

# **HEART AND SOUL: ANATOMICAL GIFTS FOR HAWAII'S TRANSPLANT COMMUNITY**

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## **FOREWORD**

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## EXECUTIVE SUMMARY

House Resolution No. 16 asked the Legislative Reference Bureau to study ways to encourage and facilitate organ donation in Hawaii. This report is submitted in response to that request. The focus of this report is on the donation of solid organs (*i.e.* heart, lung, liver, kidney), although it is recognized that there is also a great need for tissue, bone, eyes, and other parts that can help to improve the quality of patients' lives. Further, this report concentrates on donations from cadaveric (*i.e.* dead) donors rather than the donations made by live donors for liver and kidney recipients, because it is believed that a greater supply can be generated from cadavers.

### **Demand For Organs**

There are between 170 and 200 people on the transplant waiting list in Hawaii. The number of patients on a transplant waiting list can be expected to increase as advances in medical technology make transplantation a more common life-saving option. Adding to the demand side of the equation are unhealthy lifestyle habits that contribute to such illnesses as diabetes, a leading cause of kidney failure, a high fat diet, alcohol consumption, and sedentary lifestyles that contribute to liver and heart disease.

### **The Supply Of Donors**

According to the Organ Donor Center of Hawaii (ODCH), the number of cadaveric donors has hovered around 12 to 15 every year since 1987. Each donor might contribute a heart, lungs, kidneys, liver, and pancreas, besides bone, tissue, and eyes. The ODCH is one of 63 certified organ procurement organizations (OPOs) in the United States that is responsible for coordinating the donation process between hospitals, donors, and donees. Hawaii's figures for 1997 show donation of 25 tissues and 66 corneas, plus 18 solid organ donors. For the first six months of 1998, out of about 4,000 deaths there were only six donors of solid organs. In comparison with other organ procurement organizations in the nation, Hawaii ranks near the bottom.

### **How Many Donors Can This State Expect Out Of 8,000 Deaths In A Year?**

It is estimated that out of 8,000 deaths annually in Hawaii, only about 100 donors would provide solid organs suitable for transplantation. Thus, even under ideal conditions, obtaining 100 donors out of 8,000 deaths would not supply in a single year all the solid organs needed by the 170 to 200 patients in Hawaii who currently are waiting for an organ. Many factors work to reduce the supply of possible donors. The first of these include the OPO and medical community's important standards for assuring viable, healthy organs for transplantation. This means that a certain portion of organs from the dead are not going to be acceptable because of a

variety of factors, such as hepatitis, AIDS, age (usually persons over 70 years old), certain cancers which can affect organ suitability, and the fact that the donor must die in a hospital in order to properly preserve the vitality of solid organs. The continuing low rate of donation may be partly the result of advances in medical science that have extended life expectancies, as well as some public policies implemented over the past few decades that have reduced the number of deaths that could have contributed a donor organ. These public policies include requiring helmets for motorcyclists and seatbelt use for drivers and passengers, expansion of home and hospice care for the dying, lower speed limits, and so on. There is even the probability that advances in medical care for trauma cases enables lives to be saved that would not have been possible in the past.

### **Consent And The Uniform Anatomical Gifts Act**

In many states, as well as in Hawaii, the thirty-year-old Uniform Anatomical Gifts Act (UAGA)<sup>1</sup> provides the legal mechanism for donating organs. In 1986, when the UAGA was last revised, it was expected that its adoption would facilitate organ donation by, among other things, defining when death has occurred, specifying how donation can be accomplished by an adult or a person's next of kin, indicating willingness to become a donor on a driver's license, requiring hospitals to develop organ donation protocols to encourage and standardize the making of a request for organs, limiting the criminal and civil liability of physicians involved in the transplantation process, and prohibiting the sale of organs.

Because organ donation rates have remained nearly static instead of increasing over the past decade, it has been argued that the UAGA has failed to meet its objectives. However, it must also be recognized that while the donation rates have remained static, the number of waiting transplant recipients has been increasing for a variety of reasons. This phenomenon is true for Hawaii and the country as a whole and means that creatively and aggressively obtaining consent is going to remain the most important factor in increasing organ donations. Consent involves several participants: the donor (or family member) who must grant consent, the hospital and its professional staff who are the first to identify the potentially suitable donors, and the OPO, which (among other things) asks for consent from the donor or family.

One observation made in many states is that despite a provision that allows for organ retrieval without the consent of another person if a document of gift exists,<sup>2</sup> it is customary for hospitals to still obtain a relative's consent. The reason for obtaining this consent is partly historical custom that developed over the years when transplantation was an uncommon medical procedure and the historical practice of relatives having control over the disposition of the deceased's body. This practice continues because understandably, doctors and hospital personnel are reluctant to appear callous and inconsiderate of family feelings at the time of a relative's death by proceeding with organ retrieval (despite the existence of a document of gift).

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<sup>1</sup> *Hawaii Rev. Stat.*, chapter 327.

<sup>2</sup> Under section 327-2(h), *Hawaii Rev. Stat.*, an anatomical gift that is not revoked by the donor before death is irrevocable and does not require the consent or concurrence of any person after the donor's death.



Unfortunately, this action effectively sabotages the donor's wishes when the relative overrules the donation.

Perhaps the most serious sabotage that is occurring in the organ donation process is the custom of not retrieving organs when there is a document of gift extant and consent cannot be obtained from next of kin because they cannot be located or because there are no surviving relatives to give consent. Texas is the only state that has addressed this issue by allowing the retrieval of organs if a person's relatives cannot be located within four hours of death. The mere existence of a law, however, still does not guarantee that the medical staff will change their customary practices.

The withholding of consent to donate on the part of family members can be due to many factors, including: (1) not being informed that organs from the dead can be used by living patients, (2) never being asked to donate, (3) being misinformed about religious beliefs regarding organ transplantation, and so on. For the immediately needy, this means making certain that every potential donor in a hospital is asked and the opportunity for obtaining organs is not missed. This is what "routine request" system established by the UAGA was supposed to address but apparently has not. The UAGA provides for the establishment of hospital protocols for routinely asking patients if they are an organ donor and requires that the hospital (through its doctors and other medical personnel) report deaths of suitable organ donors to the local OPO.<sup>3</sup> The continuing low rate of donation may indicate that many potential donors are not being identified or not being offered the opportunity to donate. Alternatively, if asked, the family member may not be asked in a manner that promotes donation, or emotional, intellectual, religious, or other blocks prevent the person from giving consent.

From every review of the donation process, the key appears to be making it easier to obtain consent, either from the adult person before death or from the next of kin. What can be done to increase the chances of obtaining consent from people dying or soon to die? The answers lie in education and asking.

### **Routine Request And The UAGA**

It is important to ask the dying, because these people can immediately help those on the waiting list. The routine request system under Hawaii's UAGA began with a pilot routine request procedure in 1994 which expanded statewide in 1995. Under this procedure, there are now seventeen acute care hospitals in Hawaii which have been cooperating with the ODCH to routinely report suitable organ donor candidates. When a potential donor is identified, the ODCH sends a nurse to the hospital who has been trained in the technique of requesting organs in a sensitive and caring manner and also reviews medical records and maintains the donor in preparation for organ retrieval and transplantation. The ODCH also functions as an educational resource to train hospital personnel and raise awareness of the public in general. It would appear that the ODCH is working with the law and attempting to accomplish its mission using every available means to do so. Yet, when the donation data for Hawaii is contrasted with other

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<sup>3</sup> *Hawaii Rev. Stat.*, section 327-5.

jurisdictions and against the number of patients on the transplant waiting list, the donation rate is clearly lower than desirable.

Instead of the routine request procedure now in place, a more direct approach referred to as “required request” may be necessary. Under this system, every death would be reported by a hospital to the OPO. Determination of donor suitability is not left to the discretion of the doctor, but is made after the OPO has had an opportunity to ask, and to evaluate the donor.

### **Education To Obtain Consent In The Future**

After meeting the demand of those on the waiting list, it is hoped that educating the public will facilitate obtaining consent in the future when the opportunity arises. Most organ donation awareness projects like National Organ Donor Sabbath in November and National Donor Recognition ceremonies and the Transplant Games, which are held in August, help to raise public consciousness about the need for organs and the value of giving. Many states have developed programs to educate the public, racial and ethnic minorities, and children about organ and tissue donation and have sought to increase the numbers of their drivers who indicate a willingness to donate their organs upon death. Of course, until a promise to donate translates into an actual death and a donation, these numbers represent only a pool of potential donors.

### **Recommendations**

Since obtaining consent is the crux of the problem with organ donation, the Bureau recommends a two-pronged approach, first to help immediately those individuals on the transplant waiting list and the second, to increase the chances in the future that upcoming generations of donors will be willing to donate their organs or the organs of their close relative upon death. In the first case it is important to ask everyone who is dying or about to die, to consider the option of donation. This can be accomplished through the “required request” process that requires hospitals to report every death to the local OPO. There are about eight states that have adopted this procedure and the federal government has recently adopted a regulation to accomplish the same thing for hospitals participating in Medicare and Medicaid reimbursement.

Requiring hospitals to report every death removes discretion over reporting from the health care professional and gives the OPO the opportunity to use trained designated requesters to ask the donor or family for donation of organs and to evaluate the patient for suitability. Even if a prospective donor is found to be unsuitable for solid organ donation, there may be tissue, cornea, or other parts that could be donated. In addition to a required request by a trained, designated requester, additional provisions in the law would require annual death record reviews and sanctions in the form of fines. This means that there will be an analysis of the deaths that produced donations and those that did not and changes in methodology can be suggested for future donation requests. Fines could assure a level of compliance that does not exist under the UAGA. Having a required request program eliminates the need for a state registry of donors, as some states have developed from driver licensing lists, because every death must be reported and

an effort is made to ask for a donation in every case, absent obvious contravening factors, such as infectious disease or over age. This effort should help those most in need--the patients waiting for an organ for immediate transplant.

For the long term, public policy input in education and awareness programs appears to have the most beneficial effects. For example, authorizing a high level government official to take charge of educational awareness programs would bring the problem to the attention of the public on a larger scale quickly and effectively. Creating an advisory committee would also bring together the different participants in the organ donation program to help identify areas that can benefit from special targeting efforts such as concentrating on minorities, children, religious groups, and the like. Establishing a funding source through voluntary contributions, or a small fee similar to the \$1 highway beautification fee that is added onto and collected with each motor vehicle registration, could generate a funding base to pay for educational and awareness projects.

Providing for other financial benefits to organ donors, such as reducing vehicle registration or driver license fees, tax deductions, or a small payment to a service provider, including a funeral fund could also be considered, but these measures would indicate a movement away from the purely altruistic history of organ donation.

Ultimately, despite every effort to increase organ donations, it may be necessary in Hawaii to accept the fact that in the near future the supply of organs will not reach equilibrium with the demand. Demand increases because medical technology can extend waiting time even for a deteriorating organ through such processes as dialysis, and more patients may lose function of their vital organs from unhealthy lifestyles that result in diseased organs. Furthermore, increasing the supply of organs (even if every suitable donor were identified and consented) could not guarantee a perfect match for every waiting patient. At best, it is hoped that by increasing donation rates, fewer people will die waiting and over time, more recipients will receive their needed organ.

The good news is that the societal interest in organ donations seems to have skyrocketed recently. Coverage in newspapers, magazines, and television has increased. This may therefore be an opportune time for the State to introduce new initiatives in organ donation and transplantation programs because public sensitivity to this issue has been raised.

# Chapter 1

## INTRODUCTION

### **Wanted: Life From Death**

The main purpose of this study is to suggest ways to encourage and facilitate organ donation in Hawaii in order to increase the supply of organs needed by two hundred or so persons on the State's organ transplant waiting list. The goal of this report is to provide the legislature with specific actions that the State might take so that the supply of organs comes as close as possible to demand for organs. While the primary focus of this study examines the need for solid organs (such as hearts, livers, kidneys, lungs) and obtaining these organs from cadaveric (i.e. dead) donors, the need exists also for donors' tissue, bone, corneas, and other parts that can enhance as well as lengthen life.

The report consists of five chapters as follows:

Chapter 1 Introduction to the report.

Chapter 2 Organ donations in Hawaii. This chapter describes Hawaii's need for organ donors and provisions of the Hawaii's Uniform Anatomical Gift Act and the federal system established under the National Organ Transplant Act (NOTA).

Chapter 3 Reasons for low rate of donations. This chapter describes the reasons for the low rate of donations, beginning with a description of the 1993 Gallup survey report results. This survey describes how the nation in general feels about organ donation. This chapter continues with a discussion of the primary reasons for low donation rates in the nation and in Hawaii.

Chapter 4 How to increase organ donation rates. This chapter describes different examples from other jurisdictions which are believed to help increase the number of organ donations in a jurisdiction.

Chapter 5 Analysis and recommendations.

## Chapter 2

### ORGAN DONATIONS IN HAWAII

This chapter describes the organ donation statistics for Hawaii; a general description of the legislative background for organ transplantation in Hawaii; and provides a brief explanation of how the organ donation process works in this State under Hawaii's Uniform Anatomical Gift Act.<sup>1</sup>

#### Organ Donation Statistics in Hawaii

##### How Many People Are Waiting For Organs In Hawaii?

###### Exhibit 2-1

###### WAITLIST CHART JANUARY 1998

<b>Ethnicity</b>	<b>Heart</b>	<b>Liver</b>	<b>Kidney</b>	<b>Pancreas</b>	<b>Total</b>
Filipino			43		43
Japanese		3	32		35
Chinese			13		13
Caucasian		3	11		14
Hawaiian			9		9
Samoan			4		4
Korean		1	4		5
Black			2		2
Portuguese			2		2
Hispanic		1			1
Hawaiian Japanese			2		2
Hawaiian Filipino			3		3
Others			1		1
Mixed			33		33
<b>Total</b>	<b>0</b>	<b>8</b>	<b>159</b>	<b>0</b>	<b>167</b>

Source: Organ Donor Center of Hawaii.

