply with certain regulatory requirements and accreditation standards that mandate that all hospitalized patients receive the same standard of care and that medical care be directed by the organized medical staff. Further, some third party payer contracts have certain requirements concerning medical and hospital care that may, for example, involve conflicting medical necessity standards as a basis for determining reimbursement and evaluating quality of care.

Accordingly, we respectfully request that the language in the bill be amended (as underlined below) in the following manner so that the attending physician retains discretion in determining what medical treatment will be provided to the prospective organ donor prior to any organ procurement procedure and that third-party payers are prohibited from denying reimbursement for services provided pursuant to this section.

a. "During the examination period, measures necessary to ensure the medical suitability of the part may not be withdrawn unless the hospital or procurement organization knows that the individual expressed a contrary intent or the attending physician has determined that continuing these measures would not be consistent with generally accepted standards of care for terminally ill individuals."

b. Health and disability insurers, mutual benefit societies and health maintenance organizations licensed by this state may not deny payment on the basis of a lack of medical necessity for physician or hospital services rendered pursuant to and in compliance with this section.

We also request that there be further review to identify and reconcile any conflicting federal regulatory requirements and accreditation standards concerning the provision of end-of-life care, the medical decision-making process and limitations of reimbursement to services that are, under existing standards, considered medically necessary for the individual patient.

2. §327-U 9(b) Effect of anatomical gift on advance health care directive.

Proposed language in HB 2139 HD2 (emphasis added) provides that:

"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 measures necessary to insure the medical suitability of a part for transplantation or therapy, (then there will be an attempt by the attending physician and donor or donor's representative as expeditiously as possible) to resolve the conflict. **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.**"

The concern here relates to putting the attending physician in a position in which the patients' wishes as to healthcare treatment, as expressed in legal documents such as advance directives, are apparently subordinated to the organ procurement process. This

raises ethical concerns concerning the duty of the physician to act in the patient's best interest and in compliance with the patient's wishes.

Accordingly, we respectfully request that the language be amended (as underlined below) in the following manner so that it is very clear that the attending physician directs medical treatment, consistent with standards, for his or her patient:

> "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. <u>The decision as to whether such measures will be withheld or withdrawn is solely that of the attending physician and shall be consistent with generally accepted standards of care."</u>

In addition, as the bill provides that the terms of an advance directive can be lawfully suspended where organ procurement is an option, it would appear that patients should be informed about this as it materially affects their right of self-determination and involves potentially intrusive and uncomfortable measures. We recommend that the process for this disclosure be addressed in the bill. Further, should the patients or their families want to donate organs, the terms of the advance directive might have to be suspended in unpredictable ways. This may have the unintended consequence of diminishing the general willingness to make organs available and should be considered in the context of this proposed legislation.

We respectfully request your consideration of our concerns and recommendations with sections §327-N (c) and §327-U 9(b) of HB 2139 HD2.

Thank you for this opportunity to testify.

Cindy Kamikawa, RN, MS, CNA
Vice President of Nursing, Chief Nursing Officer, The Queen's Medical Center

Robin Fried, JD
Director of Risk Management, The Queen's Medical Center

Cherylee Chang, MD
Medical Director, The Queen's Medical Center Neuroscience Institute/Neurocritical Care

Kristine O'Phelan, MD
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Assistant Professor of Medicine, U.H. John A. Burns School of Medicine