An examination of these figures for early 1998 presents an overall picture of the organ transplant needs in this State. As of January 1998, there were a total of 167 people on the waiting list for organs, waiting primarily for kidneys. After kidneys, the next highest need is for livers.

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<sup>1</sup> *Hawaii Rev. Stat.*, chapter 327.

The ethnic group with the greatest need is the Filipino group, followed by the Japanese, Mixed, Caucasian, and Chinese. Ethnicity in Exhibit 1 is self-described. The importance of ethnicity is that the best chance of obtaining a good organ donation match is increased if the donor is the same ethnic group.

### **How Many Donors Were There During The Same Period?**

In contrast to the demand, only six persons of the 4,000 or so persons who died in Hawaii during January to June 1998 became organ donors. This means only 0.15 of one percent of the total deaths in the State for the first six months of 1998 became donors. Since each donor could have donated a maximum number of six solid organs (two kidneys, one heart, one liver, one pancreas, lungs), the six donors offered the chance for a new life to a maximum of 36 recipients.

In 1997, of the approximately 8,000 deaths in the State of Hawaii, only 18 persons were donors (0.225 of one percent). During this period, January 1997 to January 1998, there were 41 transplant recipients. This number includes donations from living donors and so is probably higher than it would have been if only cadaveric donations were counted. Cadaveric means donations from dead donors, as opposed to donations from a living relative.

It is impossible to estimate the number of useful organs that could be generated from the total number of deaths in a jurisdiction. According to one article, only one percent of deaths might yield usable organs.<sup>2</sup> Still, for Hawaii, a one percent rate of donation for the first six months would have resulted in 40 donors instead of six, and in 1997, one percent would have meant 80 donors, a definite improvement to reaching the objective. It is evident that a great shortage of organs exists, but this shortage could be significantly reduced with only a small percentage increase of donors. The Organ Donor Center of Hawaii estimates that of about 8,000 deaths occurring annually in this State, 100 would be suitable organ donor candidates. This figure represents about 1.25 percent of the deaths, which is very similar to the one percent cited in technical reports. Several factors affect donor suitability, including whether the death occurred in or outside a hospital, because the viability of an organ must be maintained for successful transplantation. Age may be a factor, but the average age of a donor has been increasing as medical technology improves. Also, different standards may apply for tissue and eye or cornea donations so that if a donor is too old to donate a solid organ, that person's corneas may still be successfully retrieved.

### **How Many People In Hawaii Are Potential Organ Donors?**

It is not known how many people of the total state population of 1,000,000 have indicated a willingness to be an organ donor. However, an approximation can be made from the number of drivers who have checked off a box indicating a willingness to be a donor. Hawaii's law allows a motor vehicle driver, at the time of application or renewal of the driver's license, to initial a box inscribed as follows: *If you wish to be an organ donor please initial.*

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<sup>2</sup> Phyllis Coleman, "Brother can you spare a liver?", 31 Valparaiso Univ. L. Rev.10 (1996), at note 21.

**Exhibit 2-2**

**STATE OF HAWAII DRIVER'S LICENSE APPLICATION (Not Available Online)**



This number fluctuates, but can give us a snapshot of the average number of potential donors among the driving population.

**Exhibit 2-3**

**DRIVER LICENSE ORGAN DONOR SUMMARY**  
(5/1/98 to 5/31/98)

	<b>Total</b>	<b>Organ Donor</b>	<b>Percent</b>
New licenses	3,724	1,038	27.9
Renewals	14,278	3,777	26.5
<b>Total</b>	<b>18,002</b>	<b>4,815</b>	<b>26.7</b>

Source: Organ Donor Center of Hawaii.

In May 1998, of 3,724 new license applications, 27.9 percent, or 1,038 persons, initialed this box. In the same period, of 14,278 renewal applications, 3,777, or 26.5 percent, of the drivers initialed this box. The combined total for new and renewal applications was 4,815 (26.7 percent) willing organ donors from the driving population of 18,002 for the single month of May 1998.<sup>3</sup> The State Data Book, 1997 reported 733,486 drivers' licenses in force as of December 31, 1996. If 26 percent of these drivers are willing to be organ donors, then about 190,706 people are in the organ donor pool.

In 1993, an UNOS<sup>4</sup> survey found that 20 states identified potential donors by asking the question on the written application or on the renewal card for drivers' licenses. In an additional 15 states, an employee of the division of motor vehicles asks this question of its driver applicants. In at least 11 states, the driver is expected to initiate the request to be an organ donor.<sup>5</sup> The rate of organ donation is likely to be affected by the ease by which a driver can indicate willingness to be an organ donor.

In a national poll by Gallup in 1993, approximately 28 percent of those polled reported to have affirmatively indicated a willingness to be organ donors by signing the appropriate driver's license form or a donor form in their respective states.<sup>6</sup> Hawaii's 26 percent figure is close to this national percentage.

### **The Legislative Background For Organ Transplantation**

Appreciation of the process of organ transplantation in this State requires an understanding of Hawaii's Uniform Anatomical Gift Act (UAGA) and the federal legislative actions since 1984 that set up the national structure for organ allocation.

Until the 1970s, organ transplantation was pretty much a state issue. States like Hawaii adopted the Uniform Anatomical Gift Act of 1968 with some modifications to suit the particular state's interests. The UAGA was modified in 1987 and a new UAGA was adopted by various states, including Hawaii, in 1988. The primary changes in 1988 were the addition of a definition of brain death, requiring routine request of patients by hospital staff, and prohibiting organ sales.

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<sup>3</sup> In an informal survey of the Legislative Reference Bureau, 33 percent of the staff are organ donors as indicated on their driver's license.

<sup>4</sup> UNOS is the acronym for United Network for Organ Sharing. This organization is contracted to operate the National Organ Procurement and Transplantation Network (OPTN) which was established in 1984 by the National Organ Transplant Act (NOTA), P.L. 98-507, Oct. 19, 1984. More discussion of the federal law can be found later in this chapter.

<sup>5</sup> J. R. Johnson, A Study of the United States Organ Donation Program. UNOS, May 1993, p. 10.

<sup>6</sup> Gallup, 1993, "Have you granted permission for organ donation on your driver's license or on a signed donor card?" Fifty-five percent of the Americans polled either had granted permission for future donation or were willing to donate their organs but only 28 percent had already done so that is, by making the necessary choice on their driver's license.



The federal government stepped into the organ transplant arena when Congress provided for Medicare coverage of End Stage Renal Disease in 1972<sup>7</sup> and in 1978<sup>8</sup> included kidney transplant costs in Medicare reimbursement.

By the early 1980s, organ transplantation was no longer such a rare event and society had become more aware of the benefits of organ transplantation as a way to extend life. The federal government became a larger presence in 1984 when Congress passed the National Organ Transplant Act (NOTA).<sup>9</sup> There are four titles in this Act. Under Title I, the Secretary of Health and Human Services was asked to put together a twenty-five-member Task Force on Organ Transplantation. The Task Force studied the various aspects of anatomical gifts including the ethical, medical, legal, and theological issues, and assessed immunosuppressive therapies used in transplantation, and made its recommendations in 1986. NOTA also provided in Title II for the establishment, operation, and expansion of Organ Procurement Agencies, the establishment of a national organ procurement and transplantation network to match individuals who need organs with organ donors, using specific medical criteria, and the development of a scientific registry of organ transplant recipients. In Title III, provisions prohibited the selling of organs for profit and Title IV established a national registry of bone marrow donors.

Among its recommendations, the Task Force recommended the creation of the Organ Procurement and Transplant Network (OPTN). The purpose of the OPTN is “to improve the effectiveness of the nation’s organ donation, procurement, and transplantation system by increasing the availability of and access to donor organs for patients with end stage organ failure.”<sup>10</sup>

The United Network for Organ Sharing (UNOS) is a contractor for the U.S. Department of Health and Human Services to operate the OPTN. UNOS is a private, non-profit corporation. It has adopted policies and bylaws that are reviewed by the Secretary of Health and Human Services. Notices of proposed rules are published in the Federal Register. UNOS operates a 24-hour, 7-day a week service to match organ donors and patients who need organs, educates medical personnel about organ donations, and maintains a website, [www.unos.org](http://www.unos.org), that describes its mission, tasks, and other information about organ donation.

### **Other Federal Legislation**

After the adoption of the National Organ Transplant Act of 1984, the federal government provided for reimbursement for liver transplants for persons under 18 years of age with certain types of end-stage liver disease and set out the criteria for hospitals for Medicare reimbursement

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<sup>7</sup> Amendments to Social Security Act , P.L. 92-603, sec. 2991.

<sup>8</sup> Amendments to End Stage Renal Disease in Social Security Act, P.L. 95-292.

<sup>9</sup> P.L. 98-507, Oct. 19, 1984.

<sup>10</sup> UNOS, 1997 Annual report, Appendix page A-1.

for transplantation in the Omnibus Budget Reconciliation Act of 1985 (OBRA).<sup>11</sup> Hospitals were required to have donor request policies in place, to be members of the OPTN, and associated with OPOs that were members of OPTN in order to participate in Medicare reimbursement for transplantation. Another provision of OBRA 1986 allowed Medicare to cover the cost of immunosuppressive medication for qualified transplant recipients for one year after the transplant.

Kidney transplant provisions were also affected by OBRA 1986. These provisions included reorganization of the End-Stage Renal Disease network, creation of a national ESRD registry, and the requirement that in order to receive Medicare benefits, a physician must certify that a kidney transplant was needed by a patient in order to survive.

There have been other amendments to OBRA 1986 and NOTA but the foregoing are the major provisions that were implemented, as transplants became a more commonplace and successful medical procedure. The federal government's responses have been reactive instead of proactive, in order to provide funding sources to needy organ recipients, and to standardize hospital procedures within the national scheme of organ allocation. Hospitals, medical personnel comprising an organ transplant team, and organ procurement organizations (OPOs) must work in the context of both federal laws and the particular state laws governing anatomical gifts.

## **Hawaii's UAGA And Its Main Provision**

Hawaii adopted the Uniform Anatomical Gift Act (UAGA) in 1969<sup>12</sup> following closely upon its adoption by the National Conference of Commissioners on Uniform State Laws in 1968. In 1988, Hawaii repealed its old UAGA and enacted an updated version of the UAGA that had been adopted by the National Conference, which was designed to simplify donation of organs. As of 1997, twenty states have adopted the UAGA with a few modifications to suit the individual state's needs. Hawaii's version is pretty much standard and contains little or no unique language. The UAGA, which is codified as chapter 327, *Hawaii Revised Statutes*, is the law under which organ donation currently operates in this State. The following is a discussion of the major provisions of Hawaii's law relating to organ donations under the UAGA. House Resolution No. 16, which requested the Bureau's study of the organ donation issue, pointed to the laws of Pennsylvania, Tennessee, Arizona, Kentucky, and Illinois as worthy of examination. Where relevant, some of these and other states' provisions will be mentioned in this report.

### **Who May Donate?**

Donation may be made by the individual<sup>13</sup> or next of kin.<sup>14</sup> A person must be at least eighteen years old in order to be able to designate donation of that person's organs by will, or

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<sup>11</sup> P.L. 99-272, Apr. 7, 1986.

<sup>12</sup> Session Laws of Hawaii 1969, Act 81.

<sup>13</sup> *Hawaii Rev. Stat.*, section 327-2.

<sup>14</sup> *Hawaii Rev. Stat.*, section 327-3.

other document.<sup>15</sup> A decision to donate can be revoked before death. If such a decision has not been specified, another person, specified in order of priority such as spouse, adult child, parent, and sibling, or guardian, may make a donation of a person's organs.<sup>16</sup>

The medical examiner or coroner may authorize removal of a part under certain circumstances.<sup>17</sup>

### **How Is Designation Indicated?**

In Hawaii's UAGA, the "document of gift" which means a card, a statement attached to or imprinted on a license, a will, or other writing is used to indicate a willingness to make an anatomical gift.<sup>18</sup> Hawaii, like many other states that follow the UAGA, allows for the designation to be made on the driver's license.<sup>19</sup> Hawaii's driver's license card contains an imprint with the words "Organ donor" in the lower right corner of the card. No witnesses are necessary for a donation made by signing the driver license application.<sup>20</sup>

Under Hawaii law,<sup>21</sup> the expiration of the driver's license does not invalidate the donation. Thus, unlike other states like Kentucky and Tennessee, in Hawaii the expiration of the driver's license does not require the donor to re-affirm donation at the time of driver's license renewal. In Hawaii, an organ donation requires two witnesses only when the donor cannot sign and the document of gift is signed by another individual at the direction and in the presence of the donor and of each other.<sup>22</sup>

### **What Can Be Donated?**

The UAGA describes "part" as organs, tissues, eyes, bones, arteries, blood, other fluids and any other portions of a human body.<sup>23</sup> In addition, whole body donations are also possible.<sup>24</sup>

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<sup>15</sup> *Hawaii Rev. Stat.*, section 327-2.

<sup>16</sup> *Hawaii Rev. Stat.*, section 327-3.

<sup>17</sup> *Hawaii Rev. Stat.*, section 327-4.

<sup>18</sup> *Hawaii Rev. Stat.*, section 327-1.

<sup>19</sup> *Hawaii Rev. Stat.*, section 286-109.5.

<sup>20</sup> Note that by initialing the appropriate box on the application form the driver gives his/her approval to donate organs but not initialing does not mean the driver refuses to donate. Therefore the empty box is neither a "no" nor a "don't know" or a "can't decide right now". The driver applicant has not opted out with an outright refusal.

<sup>21</sup> *Hawaii Rev. Stat.*, section 327-2(c).

<sup>22</sup> *Hawaii Rev. Stat.*, section 327-2(b).

<sup>23</sup> *Hawaii Rev. Stat.*, section 327-1.

<sup>24</sup> *Hawaii Rev. Stat.*, section 327-3(a).

Some states' definition of "part" may be from the UAGA, but may include other definitions that are more specific. For example, the Kentucky law contains the same definition of "part" but adds a definition for "Transplantable organ" as kidney, liver, heart, lung, bone marrow, while specifying that transplantable organ does not include fetal part or other tissues, hair, bones, blood, arteries, any of the products of birth or conception, teeth, skin, bodily fluids, including spinal fluid, plasma, sperm, ovum, ovaries, fetus, placenta, brain, prostate, stomach, colon, gall bladder, pancreas, thyroid, spleen, other visceral organs.<sup>25</sup>

### **How Can A Donation Be Revoked?**

A donor can revoke an anatomical gift that is not made by will only by taking one of four actions: presenting a signed statement, making an oral statement before two persons, communicating to a physician or surgeon during a terminal illness or injury, and delivering a signed statement to the donee of the gift.<sup>26</sup> As a practical matter (and this issue will be raised again later in this report), in Hawaii (and many other jurisdictions), a donor's family retains de facto veto power over the donor's wishes. Alternatively, the family may make the donor's decision to donate if the donor's wishes are not known at the time of death as long as there is no evidence that the deceased did not wish to make an organ donation. If the donor wishes to revoke a donation made by will, the donor may revoke in the manner above, or by amendment of the donor's will.<sup>27</sup>

### **Can A Person Refuse To Donate Organs?**

Section 327-2(h), *Hawaii Revised Statutes*, specifies that an anatomical gift that is not revoked by the donor before death is irrevocable and does not require the consent or concurrence of any person after the donor's death. However, as will be discussed later, the practice in hospitals in Hawaii is to obtain the consent of the family of the donor, despite the existence of a document of gift by the donor. A person can refuse to donate parts<sup>28</sup> by signing a written statement; attaching a statement to the driver's license card, or refusing orally during a terminal illness.

Where a gift is made by other than the individual, it is possible for a revocation to be made by any member of the same or prior class if the physician, etc. knows of the revocation before procedures have begun for the removal of the part.<sup>29</sup>

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<sup>25</sup> KRS311.165.

<sup>26</sup> *Hawaii Rev. Stat.*, section 327-2(f).

<sup>27</sup> *Hawaii Rev. Stat.*, section 327-2(g).

<sup>28</sup> *Hawaii Rev. Stat.*, section 327-2(i).

<sup>29</sup> *Hawaii Rev. Stat.*, section 327-3(d).

### **What Happens To The Donor's Body?**

The UAGA requires removal of the donated part without mutilation and the proper respectful disposal of the donor's body, for example, in a funeral service<sup>30</sup> where the whole body has been donated.<sup>31</sup> Where only parts of the body are donated, the custody of the remainder of the body vests in the person under obligation to dispose of the body.<sup>32</sup> The UAGA does not directly address donations made by a living donor. However, section 327-6(a)(3), *Hawaii Revised Statutes*, provides that a donor may designate the individual for transplantation or therapy needed by that individual, which presumably could be a living donor donating a kidney for transplantation to a designated relative.

### **What Are The Rights Of The Donee?**

The rights of the donee created by an anatomical gift are superior to the rights of others except with respect to autopsies.<sup>33</sup> This means that in order of priority, the body is first available for an autopsy if necessary. Then, a transplant recipient's rights to organs, tissue, corneas, etc. are next in line. If there are others, such as in the case of a donation of a body for medical school anatomy class, this right is not superior to the donee's right to an anatomical gift.

### **What Is The Role Of The Hospital?**

The UAGA provides for a method whereby the hospital has a responsibility to ascertain the patient's willingness to be a donor. In Hawaii, section 327-5, *Hawaii Revised Statutes*, requires each hospital on or before admission to a hospital to determine whether a patient who is at least 18 is an organ or tissue donor. The hospital must make a notation of that choice (to make or refuse to make an organ donation), or the donor card if any, on the hospital record. Unspecified "appropriate" administrative sanctions are authorized for failure to ask for organ donation.<sup>34</sup> The hospital is also responsible for notifying relevant donees (requesting hospital, research or educational organization, specific doctor, or appropriate organ procurement organization) of availability of organs.<sup>35</sup> This section also provides that the hospital need not make a request for an organ donation "if the gift is not suitable based upon acceptable medical standards". Hawaii has seventeen acute care hospitals (eleven on Oahu) that can serve as donor sources for organs.

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<sup>30</sup> *Hawaii Rev. Stat.*, section 327-4.

<sup>31</sup> *Hawaii Rev. Stat.*, section 327-3(a).

<sup>32</sup> *Hawaii Rev. Stat.*, section 327-8(a).

<sup>33</sup> *Hawaii Rev. Stat.*, section 327-8(a).

<sup>34</sup> *Hawaii Rev. Stat.*, section 327-5(f).

<sup>35</sup> *Hawaii Rev. Stat.*, sections 327-52 and 327-5(b).

### **What Is The Role Of Emergency Personnel?**

Certain persons (law enforcement officer, firefighter, paramedics, and so on) are required to make a reasonable search of the person and person's immediate personal effects to locate information identifying the bearer as a donor.<sup>36</sup> When found, that evidence must be sent to the hospital with notification of its contents.<sup>37</sup>

### **What Is The Role Of The Organ Procurement Organization?**

The organ procurement organization (OPO) is notified by the hospital of the death of a patient<sup>38</sup> and every hospital in Hawaii is required to establish agreements or affiliations for coordination of organs donated for transplantation.<sup>39</sup> In Hawaii, the only organ procurement organization is the Organ Donor Center of Hawaii (ODCH) and St. Francis Hospital is the only hospital in the State that performs transplant surgery. (Recovery of organs from donors can take place in other acute care hospitals where the death occurs, under proper surgical conditions). The OPO's role is to evaluate the donor and manage that patient in preparation for surgical recovery of parts. The OPO performs several functions including education of hospital staff, duties that are not specified in detail in the law.

### **What Is The Role Of The State?**

Under the UAGA, the role of the Hawaii state government in organ donation is limited. The counties, which administer the driver licensing law, collect relevant organ donation figures that are then transmitted to the Organ Donor Center of Hawaii. The law limits liability of the emergency and hospital personnel involved in transplantation procedures.<sup>40</sup>

As will be described later in this report, some states that have given a greater role to state officials or government offices have shown increased awareness and understanding of the need to increase organ donations among its citizens.

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<sup>36</sup> *Hawaii Rev. Stat.*, section 327-5(c)(1).

<sup>37</sup> *Hawaii Rev. Stat.*, section 327-5(d).

<sup>38</sup> *Hawaii Rev. Stat.*, section 327-5(e).

<sup>39</sup> *Hawaii Rev. Stat.*, section 327-9.

<sup>40</sup> *Hawaii Rev. Stat.*, sections 327-9 and 327-11.

## Other UAGA Provisions

Other UAGA provisions include a determination of death and legal definition of brain death. In Hawaii, determination of death is defined in section 327C-1, *Hawaii Revised Statutes*, as (a) irreversible cessation of spontaneous respiratory and circulatory functions, or (b) in the event that artificial means of support preclude a determination that respiratory and circulatory functions have ceased, then, based on ordinary standards of current medical practice, the person has experienced irreversible cessation of all functions of the entire brain, including the brain stem. Death must be pronounced before artificial means of support are withdrawn and before any vital organ is removed for transplantation.

The UAGA also provides that the physician who declares a person dead shall not be the same physician who performs the transplant.<sup>41</sup> The UAGA exempts the physician, hospital, and other entities involved in the transplantation, removal, preparation, and other activities involved in the transplantation process, from strict liability except for negligence or willful misconduct.<sup>42</sup>

Hawaii's UAGA contains no provision regarding financial liability of the donor. In practice, in Hawaii, from the time consent is given for organ donation, hospital costs are stricken from the donor's hospital invoice and picked up by the OPO; all other costs relevant to the original admission (injury, trauma, etc.) remain the financial responsibility of the donor or estate.<sup>43</sup>

The UAGA prohibits the sale of organs for profit,<sup>44</sup> provides that a person may not knowingly purchase or sell a part for transplantation for valuable consideration. A person who does so is guilty of a felony and upon conviction subject to a fine not exceeding \$50,000 or imprisonment not exceeding five years, or both. "Valuable consideration" does not include reasonable payment for removal, processing, disposal, preservation, quality control, storage, transportation, or implantation of a part.<sup>45</sup>

Confidentiality requirements protect both the privacy of the donor's medical records and the donee from receiving unsuitable transplants. For example, in Hawaii,<sup>46</sup> the law states that an anatomical gift authorizes any reasonable examination necessary to assure medical acceptability of the gift for the purposes intended.

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<sup>41</sup> *Hawaii Rev. Stat.*, sections 327-8(b) and 327D-20.

<sup>42</sup> *Hawaii Rev. Stat.*, section 327-51.

<sup>43</sup> Telephone interview, July 29, 1998, Felicia Wells-Williams, Professional Education Coordinator, Organ Donor Center of Hawaii.

<sup>44</sup> *Hawaii Rev. Stat.*, section 327-10.

<sup>45</sup> *Hawaii Rev. Stat.*, section 327-10(b).

<sup>46</sup> *Hawaii Rev. Stat.*, section 327-11.

## Declaration Governing Life-Sustaining Treatment

It is possible for an organ donation to come from a patient who has declared ahead of time, specific medical treatment wishes including instructions to hospital personnel to withhold life-sustaining procedures.<sup>47</sup>

No physician participating in a decision to withdraw or withhold life-sustaining procedures from a declarant may participate in transplanting the vital organs of the declarant to another person.<sup>48</sup>

## Summary

There is a severe lack of organs being donated annually in Hawaii. We have estimated that less than one-half of one percent of all deaths in Hawaii involves organ donations. Even if this percentage could be increased to only one percent of all deaths in this State, many more organs would become available to those who need it. Although 26 percent of drivers in Hawaii indicate a willingness to donate their organs after death (which is close to the national average), the organ donation rate is very low because the next of kin of such drivers have a veto power in the organ donation process. It is evident that the UAGA that Hawaii has adopted has not significantly changed the donation picture in its thirty-year history because the law has not been able to change the behavior of our citizens toward granting organ donations after death.

In the next chapter, discussion centers on the reasons for low donation rates ranging from ignorance of organ transplantation options and personal reservations about donating organs because of emotional or religious beliefs.

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<sup>47</sup> *Hawaii Rev. Stat.*, chapter 327D.

<sup>48</sup> *Hawaii Rev. Stat.*, section 327D-20.

<sup>48</sup> *Hawaii Rev. Stat.*, chapter 327.



## Chapter 3

### REASONS FOR LOW RATES OF ORGAN DONATION

In the earlier chapter, discussion centered on the miniscule number of actual organ donors in Hawaii and the number of drivers who have indicated a willingness to donate organs upon death. A discussion of the provisions of Hawaii's law governing organ donation and transplantation revealed that despite its thirty-year history, little progress has been made in raising the rate of donation among Hawaii's residents. Yet the UAGA which Hawaii follows was designed to help facilitate organ donation.<sup>1</sup>

Hawaii's UAGA law requires hospitals to inquire if a patient is an organ donor; and also requires emergency personnel to bring to the attention of the hospital personnel the existence, if any, of an organ donor card or driver's license card that states "organ donor" on its face. Additionally, the law provides for the hospital to work cooperatively with the organ procurement organization (OPO) when a donor becomes available so that various mechanisms to help the donor family deal with and accept the donation process can begin to operate. The law also provides that principals involved with the transplant process are immunized from liability except for wilful negligence. The question then is "why then are the organ donation rates still so low?"

There is no single answer, just as there is no single reason why people continue to smoke or fail to use seatbelts when there is overwhelming evidence that to do otherwise is a life-enhancing act. Modifying behavior and asking people to change their attitudes toward their own mortality depend on a complex set of personal motivations. Public policy can initiate the change process with laws to facilitate organ donation for the parties involved, such as hospitals, medical professionals, and organ allocation organizations, but the actual donation must still be an individual decision.

In this chapter we will examine the reasons for the low rates of organ donation in Hawaii. First, to get an overall feeling of the American scene, a summary of the 1993 Gallup poll will be presented. The remainder of this chapter describes the most likely reasons why the rate of organ donation continues to grow very slowly in Hawaii.

#### **The Gallup Poll Of 1993**

In February 1993 the Gallup Organization conducted a survey for The Partnership for Organ Donation, Boston, Massachusetts and released its report as "The American Public's Attitudes Toward Organ Donation and Transplantation". This survey can be accessed through the Internet at [www.transweb.org](http://www.transweb.org) and is presented here in summary. Italicized sentences or

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<sup>1</sup> House Standing Committee Report No. 960-88 on S.B. No. 1541 (Act 267, Session Laws of Hawaii 1988), adopting the 1988 UAGA said: "This bill will facilitate the donation and recovery of organs and tissue for transplantation."

phrases below indicate direct quotes from the Gallup report. According to this survey, *education is a demographic variable which positively correlated with likelihood to donate organs.*

Seven areas of inquiry were examined by the pollsters:

1. Support for Organ Donation
2. Perspectives on Organ Donation
3. The Decision to Donate
4. Importance of Family Communication
5. Sources of Information
6. Potential barriers to Donation
7. Alternative Approaches

### **Support For Organ Donation**

There is widespread support for organ donation. The survey found that “...*nearly nine in ten Americans support the general concept of organ donation.*” *More than one-third (37%) reported that they are very likely to donate their own organs after death, and another third reported they are somewhat likely to donate. Only 25% are not likely to donate their organs but nearly half of these might be persuaded to donate, as they could give no concrete reason for their unwillingness to donate. Thirteen percent cited perceived medical reasons, while ten percent felt they were too old.*

### **Perspectives On Organ Donation**

The questions dealing with perspectives on organ donation asked the respondents about their opinions regarding the positive consequences of donation such as helping the deceased family deal with grief, giving the donee more years of healthy life, whether the respondent believed most donees received a transplant, and whether the respondents themselves would accept an organ transplant. Most respondents (59%) believe organ donation helps families cope with grief, but 39% believe organ transplantation is an experimental medical procedure.

*More than two-thirds of the respondents believed that most people who need transplants do not receive them, and one in five, or 20% believe that the supply is adequate for the demand.* Furthermore, those individuals who oppose organ donations are more likely to believe supply is adequate. Nearly four in five Americans would accept an organ if necessary for their health. Of respondents who said they would not donate their organs, 46% said they would accept an organ, but 43% of the respondents who refuse to donate would not themselves accept an organ transplant to regain their health.

## **The Decision To Donate**

The decision to donate is influenced by the individual's view of death and a willingness to make an affirmative decision to donate. The survey indicated that more than one-third of Americans admit to some level of discomfort to think of their own deaths, and generally younger respondents and those with less education appear less comfortable. *Although 85% approve of organ donations, only 42% have themselves made a personal decision about donating their own organs. And 25% have made a decision about the donation of family members' organs. Further, only 28% have indicated on their driver's license or a signed donor card to grant permission to donate their organs upon death.*

According to the Gallup organization, the results of the questions about the decision to donate show “...a significant level of misinformation about the necessary 'permission' currently required for organ donation. Nearly four in five Americans incorrectly believe a signed donor card is required prior to organ donation (it is not required). More than one-third (34%) fail to realize that surviving family permission is required.”

## **Importance Of Family Communication**

The fact that family permission is required for organ donation raised the issue of whether people tell their family members about their wishes or even know about their family members' own wishes regarding donating organs. This survey discovered that 27% of the respondents do not know their family's position about organ donations and 52% of the respondents have discussed and expressed their feelings about donating their own organs with other family members. Women are more likely than men to have discussed their wishes regarding organ donation. Those who do not wish to donate their organs are even less likely to have discussed this matter with family members.

The survey also discovered that a family discussion regarding funeral arrangements and other specifics of a will does not always include a discussion about wishes regarding organ donation. Finally, the survey concluded this section with two questions: respondents were asked to project their likelihood to donate family members' organs under two conditions: when no discussion of the issue with family had occurred and when a family member had requested their organs be donated upon their death. *The results suggest that family discussions on potential organ donation could have a powerful impact on final decisions. Less than half of respondents (47%) would be likely to donate a family member's organs if the subject had not been discussed prior to death. However, if a family member requests their organs be donated, nearly all respondents (93%) would be likely to honor that wish. Family requests would substantially increase the proportion of organ donation opponents who would donate a family member's organs upon their death. However, nearly one in four of these respondents who oppose the general concept of organ donation would not honor a family member's request that their organs be donated.*

## Sources Of Information

The public's awareness of organ donations comes from general news coverage (74%) and from public service ads (60%).

## Potential Barriers To Donation

The potential barriers to donation include religious beliefs, the desirability of intactness of the body for burial, and beliefs about who pays for the medical costs of organ transplantation. In this section, the survey found for example, that *“religious barriers to organ donation do not appear to be widespread and there were no substantial differences among major religious groups with the statement, ‘organ donation is against your religion.’”*

The survey also asked respondents whether it is possible for a brain dead person to recover from his or her injuries and found that nearly two-thirds of Americans recognize that a brain dead person cannot recover from his or her injuries. However, more than one in five (21%) appear to believe there is some hope of recovery, and an additional 16% are unsure. The survey concluded that *educational efforts regarding the implications of “brain death” might be useful in increasing support for organ donation since 33% of those opposed to organ donation in general believe that it is possible for a brain dead person to recover.*

As to medical costs for organ donation, the survey found that *although the majority of respondents recognize that donor families are not required to pay extra medical bills associated with the donation, there is a substantial amount of uncertainty surrounding this issue. Nearly one in three respondents (29%) indicates that they did not know whether or not a donor's family must pay extra medical bills. There is also a fairly strong perception that income may impact whether or not a person receives a needed transplant, and more than a third of Americans believe that organs can be bought and sold on the black market in the United States.*

## Alternative Approaches

The question of financial incentives and the use of animal organs for transplants in humans revealed the respondents' opinions of alternative approaches. The survey found that *financial incentives would impact less than 20% of respondents' likelihood to donate their or family member's organs. Twelve percent would be more likely to donate, while 5% would be less likely. Younger respondents and those who are nonwhite appear more amenable to financial incentives. Those who oppose donation are even less likely to donate their own organs if financial incentives were offered to donors' families.*

There is no reason to believe that many of the findings by the 1993 Gallup poll would not be relevant to Hawaii today. Across the country many states face the challenge of finding ways to increase organ donation rates. The next section in this chapter discusses the likely reasons for low donation rates.

## Reasons Why People Do Not Donate

Nearly every article that examines the question of low rates of organ donation lists the following general reasons people do not donate organs:

1. General lack of awareness of the issue; this includes not being asked; not having thought about it; not realizing that organ transplantation has become an acceptable medical procedure whereby many organ recipients can return to a normal life.
2. Belief and superstition that one's religion prohibits donation; that the organ donation process mutilates the body or prevents traditional funeral services from being conducted as usual.
3. Basic distrust of the medical system; fear that medical personnel will do less than necessary in order to hasten death and retrieve needed organs.
4. Belief that certain physical infirmities prevent donation, such as having a certain disease like cancer, or being too old to donate a body part.
5. Dislike having to think about and discuss the reality of one's death.

## Lack Of Awareness

Despite its non-experimental nature, organ transplantation is not within the average person's common experience. While former heart bypass patients are all around us, fewer island families have relatives or close friends who have undergone an organ transplant. In a state of about 1,000,000 persons, a waiting list for organs of 167 persons represents 0.000167 percent of the resident population. Instead of having personal association with someone who is on the waiting list for a donor organ, the level of awareness for most people has been raised primarily by recipients' fundraising efforts that are publicized in news media. This is in line with the Gallup finding that general news coverage provides most of the public's awareness of the need for organs. Although not directly related to the need for solid organs, publicity efforts to increase bone marrow donations also help to increase public awareness about organs needed for transplant recipients. More recently in 1998 there has been a spate of articles and television reports about the need for organ donors.<sup>2</sup> The government plays little or no role in these publicity events.

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<sup>2</sup> For example, in the print news media alone, the following articles have appeared: *The Honolulu Advertiser*, Nov. 14, 1998, "Churches to begin appeal for transplant donors"; *Midweek*, July 29, 1998, "Making Miracles, Changing Lives" and "Waiting for a new life" (cover story); *Honolulu Star-Bulletin*, July 24, 1998, "Filipinos hear plea to donate their organs so others may live"; *Honolulu Star-Bulletin*, July 15, 1998, "Organ transplant priority still a matter of geography"; *Honolulu Magazine*, July 1998, "Hawaii's Kidney Crisis," pp. 38-43; *The Honolulu Advertiser*, April 19, 1998, "Donor list far behind need for organs" and "No '98 donations yet in Hawaii"; *Honolulu Star-Bulletin*, April 16, 1998, "Isle organ donors this year: 0"; *The Honolulu Advertiser*, March 27, 1998, "Sickest to get transplants"; *Honolulu Star-Bulletin*, January 31, 1998, "Hawaii badly lacking in donors of the 'the gift of life'"; *Pacific Business News*, January 5, 1998, "End holiday season with grand finale: gift of saving a life."

Allowing a driver to become an organ donor by marking the proper initials on the driver license application form is one example where government policy provides the citizen an opportunity to indicate a willingness to donate one's organs.<sup>3</sup> However, the item on the application form is not prominently displayed or highlighted in any way so that this question could easily be missed. Organ donation awareness might be heightened if a counter person who is collecting the application form asks the applicant whether the applicant considered and answered that question on the form.

### **Not Being Asked**

Sometimes a person is made aware of the option to make an organ donation in a passive manner (as in the driver license application form), or the person might be asked more directly. A more direct opportunity for organ donation is possible when the average person is admitted to a hospital in Hawaii. Section 327-5(a), *Hawaii Revised Statutes*, requires routine inquiry and required request on or before admission to a hospital. Theoretically this means that the law requires that a patient who is admitted for an appendectomy, a broken ankle, or any other routine, non-acute or life-threatening medical procedure must be asked upon admission, whether the patient is an organ donor. In actual practice, it is likely that a patient is not asked if admitted only for routine hospitalization but may be asked before surgery. An item in a Kaiser Permanente Newsletter<sup>4</sup> recently included a column as follows:

It's the Law

Staff must document information before surgery

If you are admitted to Moanalua Medical Center or plan to have outpatient surgery, you will need to provide certain information, prior to your procedure, that will become part of your medical record. According to state law, it is necessary for a Kaiser Permanent staff member to ask if you have a living will, want a priest, or wish to donate your organs if you do not survive the procedure.

Please do not become alarmed or be offended when asked these questions; they do not indicate that your condition is more severe than you have been told. All hospitals must obtain this information to abide by state and hospital accreditation requirements.

According to the Partnership for Organ Donation, "despite required request legislation, families are not asked to donate in seventeen percent of all brain death situations. . . a number of factors may explain this outcome. The patient may not be recognized as a medically suitable donor, and thus the option of donation is not included in the discussion with the family. Some

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<sup>3</sup> *Hawaii Rev. Stat.*, section 286-109.5, requires "the examiner of drivers to design and implement a system to request anatomical gift information from all applicants for a driver's license or license renewal, at the time of application, including a method of directly imprinting on a license an applicant's designation of whether the applicant wishes to be an organ donor. The request shall elicit whether the applicant wishes to be an organ donor in the event of the applicant's death."

<sup>4</sup> Kaiser Permanente, Hawaii Region, "Planning for Health," Spring 1995, p. 7.

physicians are concerned about a perceived conflict of interest if the primary care team becomes involved in making a request for donation. But perhaps most often, health care professionals do not approach families about donation for fear of aggravating their grief; they may mistake normal grieving behaviors for a family's inability to consider donation."<sup>5</sup>

It has been “. . . estimated that 38% of potential donors' families deny consent when asked.”<sup>6</sup> Other donors are lost when hospital personnel fail to consider the severely injured patient as a potential donor and do not recognize when brain death has occurred, or when the health care provider feels that due to time constraints, brain death cannot be explained to the patient's family, or the health care provider believes the family cannot understand brain death. The estimate is that about “. . . thirty percent of medically suitable donors are lost before families can become involved in the decision (to donate).”<sup>7</sup>

The manner and timing of the request can also affect whether consent is given to donate a family member's organs. The Partnership for Organ Donation, Inc., reported that having personnel trained in grief counseling and bereavement and who can explain in nontechnical terms about brain death, donation, and the like is invaluable to the donation consent process. Second, it is important to separate the time that the family is informed of death, and the time that an organ donation is requested (termed, “decoupling”) so that the family first accepts the death before considering whether or not to donate.<sup>8</sup> The Partnership for Organ Donation found, for example, that 87% of neurosurgeons surveyed agreed that neurosurgeons have introduced organ donation to the family prior to the declaration of death or in the same conversation.<sup>9</sup> Here, awareness of how to approach a grieving family requires changing the behavior of health care providers, not the donor family.

## Religion

There are more religious objections to organ and tissue donation than to receiving a transplant.<sup>10</sup> The decision to donate is as individual as the decision to undergo a transplant. Similarly, an individual's understanding of his/her religious doctrine is affected by the special emotional interrelationship of that person's religion and personal beliefs. A review of all major religions by UNOS in its Medical School Curriculum on Donation and Transplantation explained: “None of the major religious traditions have explicit prohibitions to the free donation of the organs of a person who has died. . . . In particular cases, specific restrictions may apply

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<sup>5</sup> The Partnership for Organ Donation, Inc., “Solving the Organ Donor Shortage,” Boston, Mass., 1991, p. 13.

<sup>6</sup> *Ibid.*, p. 12.

<sup>7</sup> *Ibid.*

<sup>8</sup> *Ibid.*, p. 18.

<sup>9</sup> *Ibid.*, p. 20.

<sup>10</sup> United Network for Organ Sharing (UNOS), Donation and Transplantation, Medical School Curriculum, section 7, pp. 1-2.

within each of the religious traditions, and so people considering organ donation who have questions about their own case should be referred to clergy.”<sup>11</sup>

Perhaps one of the most frequently cited religious reasons for not donating is the mistaken belief that removal of organs will so disfigure the body to prevent an open casket funeral, a custom in several religions. Typical of this belief is the following comment by the wife of an organ donor in Hawaii:<sup>12</sup>

She said her family had concerns about organ donation because they are Catholic. “Even I was ignorant,” she said, explaining she believed it would prevent the body from being viewed, which is customary in Catholic funeral services. “That’s not true,” she said, suggesting Catholics talk to their priests.

Ignorance of religious doctrine can be corrected with the assistance of clergy and through publicizing interviews such as the one described above.

It is evident the role of the clergy in educating the public about organ donation is important if these mistaken beliefs are to be changed. Since 1996 there is one weekend each year set aside to raise the level of discussion of organ donations in the religious context. This is the Annual National Donor Sabbath, held in 1997 on the weekend of November 14-16. “The event attempts to have members of the clergy from all faiths raise awareness about the need for organ and tissue donation through their congregations.”<sup>13</sup>

### **Basic Distrust Of The Medical System**

In this general category of impediments to organ donation is the belief that by agreeing to organ donation, the medical staff will not use due diligence to prevent death. Related to this distrust of health care professionals is a perception of inequity in the allocation of organs (that the rich and the Caucasians are more likely to receive an organ than the poor and nonwhite). Distrust of the medical system, like distrust of police, other government officials, the judicial system, or any other institutional process, can be found in almost every society, among many groups and for many reasons, usually but not limited to the disenfranchised, the poor, and the uneducated. Distrust of organ donation appeals may be heightened by the greater level of technical expertise needed to comprehend the life and death decisions being made in the hospital and the higher level of powerlessness felt by individuals in that context.

It has also been pointed out that distrust among minorities may be due to having to deal with the medical providers who are largely white. For example, the most common reasons for blacks not wanting to donate organs were found to be: (1) lack of awareness about

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<sup>11</sup> *Ibid.*, pp. 2-3.

<sup>12</sup> *Honolulu Star-Bulletin*, “Filipinos hear plea to donate their organs so others may live,” July 24, 1998, pp. 1-12.

<sup>13</sup> International Office of Transplant Recipients International Organization, Inc., *Lifelines* (Washington D.C., July/August 1997), p. 1.



transplantation; (2) religious myths and misperceptions (superstitions); (3) distrust of the medical community; (4) fear of premature death; and (5) racism.<sup>14</sup>

Whether or not these ethnic factors also affect organ donation in Hawaii, where there is a mixture of ethnic groups is not documented. However the reality is that among the patients waiting for organs, nonwhite ethnic groups make up a larger proportion than whites (see Exhibit 1 in chapter 2). A distrust of the system will work against an ethnic group that continues to have a low rate of organ donation, “. . .because in about twenty percent of cases, optimal tissue matching practices require same-race donors and recipients.”<sup>15</sup>

### **Belief That Certain Physical Infirmities Prevent Donation**

Organ donors are evaluated by the Organ Donor Center of Hawaii (ODCH). According to the Sample Organ and Tissue Donation Policy provided to the Bureau by the ODCH, organ donors can be as young as a newborn and as old as 70 years of age. According to this policy the following illnesses are contraindications for donation: (a) metastatic cancer; (b) autoimmune disease; (c) high risk behavior for AIDS; and (d) syphilis, HTLV and HIV antibodies. However, unless and until a donor or donor family consents to making an organ donation, the issue of identifying any contraindication to donation would not arise.

### **Unwillingness To Discuss And Accept The Reality Of One's Death**

Just as some people never direct the writing of a will or end of life medical instructions because the act requires acknowledging the end of one's life, there are people who refuse to donate organs because it requires accepting the inevitability of death. In most cases, in order to give an organ a donor must accept one's own mortality. For some people this is unacceptable and organ donation then also becomes a topic that cannot be discussed with family members.

The value of family discussions about organ donation is highlighted in the Gallup poll cited earlier and bears repeating here. When a family member's wishes regarding organ donation was unknown, only 47% of the respondents said they would be likely to consent to donating the family member's organs. But this figure nearly doubled to 93% if the respondent knew that the family member wished to donate organs upon death and the member had discussed this fact beforehand. Knowing how a family member feels about organ donation can significantly affect the likelihood that a surviving spouse or other relative will consent to donation.

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<sup>14</sup> The Partnership for Organ Donation, Inc., “Solving the Organ Donor Shortage,” Boston, Mass., 1991, p. 16, citing C.O. Callender, “The Results of Transplantation in Blacks: Just the Tip of the Iceberg,” Transplantation Proceedings, Vol. 21, No. 3, June 1989, pp. 3, 407.

<sup>15</sup> The Partnership for Organ Donation, Inc., “Solving the Organ Donor Shortage,” Boston, Mass., 1991, p. 16.

## **Summary**

While a majority of Americans are willing to donate their organs there remain a number of reasons why they have not done so in the numbers necessary to meet the demand. The reasons for not donating organs can range from deeply held religious beliefs to simply not having been asked to donate. There is good reason to believe that the opinions found in the national poll by Gallup are similar to the opinions about organ donation held by Hawaii residents. Further, the likely reasons for low organ donation rates in Hawaii are similar to the reasons given in many other surveys. In order to overcome these impediments to donating organs, several options are available as inducements to donation. These options are discussed in the next chapter.

## Chapter 4

### WAYS TO IMPROVE ORGAN DONATION RATES

House Resolution No. 16 asked the Legislative Reference Bureau to suggest ways to increase organ donation in Hawaii. A literature review on the subject of organ donations revealed that Hawaii is not the only state in the United States, experiencing this shortage. Nor is the United States the only country in the world with an organ shortage. Both Europe and Asia have different methods of acquiring organs, but there is still a shortage in these continents.

Nationwide, 55,000 people are waiting for organs while about 20,000 have received transplants. About ten persons on the national waiting list die each day because an organ cannot be found in time. Comparisons among the fifty states' organ donation rates are not altogether appropriate because while there are fifty states, there are 63 OPOs, some of which serve portions of different states, combined. Furthermore, organ procurement organizations may differ in their criteria for acceptable donor organs that can affect the donation rate of donation. While Hawaii's supply of donated organs does not meet the demand and the rate can be improved, this is not a time for hand wringing.<sup>1</sup> In five states: Alaska, Idaho, Montana, Rhode Island, and Wyoming, there are no transplant programs.<sup>2</sup>

Every state that has examined this issue is attempting to address the deficiency in organ donations in different ways. In some states the extent of government involvement is as passive as merely adopting the UAGA.<sup>3</sup> Other states have laws granting certain state officials authorization to take a more active role to educate the citizens of the need for more organ donors.

Many different tactics taken together are necessary in order to improve organ donation rates. Education is a key, but this process takes awhile to implement properly and its effects are evident only over the long term. Unfortunately, organs are needed today, not years from now. This chapter describes some of the programs implemented by other states and proposals put forth by researchers in the field who have examined and thought about this issue. Comparisons will be drawn with Hawaii's situation as appropriate.

The general methods by which modifying state public policy are thought to have a positive impact on organ donations include:

- Authorize a high profile government official to head up the program to lend government sanction to organ donation drives and educational efforts (example from Illinois)

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<sup>1</sup> See "Many organ banks lag in transplants," *The Honolulu Advertiser*, Sept. 18, 1998 and "Some organ banks better finding matches," *Honolulu Star-Bulletin*, Sept. 18, 1998.

<sup>2</sup> CSG Health Policy Monitor, Summer 1998, vol. 3., No. 2., p. 2.

<sup>3</sup> As of 1998, twenty states had adopted the 1987 UAGA.

- Establish a commission or committee comprised of community leaders who can help promote organ donations, examine and propose new policies, and regularly report on progress to the legislature and the people of the state (example from Pennsylvania and other states)
- Establish funding sources for public awareness or outreach programs through a minimal fee or optional donation at different entry points when a citizen interacts with a government agency (examples from Pennsylvania, Kentucky, Florida, and other states)
- Change the consent concept for organ donations that currently gives a family member veto power over a donation (example from Texas)
- Raise public awareness about organ donations in general through a variety of educational means (examples from Illinois, Pennsylvania)
- Increase the number of “entry points” when individuals are given the opportunity to become an organ donor (examples from Illinois, Pennsylvania)
- Solicit the help of educational, minority, community, and spiritual leaders to spread the word about the need for organs in the state (examples from Illinois, other established organ procurement organizational activities)
- Promote discussions about organ donations among ethnic and minority groups, in schools, churches, and other group and community activities through targeted education (examples from current organ procurement organization activities)
- Give rewards to organ donors ranging from financial awards to public recognition of donors (suggestions from literature review)
- Require hospitals to publicly report deaths and to coordinate with organ procurement organizations or face fines (examples from Maryland, Pennsylvania, and other states as well as a recent regulation published by the Health Care Finance Administration for hospitals participating in the Medicare, Medicaid programs)

This chapter will examine each of the foregoing methods in more detail. House Resolution No. 16 specified Pennsylvania, Tennessee, Arizona, Illinois, and Kentucky as states that the Bureau should examine for ideas about ways to increase organ donation. Many other states are using statutory language from Pennsylvania and Illinois for ideas to increase their own organ donation rates. For example, New Jersey as recently as August 1998 followed the Pennsylvania language by amending its anatomical gifts law to allow the intent of an organ donor to withstand revocation by a relative if the donation is evidenced by a donor card, donor designation on a driver’s license, or an advanced directive. Maryland adopted the William H. Amoss Organ and Tissue Donation Act of 1998 to adopt the required referral law found in

Pennsylvania and a few other states. States that have been reported by various publications as having successful organ donation awareness and education programs like Illinois, and others, which have developed a funding mechanism to pay for these programs, are highlighted in this chapter.

## Active Government Involvement

### Identify The Organ Donation Program With A High Profile Official

Identifying organ donation with a high-level government official raises the visibility of a program to the state's citizens. The effect of a state official championing the cause associates the program with official sanction, brings the news media to the events with coverage in television, newsprint, and presents opportunities for describing the nature of the problem and possible solutions. It is the repetition and visibility that imprint the issue in people's consciousness.

In Illinois, the Secretary of State lends the full weight of the office behind the organ donation effort. Appearances by the Secretary of State at organ donation functions, community donation drives, and other related events emphasize the Illinois State government's interest in increasing organ donations. Illinois has a unifying theme for their organ donation program -- "Life goes On" -- which helps to immediately identify the program on all printed documents and media efforts. The use of this theme and the availability of the Secretary of State in the organ donation program may have been a strong influence in raising public awareness to the need for organs and the benefits to society in general. The Secretary of State also organized an Organ Donor Awareness Conference during National Organ and Tissue Donor Awareness Week in April 1994 to promote organ donor awareness among the medical community. At least one author pointed out that ". . . it appears that a strong commitment from "top" state officials is the key to success."<sup>4</sup>

In Hawaii, the news media coverage has usually shown the Governor (or the Lieutenant Governor in the Governor's absence) performing a ceremonial role when attending an organ donor function.<sup>5</sup> News media coverage has been good in both print and television. However, such publicity occurs on an ad hoc basis, without an unifying theme. In Hawaii, the organ donation program is not specifically identified with any high-level state official. Nor is the Governor's or Lieutenant Governor's presence a sponsored event that furthers a legislative purpose to promote organ donation.

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<sup>4</sup> J.R. Johnson, "A Study of the United States' Organ Donor Programs," Richmond, Va: UNOS, 1993, p. 14.

<sup>5</sup> See "Filipinos hear plea to donate their organs so others may live," *Honolulu Star-Bulletin*, July 24, 1998, for comment by Lieutenant Governor Mazie Hirono, and "Cayetano suggests payments to encourage organ donation," *The Honolulu Advertiser*, Aug. 31, 1998.

## **Create A Commission Or A Committee For Organ Donations**

The usefulness of a committee made up of organ transplant recipients, donor family members, members of the medical community, religious leaders, and so on help to give perspective on an issue that while many support, is still filled with misinformation, superstition, and misunderstanding in some sectors of the community. A committee can help collect community opinion, serve as a sounding board to new ideas about donation, and serve as outreach volunteers as needed.

In Pennsylvania there is a fifteen-member Organ Donation Advisory Committee appointed by the Governor. The Committee meets at least biannually to review progress in the area of organ and tissue donation and recommends education and awareness training programs, suggests legislation, recommends priorities in expenditures, and advises the Secretary of Health on matters relating to administration of the fund. A report concerning its activities and progress is sent to the General Assembly each legislative session.<sup>6</sup>

In Illinois, the Secretary of State is a member of the Organ Donor Ad-Hoc Committee, which is comprised of representatives from the funeral directors association, Red Cross, Organ Bank, Eye Bank, Coroners Association and others. The committee meets periodically to discuss current issues relating to organ donation and inform members of present and future organ donor awareness programs.<sup>7</sup>

Virginia has an advisory board, the Virginia Transplant Council made up of more than fifteen representatives of organizations that are involved in some way with organ, tissue, or eye donation, procurement, or transplantation. Other members who may be nonvoting, associate members include the Virginia Departments of Education, Motor Vehicles, and other appropriate agencies. The council is headed by an executive director who is a state employee and the State Board of Health is designated the budgetary administrator of the Council and receives funds as provided by the General Assembly. The Council must submit reports to the Board of Health on its activities, programs, and funding. The council's purpose is to advise the Board of Health, conduct educational and informational activities as they relate to organ, tissue, and eye donation, procurement, and transplantation efforts in Virginia.<sup>8</sup>

Georgia also has an Advisory Board on Anatomical Gift Procurement made up of more than twenty individuals from the transplant, consumer, and governmental communities. The Board has seven main functions among which are to advise the Department of Human Resources on the implementation of the Anatomical Gift Act; identify areas of need in supply and demand for human organs; recommend a formal policy for the state to foster a statewide network for procuring organs; encourage improved public education and awareness regarding

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<sup>6</sup> *Penn. Consolidated Stat.*, section 8622(c), Organ Donation Awareness Trust Fund Advisory Committee.

<sup>7</sup> J.R. Johnson, "A Study of the United States' Organ Donation Program," Appendix B: Material from the Illinois Office of the Secretary of State, "Working together".

<sup>8</sup> *Code of Virginia*, section 32.1-297.1, The Virginia Transplant Council.

anatomical gifts, and reporting biennially to the Governor and Legislature, regarding progress and actions of the Board.<sup>9</sup>

A very recent law in Maryland (1998) has created a state advisory council on organ and tissue donation issues, to expand legislative support for organ donation.<sup>10</sup>

### **Establish A Government Authorized Funding Source For Organ Donation Education Programs**

The cost of educational programs can be borne by government through a special fund that is replenished from fees that are nominal, added to such transactions as a motor vehicle transfer fee, or an optional \$1 donation tacked on to driver's license application fees, or to a state tax return. If Hawaii with its 733,486 drivers (in 1996) required each to pay an extra \$1 at the time of new license application or renewal<sup>11</sup> a small fund could be established to start some programs. Alternatively, \$1 can be added to the annual vehicle registration fee, in the same way that \$1 is now collected for the highway beautification and disposal of abandoned vehicle revolving fund.<sup>12</sup> There were 704,693 passenger vehicles registered in 1997. If all vehicles, including ambulances, busses, trucks, trailers, and so on were included, there would be about 907,000 registrations available for a \$1 add on fee to benefit an organ donation awareness fund.

As will be seen in other parts of this chapter, Pennsylvania, South Carolina, Kentucky, Florida, and Illinois, provide examples of how some states have created a method of paying for organ donation awareness or outreach programs through a special fund, or through legislative appropriations.

In Maryland, driver's license renewers will be given the opportunity voluntarily to donate \$1.00 into a newly created fund to pay for education regarding organ donations.

### **Consent And Its Variations**

No discussion about ways to improve organ donations would be complete without a digression into the varied and sometimes confusing world of consent and its progeny. Unfortunately the writers who use the word "consent" in organ donation issues have no standardized meanings so that different terms are used synonymously. For example, the term "mandated choice" has been used for "presumed consent" and "presumed consent for "opting-out".<sup>13</sup> The Texas four hour law (see further discussion below) has been described as a

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<sup>9</sup> *Code of Georgia*, sections 44-5-149 to 150.

<sup>10</sup> See [www.mdtransplant.org](http://www.mdtransplant.org) for more information on the William H. Amoss Organ and Tissue Donation Act of 1998.

<sup>11</sup> *Hawaii Rev. Stat.*, section 286-107.

<sup>12</sup> *Hawaii Rev. Stat.*, section 286-51(b),

<sup>13</sup> J.R. Johnson, "A Study of the United States' Organ Donation Program," p. 5.

“presumed consent” law, by many authors, and a law of “informed refusal”<sup>14</sup> by another. The UAGA provision authorizing the medical examiner to consent to donation under certain circumstances<sup>15</sup> has been described as “quasi-presumed consent.”<sup>16</sup>

Traditionally, the intent of the UAGA has been that donors are asked to consent to the donation of their organs after death by indicating this wish on their driver’s license form or by other means such as a donor card of some kind. If the driver has not indicated willingness to donate, a relative is asked to give consent at the hospital. To further facilitate and assure donation, the UAGA requires hospitals to make a routine inquiry and request donation of hospital patients. The way the UAGA operates at present is sometimes called “opting in”. In other words, a person must affirmatively indicate, “yes, I wish (or I wish my relative) to be an organ donor”. This is the way the organ donation system works in Hawaii today and is the majority-held view.

In an effort to simplify organ donations, the UAGA also provides language that would appear to give the donor final say in how the donor’s organs would be dealt with. Section 2(h) of the UAGA as adopted in Hawaii reads: “an anatomical gift that is not revoked by the donor before death is irrevocable and does not require the consent or concurrence of any person after the donor’s death.”<sup>17</sup> (Emphasis added.) However, despite this statutory provision, Hawaii’s hospitals request an additional consent from (specified) family members. This additional consent often subverts the intent of the donor and the UAGA. Observers point out that a hospital’s request of an additional consent from the potential donor patient’s family, which developed over past practice, is probably being made to avoid a lawsuit and bad publicity, or to maintain good public relations, or made in consideration of the feelings of the patient’s family. Historically, there are at least two reasons medical personnel ask for relative’s consent. First, the surviving relative has always had control over disposal of the deceased including granting permission to conduct an autopsy. Second, asking for consent to take organs developed over the years when transplantation was an uncommon medical practice. Both reasons, combined with reluctance to appear callous at a time of family grief, all serve to continue the practice. The fact that a person’s family can veto the wish of the donor means that the original intent of the Hawaii law, UAGA, which was to facilitate donation and recovery of organs and tissue for transplantation, often results in a contrary result in its application. Some people believe this is the reason that despite its more than thirty year history, the provisions in the UAGA have failed to increase organ donation.<sup>18</sup>

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<sup>14</sup> *Ibid.*, p. 14.

<sup>15</sup> *Hawaii Rev. Stat.*, section 327-4.

<sup>16</sup> J.R. Johnson, “A Study of the United States’ Organ Donation Program,” p. 3.

<sup>17</sup> *Hawaii Rev. Stat.*, section 327-2(h).

<sup>18</sup> J.R. Johnson, “A Study of the United States’ Organ Donation Program,” p. 4. It has been said that “. . . in holding with tradition rather than relying on the clear terms of the law, medical personnel routinely require additional consent.” Citing D. Sipes, “Does it matter whether there is a public policy for presumed consent in organ transplantation?” *Whittier Law Review*, vol. 12:505-535.



There are two ways to approach the consent issue, first by working through the UAGA by educating and encouraging family discussions so that a donor's wishes are made known and hopefully respected by family members. The second alternative is to improve organ donation rates by amending the law regarding the kind of consent that makes it acceptable for organs to be retrieved with little overt action by the donor. So far, modifying peoples' behavior through education has been the more popular route taken by states rather than changing the definition of consent. The varieties of consent proposals are presented below.

### **Promote Family Discussions About Organ Donations To Facilitate Consent From Next Of Kin**

As the Gallup poll found, fewer than one in three individuals have taken the initiative to discuss with their family their personal wishes about organ donation even after having designated on their driver's license a wish to become an organ donor.

Under the UAGA, the organ donor is not advised to inform his or her family about their organ donation decision. In fact the donor may be under the impression that no other person's approval is needed and that his or her wishes will be respected and acted upon accordingly, so no discussion with family or anyone else, is necessary. Therefore the patient's choice to donate may come as a surprise to the family at the time of death, when they are less likely to think unemotionally and clearly about the issue. In practice, even after a person has agreed to be an organ donor and has this fact recorded on the driver's license card, the hospital will ask family members whether or not they wish to have their relative's wishes honored, giving the family effective veto power over the wishes of the deceased. Hawaii follows the UAGA model.

The Secretary of State in Illinois (who is charged with promoting the organ donation program) sends a follow-up letter to each new registrant registering in the Illinois organ donor registry, reminding them to tell their families about their decision. This letter can be the catalyst for a discussion among family members of their own views about organ donation so that when and if consent must be obtained it may be easier to speak with the family and result in a donation.

### **Solicit Help From Other Professional Organizations To Raise The Discussion Level Among Citizens**

Another way to influence receiving consent from next of kin is to raise the issue in the family context when wills and trusts are being written.

Peter Wolk, of the National Center for Nonprofit Law has suggested that all state bar associations be solicited by organ donation groups to include in their continuing education training material or other information to encourage its members who practice in estate planning to discuss organ donation with the client. This can include asking the following kinds of questions of their clients who come in for wills, trusts, and the like:

1. Do you wish to be an organ and tissue donor?
2. If yes, have you signed an organ and tissue donor card or indicated on your driver's license your intent to be an organ and tissue donor?
3. Have you told your family about your intention to be an organ and tissue donor?

This kind of reminder could be helpful to raise the organ donation awareness level at a time that death issues regarding the person's estate are being discussed.

The Legislature could facilitate this process by adopting a Concurrent Resolution requesting the Hawaii Bar Association to adopt this kind of policy for its members. See Appendix B of this report for suggested language for a Concurrent Resolution.

In Maryland, its attorneys have specific, explicit language about organ donation approved by the legislature for inclusion into advanced medical directives and living wills. In Hawaii, any person who has declared specific wishes regarding medical treatment at the end of life can be an organ donor.<sup>19</sup>

### **Presumed Consent**

Educating people so that they would be more willing to give consent for themselves as well as for their next of kin takes time and effort by the organizations and individuals involved in the organ donation process. In order to make the retrieval of organs less discretionary for the individual some states have proposed the "presumed consent" option. Presumed consent means a person is presumed to have agreed to organ donation if no refusal has been registered. In other words "In presumed consent, being a donor is the norm, while being a non-donor is the exception".<sup>20</sup> In its purest form of presumed consent, only the individual himself can "opt out" or object to making an organ donation. In Europe, Austria is the only country with the purest form of presumed consent. A "weak version" of presumed consent requires permission of the family if the family can be located. Contrast the presumed consent norm with the law as provided by the UAGA, where being a non donor is the norm and non consent is presumed so that to become a donor, one must "opt-in". This opting-in policy is what Hawaii practices.

Presumed consent has been in effect in several foreign countries including Singapore, Belgium, France, Finland, Norway, Denmark, and Austria. It is claimed to have doubled organ recovery in Belgium.<sup>21</sup> In Belgium, a law on the procurement and transplantation of organs based on presumed consent was passed in 1986. In 1990 an article reviewing the effect of the law reported that "the total number of organs available for transplantation increased from 223 in

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<sup>19</sup> *Hawaii Rev. Stat.*, chapter 327D.

<sup>20</sup> H. Gabel, "How presumed is presumed consent?", *Transplant Proceedings*, Feb. 1996, pp. 27-30.

<sup>21</sup> J. Michael Dennis, et al., "An Evaluation of the Ethics of Presumed Consent and a Proposal Based on Required Response," UNOS Presumed Consent Subcommittee, Ethics Committee, June 30, 1993.

1984 to 532 (+183%) in 1988. Furthermore, “the total number of kidneys, hearts, and livers transplanted increased from 234 to 561 within five years (+140%).” By comparing the data from three European countries having presumed consent laws (Belgium, Austria, and France) with three European countries with opting-in policies (United Kingdom, Federated Republic of Germany (FRG), and the Netherlands) the presumed consent countries were able to transplant 34.7 kidneys, 9.7 hearts, and 12.4 livers per million inhabitants whereas the opting-in countries could transplant only 26.3 kidneys, 3.2 hearts, and 1.5 livers per million inhabitants during the same period.<sup>22</sup>

In 1993 the Pennsylvania legislature proposed a version of presumed consent which provided that organs and tissues could be removed for transplantation unless there was an expressed opposition, was rejected.<sup>23</sup> No reference was made in the proposed language for locating and obtaining family authorization.

The Texas statute which authorizes the medical examiner to permit the removal of organs after determining that there is no reasonable likelihood that a family member can be located during the four hours after death, is the first of its kind in the nation.<sup>24</sup> Additionally, Texas law provides that if a donor has expressed a desire to donate the family cannot veto this wish<sup>25</sup>. The adoption of the Texas law was in response to a low donation rate in that state. Texas had 126 people die in 1990 waiting for an organ and 835 people on the waiting list.<sup>26</sup> Interestingly, it is still conjectured that although hospitals and doctors should honor the donor’s wishes they will continue to ask family members for their consent even though hospitals and doctors would not be civilly or criminally liable.<sup>27</sup> It is not clear why this practice for relative’s consent would continue, as the Texas Anatomical Gift Act provides that if the decedent is a donor 18 years or older the decedent’s gift shall be honored without obtaining the approval or consent of any other person.<sup>28</sup> And Texas law further provides that any person who acts in good faith (defined as making a reasonable effort to locate and contact the decedent’s next of kin in

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<sup>22</sup> L. Roels, et al., “Effect of a presumed consent law on organ retrieval in Belgium,” *Transplantation Proceedings*, vol. 22, no. 4 (August 1990), pp. 2078-2079 and L. Roels, et al., “Three years of experience with a ‘Presumed Consent’ legislation in Belgium,” *Transplantation Proceedings*, Vol. 23, No. 1, February 1991, pp. 903-904.

<sup>23</sup> Senate Bill 794 P.N. 857 (session of 1993) read as follows: Sec. 8631. Presumption of anatomical gift. Organs and tissues may be removed, upon death, from the body of any Commonwealth resident by a physician, surgeon or technician for transplantation or for the preparation of therapeutic substances, unless it is established that a refusal was expressed in accordance with this subchapter.

<sup>24</sup> *Texas Codes Ann.*, section 693.003(c), Health and Safety Code, Consent required in certain circumstances.

<sup>25</sup> *Texas Codes Ann.*, section 692.003(e), Health and Safety Code, Manner of executing gift of own body.

<sup>26</sup> “Dick Stanley, “Organ-procurement conflict arises over presumed consent,” *Austin American Statesman*, Sept. 29, 1991.

<sup>27</sup> J.R. Johnson, “A Study of the United States’ Organ Donor Programs,” p. 15.

<sup>28</sup> *Texas Codes Ann.*, section 692.014, Procedures, Health and Safety Code.

order of priority within the four-hour window) liability is limited except in the case of negligence.<sup>29</sup>

Under a presumed consent proposal, unless a person “opted out” by indicating a refusal to donate an organ, that person’s organs would be available for donation even without family permission. “Singapore is the first Asian country to implement the opting out system of obtaining cadaver kidneys for transplantation.”<sup>30</sup> In Singapore, every citizen and permanent resident agrees to donate kidneys upon the citizen’s death unless that person has opted out by signing an objector’s form. Singapore’s Human Organ Transplant Act was adopted in 1987 and covers the following areas: removal of kidneys, legal criteria of death and the preconditions which must exist before kidneys can be removed, and a prohibition against trade in organs.

There are several significant characteristics about Singapore’s law. First, the death must have been caused by an accident and the coroner must consent to removal of the kidneys. No organ (i.e. kidney) may be retrieved if the person has filed an objection form during that person’s lifetime. The opportunity to object is accomplished by sending all Singaporeans a letter informing them of this option on their twenty-first birthday. Anyone who has filed an objection has that objection registered within twenty-four hours by the director of medical services. This list is in computerized form that can be accessed by five of the major hospitals in Singapore. Anyone who has not opted out during his or her life is granted priority for kidney transplantation.

An even stronger application of denying family members a veto over a patient’s explicit wish to donate organs, is to propose a statutory fine upon the hospital which refuses to retrieve organs from an otherwise suitable and available donor. No state has chosen the “opt-out” proposal or the suggestion to fine an uncooperative hospital for refusing to retrieve a suitable organ, with or without family consent. To be discussed later in this chapter, but noteworthy to mention here is the recent federal rule adopted by the U.S. Health Care Financing Administration (HCFA) that now requires all hospitals participating in Medicare and Medicaid reimbursement programs to report all deaths to the local OPOs.<sup>31</sup> The sanction under HCFA regulation is the withdrawal of certification for Medicare and Medicaid reimbursement. Some states that have adopted laws providing similar language requiring referral of all hospital deaths to the OPO impose fines upon uncooperative hospitals. For example, in Pennsylvania noncompliance with the required referral provision subjects a hospital to a fine of \$500 for each instance of noncompliance.<sup>32</sup>

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<sup>29</sup> *Texas Codes Ann.*, section 692.016, Limitation of Liability, Health and Safety Code.

<sup>30</sup> P. Soh, et al., “Profile of an Asian ‘opting-out’ system—the institutional and legal arrangements in Singapore,” *Transplantation Proceedings*, vol 24, no. 4 (August 1992), pp 1323-1324.

<sup>31</sup> U.S., Department of Health and Human Services, Federal Register, June 22, 1998, Final Rule on Medicare and Medicaid Programs; Hospital Conditions of Participation; Identification of Potential Organ, Tissue, and Eye Donors and Transplant Hospitals’ Provision of Transplant-related Data.

<sup>32</sup> *Penn. Consolidated Stat.*, section 8617(g).

In Hawaii there is a precedent for implying consent by statute in the area of testing for driving under the influence of drugs or alcohol. Under the “DUI” consent concept, a driver agrees to submit to a chemical test of blood, breath, or urine when applying for a driver’s license.<sup>33</sup> A statutory provision to allow the retrieval of a driver’s organs upon death, with the proviso to permit a driver to opt out of consenting to organ donation at the time of submitting a driver’s application, might be structured like the one implying consent to submit to alcohol and drug testing. Under the current UAGA law in Hawaii, a driver only indicates a “yes” and not a “no” option. Changing the Hawaii law on anatomical gifts in this manner would make it resemble the presumed consent law and possibly increase the supply of organs for transplantation. It would require a registry that can be accessed by the OPO to determine whether or not a person objected to donation. If the registry is properly maintained and accessed by an OPO, it would not require emergency personnel searching personal effects for the document of gift, in the case of an accident victim. Some writers argue that under this scenario greater diligence is required of the OPO and persons involved in organ retrieval, because of the possibility of retrieving organs from someone who might have opted out. Some writers point out the possibility that the higher donation rates that have been reported by presumed consent countries is the result of a well executed educational campaign that encourages citizens to donate rather than to the law itself.

Much of the debate about presumed consent deals with philosophical issues over the degree of self-determination or individual autonomy that should or should not be granted to a citizen regarding what happens to one’s body. The person who favors individual autonomy would more likely support pure presumed consent—that is, absent express refusal no permission is needed from anyone to take an organ. However, one who feels that next of kin are entitled to have a say in the disposition of a relative’s body would prefer being asked for permission to take organs from that relative.

### **Required Response**

Those who find presumed consent in any of its variations unacceptable to the principles of individual freedom upon which the United States has been founded have suggested the “required response” proposal. Required response is a method whereby all adults would be required to register their donation wish that would be collected into a national registry. (This proposal is similar to the Singaporean experience except that in Singapore, the accident victim donates only kidneys and the register is an “opt-out” list.) In the required response proposal, there would be an indication one way or another (yes or no). The list would be available to organ procurement organizations and the family need not be viewed as an obstacle because the required request form would be a legal document.<sup>34</sup> (See Appendix C for a sample Required

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<sup>33</sup> *Hawaii Rev. Stat.*, section 286-151(a) provides: “Any person who operates a motor vehicle or moped on the public highways of the State shall be deemed to have given consent, subject to this part, to a test or tests approved by the director of health of the person’s breath, blood, or urine for the purpose of determining alcohol concentration or drug content of the person’s breath, blood, or urine, as applicable.”

<sup>34</sup> J. Michael Dennis, et al., “An Evaluation of the Ethics of Presumed Consent and a Proposal Based on Required Response”.

Request Form). The advantage of a required response policy is that every adult would be asked; thereby solving one of the dilemmas identified by many polls -- that the respondent never considered organ donation because they were never asked.

The UNOS subcommittee that examined the required response proposal said:<sup>35</sup>

The Subcommittee proposes the policy of required response as the first part of a larger reform strategy. Over time, ideally, the legal regime regulating organ donation will approach the policy of “presumed consent” wherein organs and tissue are recovered without active consent seeking on the part of OPOs. The envisioned policy evolution is as follows: As adults increasingly “opt-in” to the donation system by expressing “yes” via required response, the practical necessity of checking the database recording preferences will diminish. The evolution is for a societal consensus on transplant donation to emerge, as recorded through required response, so that consent may be safely “presumed” because of universal approval of organ donation. . . a key element in this evolution would be a public education campaign coordinated with the implementation of required response. (Emphasis added.)

Several states have taken measures whose thrust is consistent with the policy of required response . . . Donor registries have not yet been organized on a scale and accessibility necessary to be useful to organ procurement organizations. Four States (Florida, Ohio, Illinois, and Oregon) have gone furthest in registering donors however, it is unclear whether the collected information assists procurement organization in the identification of donors.

Although the states would administer the form and collect signatures, the information itself would be centralized in a National Donor Registry (NDR). On a weekly basis, states would collect signed forms and ship them to the relevant organization for processing. The NDR would be accessible by all OPOs on a real-time basis so that OPOs can be told of the individual’s preference towards donation regardless of the individual’s place of residence (in or out of state). (Emphasis added.)

A national registry of names resulting from a required response proposal should not be confused with the UNOS maintained national transplant registry which is a list of people awaiting a suitable organ match for transplantation.

### **State Registries**

State registries or databases of donors require that a state collect the names of all persons willing to be organ donors into a central file. As alluded to in the earlier discussion under required response, registries serve several purposes, but primarily give the state an idea of how many donors a state might have from driver license provisions that ask if the driver is willing to donate his organs. In some cases these registries are used and accessed by OPOs.

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<sup>35</sup> J. Michael Dennis, “An Evaluation of the Ethics of Presumed Consent and a Proposal Based on Required Response,” from its Characteristics of Required Response, pp. 18-19.

A survey of motor vehicle provisions in 1993 revealed that ten states have some version of organ donor lists or registries.<sup>36</sup> However, there is wide variation in computerization and access to these lists. In seven of these ten states, these records are maintained for internal use only. Some donor registries are maintained in manual files and are not computerized. Very few states know how many of their drivers were registered donors. Most states can only claim to approximate the number of their registered donors. Access to these donor records is allowed to the state's organ donor center in about six of these states. Some states have next of kin information, others do not.

Texas law provides for a statewide database of donors to be developed “. . . in cooperation with qualified organ, tissue, and eye bank organizations.”<sup>37</sup>

Illinois also established a donor registry to keep track of individuals willing to be donors through the driver's license and identification card database. Organ procurement personnel, coroners, law enforcement and the Cook County Medical Examiner have access to an 800 line that is staffed 24 hours a day, seven days a week. The hotline receives about fifty-five calls each month from organ banks. The donor information is confidential.<sup>38</sup> Said one Illinois official, “the registry will help measure the effectiveness of outreach and education efforts. We always have reporters calling and asking how many donors we recruit, but until the registry was designed, we had no way to count them”.<sup>39</sup>

Florida maintains an organ and tissue donor registry. The state's agency for Health Care Administration and the Department of Highway Safety and Motor Vehicles has developed and implemented an organ and tissue donor registry which records, through electronic means, organ and tissue donation documents. The registry is accessible 24 hours a day, 7 days a week to hospitals and OPOs through a code. The registry is paid for from the Florida Organ and Tissue Donor Education Trust Fund and an annual assessment against each registered OPOs, tissue, and eye bank.<sup>40</sup>

In Georgia, the Department of Public Safety makes available to federally designated OPOs the name, license number, date of birth, and recent address of drivers. This information is used for the purpose of establishing a statewide organ donor registry accessible to organ, tissue and eye banks only.<sup>41</sup>

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<sup>36</sup> J.R. Johnson, “A Study of the United States' Organ Donor Programs,” p. 12.

<sup>37</sup> *Texas Codes Anno.*, section 521.401(c), Statement of Gift.

<sup>38</sup> Illinois Organ/Tissue Donor Registry information sheet.

<sup>39</sup> J.R. Johnson, “A Study of the United States' Organ Donor Programs,” Appendix B from State of the Art: Illinois, State Health Notes, March 8 1993, p. 3.

<sup>40</sup> *Fla. Stat. Anno.*, section 732.915, Delivery of document, organ and tissue donor registry.

<sup>41</sup> *Code of Georgia*, section 40-5-25 (3), Application, fees.

A registry is useful only if it maintained regularly and accurately, can be accessed by authorized persons at all hours of the day, and is equipped with sufficient protections for confidentiality and privacy. In Hawaii, names of drivers who have initialed the question about being an organ donor is confidential and only the number of drivers who have indicated a willingness to donate organs is forwarded to the ODC. The creation of a registry would require the cooperation of the various county division of motor vehicles so that donor's names are accurately recorded, added, or removed, as necessary. It would also require a computer system capable of maintaining the registry on a 24-hours, 7 day a week basis, with protections for confidential access by authorized agencies only.

### **Raising Public Awareness**

Most states have concentrated on educating the public about organ donations in the hope of encouraging voluntary participation instead of challenging the tradition which gives relatives authority to veto organ donation by adopting some form of presumed consent.

As the Gallup survey revealed in 1993, 47% of the respondents simply do not think about the organ donations in the course of everyday life. Organ donation may be viewed by some as still an experimental procedure; at least nearly two-fifths of the respondents in the Gallup poll thought so. To raise public awareness, outreach and publicity of many kinds must be used to reach everyone. Education elements include making people realize that:

- (1) Organ donation is a viable medical option that requires the gift of a donor's organ in order to succeed;
- (2) Removal of organs occurs only under specific conditions after death has been declared;
- (3) Removal of organs does not disfigure the deceased and therefore does not preclude an open casket funeral;
- (4) Many religions support donation;
- (5) Survivor's families often feel positive good has come of their personal loss

### **Media Campaigns**

Public service announcements on television and radio, human interest stories in the newspaper, posters on public transit buses, are examples of media campaigns. News articles that show organ transplant recipients returning to a normal life of raising a family, playing sports, traveling, all help to emphasize the normality of this type of surgical procedure.



In Illinois, the Secretary of State is responsible for issuing driver's licenses and specifying the format to indicate an organ donation is intended by the driver. The Secretary is also responsible for sending each applicant or licensee a brochure to advise how a document of gift may be made, and the "Secretary of State may undertake additional efforts including education and awareness activities to promote organ and tissue donation."<sup>42</sup>

Illinois promotes organ donation awareness education through "paid radio, television and print media". Illinois spends \$1,000,000 each year to pay for this media campaign. There is a "Live and Learn" special fund started with a \$2,000,000 budget in 1993, funding for which comes from an increase in motor vehicle title and transfer fees. Organ donation awareness is raised among drivers in Illinois from the placement and playing of an informational videotape for people to watch while waiting to obtain or renew their driver's license. Also in Illinois, posters and brochures are placed in drivers license facilities as ways to make drivers aware of the need for more donors. Among its print media, "medical and religious reporters are targeted for specific stories of interest to their audience."<sup>43</sup>

### **Targeted Groups (Minorities)**

In Florida, the education program relating to anatomical gifts contains a specific legislative finding as follows:

The Legislature finds that particular difficulties exist in making members of the various minority communities within the state aware of laws relating to anatomical gifts and the need for anatomical gifts. Therefore, the program shall include, as a demonstration project, activities especially targeted at providing such information to the nonwhite, Hispanic, and Caribbean populations of the state.<sup>44</sup>

In Illinois, African-Americans and Hispanics are targeted at fairs, festivals, community gatherings, and the like, with information booths and appearances by high profile leaders from those communities to help promote the organ donation theme among minorities. Bilingual information also helps to include minorities in these efforts.

In Hawaii, the Organ Donor Center of Hawaii has a Minority Organ Tissue Transplant Education Program (MOTTEP) that educates minority groups about the advantages of organ donation and the disproportionate need for organs among the minority population. For example it was revealed that in Hawaii while there are about five Caucasian organ donors for each Caucasian needing an organ transplant, there is only one Japanese donor for three who need it, and one Filipino donor for every six Filipino transplant patients waiting for an organ.<sup>45</sup>

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<sup>42</sup> *Ill. Comp. Stat.*, section 5/6-110(b).

<sup>43</sup> George H. Ryan, Illinois Secretary of State, Illinois Life Goes on Organ/Tissue Donation Awareness Program, "Media Campaign" sheet.

<sup>44</sup> *Fla. Stat. Anno.*, section 732.9215, Education program relating to anatomical gifts.

<sup>45</sup> MOTTEP in Motion, Newsletter of the National Minority Organ/Tissue Transplant Education Program, Spring 1998, p. 1.

### **Targeted Groups (Children/Schools)**

In Maryland, a recently adopted law (often referred to as the William H. Amoss Organ and Tissue Donation Act of 1998) allows minors to designate themselves as an organ donor on their licenses with parental consent. Under the UAGA, no provision existed for a minor to become a donor.

Virginia, too, allows a minor to make a donor designation, with the consent of the parent or guardian.<sup>46</sup>

The Illinois education program relating to anatomical gifts involves students in grades K through 12 while in Florida's education program relating to anatomical gifts the law specifies development of a program to educate high school children. Illinois's State Health Notes for March 6, 1993 reported that an annual poster contest started in 1991 where winners received savings bonds that had been donated by the American Legion and the posters were hung in the driver licensing facilities.

In Pennsylvania, a portion of the Organ Donation Awareness Trust Fund is dedicated to the production of information pamphlets designed by the Department of Health informing people about the state's organ donation law, how to contribute to the awareness fund, and so on. Another portion of the same trust fund is dedicated to awareness programs in the secondary schools with moneys being spent by the Department of Education. Educating youngsters about the potential life-saving benefits of organ donation might influence behavior when they become adults or when the child takes material home and raises the issue with parents. Children are made aware of organ donations through poster drawing contests and the like.

Pennsylvania's educational awareness efforts are paid for from the fund that is replenished by a \$1 additional fee attached to a motor vehicle registration fee and a driver's license fee. Additional funds may come from voluntary contributions made by a taxpayer on the taxpayer's state income tax form. If the taxpayer is due a tax refund, the taxpayer may deduct an amount from that refund to be designated to the Organ Donation Awareness Trust Fund. Other taxpayers who do not receive tax refunds can send contributions directly to the address of the Organ Donor Awareness Trust Fund which is printed on the tax form.

In Kentucky, an organ donor awareness fund (Trust for Life) was established in 1993 to be funded from a voluntary \$1 collected from drivers. Money from the fund will be used for outreach and education.<sup>47</sup>

In contrast, publicity in Hawaii appears on an ad hoc basis without any intentional government intervention. News items highlighting the fundraising efforts by someone who

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<sup>46</sup> *Code of Va.*, section 46.2-3.42, What license to contain; uniform donor document.

<sup>47</sup> Telephone interview, September 24, 1998, Sara Ball, Director of Administrative Services, Kentucky Organ Donor Affiliate.

needs an organ or bone marrow transplant can be used as an occasion to point out the wide disparity between donation and need for organs.

### **Targeted Groups (Religious Beliefs)**

Incorrect information about religious beliefs, superstition, or other dogma may lead to the belief that donating vital organs leaves the body less suitable for the hereafter. Demystifying organ donation and correcting some misconceptions about religious beliefs might increase organ donations.

In Illinois, clergy outreach guides with sample sermons, newsletter articles, bulletin inserts and donation information are sent to religious leaders of the African-American and Hispanic communities.<sup>48</sup> Participation by organ donation groups and the Secretary of State in the annual Donor Sabbath held in November help to dispel long-held religious prohibitions about making an organ donation. In some communities, the influence of the religious leaders becomes critical to successful organ donation campaigns among minority ethnic groups because the church influences the behavior of the congregation.

In Hawaii, again with no government involvement, articles that quote religious leaders about donating organs help to educate the public. For example, in the cover article about organ transplants, July 29, 1998 issue of *Midweek*, three religious leaders in Hawaii were quoted as follows:

Says the Rev. Mark Alexander, theologian of the Roman Catholic Diocese of Honolulu, "The pope has encouraged it (organ donation) as a way of acting on the Biblical command to love your neighbor. It's a way to continue loving and serving your neighbor even after your actual death."

"I can't speak for God," says Rabbi Avi Magid of Temple Emanu-El, "But given the assumption of heaven as a place to go, I think God would be happy to reach down for someone who gave of him or herself to save another life."

The Rev. Chikai Yosemite, bishop of Honpa Hongwangi, supports organ transplants: "It is based on dana, the concept of selfless giving. And one of the most important sutra teaches that "those who possess should share with the less fortunate."<sup>49</sup>

### **Increase Donations By Increasing Entry Points**

An entry point might be viewed as the point where a citizen interacts with the government in some way, like registering to vote, or applying for a driver's license, or registering a motor vehicle, filing a tax return, filling out a borrower's card at the local library,

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<sup>48</sup> George H. Ryan, Illinois Secretary of State, Illinois Life Goes on Organ/Tissue Donation Awareness Program, "Grassroots" sheet.

<sup>49</sup> *Midweek*, July 29, 1998, "Making Miracles, Changing Lives" (cover story).

and so on.<sup>50</sup> When voter registration numbers fell, for example, the states looked for ways to make it easier for a citizen to register to vote. In Hawaii, a Wikiwiki registration form can be found in the yellow pages telephone book. Similarly, a voter registration form is made available to an applicant for a driver's license<sup>51</sup> so that the applicant can register to vote at the same place that a driver's license is paid for. A change in public policy was designed to increase the numbers of voters by simplifying the registration process.

The same kind of facilitation could occur for organ donations. Whenever a citizen interacts with a government agency, there are opportunities to raise the question of organ donation. In the UAGA for example, the driver's licensing application or renewal process is used as the entry point for asking whether a person is willing to be an organ donor.

In Illinois, a successful campaign has 3,700,000 participants in the organ donor program from a potential source of 9,600,000 drivers.<sup>52</sup> This is about 38.5% of the driving population in Illinois. In Illinois, this entry point is further embellished upon with a variety of other methods and the method of asking the question is also different. As described in its information packet: When setting up a Donor Registry it is important to carefully word the question that requests participation and to reflect on whether to print "no" as well as "yes" responses on the driver's license or registry card. In Illinois, the Organ Donation Request Act prohibits hospital and organ bank personnel from requesting donation if there is prior "notice of opposition." For that reason, Illinoisians are asked if they want to "participate in the registry," not if they want to be organ or tissue donors.<sup>53</sup>

The question applicants are asked is: "Do you intend to sign the organ donor portion of your driver's license/ID card and participate in the registry as a potential donor?" If a person answers yes, a "Y" appears on the license or ID card. If the answer is no or undecided, no indication is made on the card.

The staff of one hundred thirty seven driver services facilities participate in continuing education in order to improve the way they ask new or license renewing drivers for their intention to join the registry, to increase a facility's organ donor registry participation rate. Each facility that reaches a fifty percent or higher rate is recognized with an award. Illinois goes another step by using the organ donation information obtained by the driver service facilities to build an organ donor registry. The Secretary of State (who is charged with promoting the organ donation program) sends a follow-up letter to each new registrant reminding them to tell their families about their decision.

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<sup>50</sup> An entry point is also referred to as a "universal moment" in *Controversies in Organ Donation*, National Kidney Foundation, Inc., NY, June 1993, p. 4.

<sup>51</sup> *Hawaii Rev. Stat.*, section 286-108(a).

<sup>52</sup> George H. Ryan, Illinois Secretary of State, Illinois Life Goes on Organ/Tissue Donation Awareness Program, Introductory letter, "Organ/Tissue Donor Registry" sheet.

<sup>53</sup> *Ibid.*

Information about organ donation is sent to people who do not sign up for the registry at the time of renewing or applying for a driver's license. This effort hopefully makes them more aware of the program and ready to change their mind when the next renewal period arrives in four years time.

Illinois also uses the renewal notice and direct mail (with a tear off card) to inform its drivers about the organ donor registry program. According to Illinois' information packet information, "We have seen first-hand that greater public awareness increases not only registry numbers, but actual organ and tissue donations."<sup>54</sup> Illinois' efforts to train its staff to ask each driver, to give recognition to the government offices that meet goals, and the follow-up by the secretary of state all positively reinforce the behavior of the citizen. Educational materials sent to a nondonor are designed to broaden the citizen's perspective about organ donation to help them change their mind at the next entry point.

In Pennsylvania, an indication on a driver's license that the driver consents to organ donation is noted on the front of the driver license card. This notation ". . . is deemed sufficient to satisfy all requirements for consent to organ or tissue donation."<sup>55</sup> And further, ". . . the intent of a decedent to participate in an organ donor program as evidenced by the possession of a validly executed donor card, donor driver's licenses, etc. shall not be revoked by any member of the classes specified (spouse, child, parents, et al.)"<sup>56</sup> Aside from these provisions Pennsylvania does not appear to have a concerted program for educating its motor vehicle drivers of the need for organ donors as Illinois has developed.

In comparison, Hawaii had 733,486 drivers' licenses in force at the end of 1996.<sup>57</sup> Assuming a 26.7% organ donation rate (based on the rate in May 1998 -- see Exhibit 3 in chapter 2), there might be 195,840 donors from the Hawaii driving population. In Hawaii, each driver is asked on the license application to indicate "if you wish to be an organ donor please initial" on its official license application form. Then the words "organ donor" is printed on a driver's license lower right corner in red print, if a person is willing to be an organ donor. Unlike Illinois, there are no informational videos for the public to watch while waiting to be processed, and the counter staff do not receive formal training. Hawaii does not allocate funds specifically targeted towards encouraging drivers to agree to donating organs or recognize or reward the employees in the driver license facilities (or satellite city halls which also collect the license application or renewals) who seek to raise the organ donor numbers. Hawaii also does not have an organ donor registry as in Illinois. Finally, there is no effort to follow up with a letter to the driver/donors to thank them and there is no single official who is authorized to do so. Nor is there a program to educate those who did not sign the appropriate space on the driver application to help them change their minds by their renewal date.

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<sup>54</sup> *Ibid.*

<sup>55</sup> *Penn. Consolidated Stat.*, section 8619.

<sup>56</sup> *Penn. Consolidated Stat.*, section 8617(c).

<sup>57</sup> The State of Hawaii Data Book 1996, Table 18.16, p. 468.

### **One-Time Mailout Of Donor Cards By A Government Agency**

One idea that may be worthy of notice is a one-time mailout of an organ donor card with a short descriptive brochure that accompanies a tax return. The 104th Congress passed as part of the Health Insurance Portability and Accountability Act,<sup>58</sup> a provision directing the department of the treasury to include information on organ and tissue donation with each tax refund check mailed between 1 February and 30 June, 1997. This huge public education program called the Donor Insert Card mailing asks the recipient to become a donor by signing a donor card and discussing that fact with family members.<sup>59</sup>

Perhaps a similar type of one-time mailout of informational brochures can be enclosed with the tax form mailed to taxpayers in Hawaii. The ODCH and other tissue, bone marrow, and eye bank organizations can help provide information. Other kinds of publicity can be used. For example, on the back of U.S. postage stamp folders can be found information about the National Marrow Donor Program. (See Exhibit 4.)

#### **Exhibit 4-1**

#### **NATIONAL MARROW DONOR PHOTOCOPY AD**

### **Rewards To Donors**

An UNOS survey found the following incentives agreeable to most people: (a) a cash award to the donor's estate (b) a cash award to the charity of the donor's choice (c) a limited low cost life insurance policy that can be redeemed by the donor's family after the donation (d) giving the donor's family a "preferred status" should one of them require a transplant in the future. Of these four choices, preferred status was favored over all, followed by a \$2,000 payment to the donor's family for funeral expenses. Of all respondents surveyed, 52% agreed

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<sup>58</sup> P.L. 104-191 (104 Congress 1997).

<sup>59</sup> Tax Refund Donor Insert Card Release on [www.unos.org](http://www.unos.org), Sept. 25, 1998.

that some form of financial or nonfinancial compensation should be offered in the United States to increase organ donation.<sup>60</sup>

The 1993 Gallup poll found that if there were a financial incentive 80% of the respondents would not change their minds about the likelihood of donating but 12% would be more likely to donate, five percent less likely to donate. Younger and nonwhites appeared more likely to favor financial incentives.

### **Financial Incentive For The Donor And Family**

Financial incentives has been defined as “any material gain or valuable consideration obtained by those directly consenting to the process of organ procurement, whether it be the organ donor himself (in advance of his demise), the donor’s estate, or the donor’s family.”<sup>61</sup> Federal law currently prohibits the sale of organs for profit.<sup>62</sup> One state, Pennsylvania, has adopted a policy of financial rewards which as yet has not been challenged as “a transfer for valuable consideration”.

Ten percent of the Pennsylvania Organ Donation Awareness Trust Fund which is a special fund into which contributions from a \$1 per driver’s license or identification card and other sources are deposited can be used for “reasonable hospital and other medical expenses and incidental expenses incurred by the donor or donor’s family in connection with making a vital organ donation. The expenditures cannot exceed \$3,000 per donor and must only be made directly to the funeral home, hospital, or other service provider related to the donation and . . . not directly to the donor’s family, next of kin or estate.”<sup>63</sup>

One writer<sup>64</sup> has said that by treating this section of the law as a pilot program and one monitored by an advisory committee, Pennsylvania could apply for an exemption from the federal prohibition. Also, by making the \$3,000 payment to a body that is not the donor’s family “. . . compensation to the provider is not “valuable consideration” to “acquire, receive or otherwise transfer “ the organ. Coleman however finds “this argument flawed because if the provider was not paid by the Fund, the donor’s estate would be liable. Therefore, patients who are worried about hospital bills or funeral expenses may well feel the same pressure to help their families and donate as if the money were being paid directly to their heirs.”<sup>65</sup>

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<sup>60</sup> Kittur, Dilip S., et al., “Incentives for Organ Donation,” UNOS update Jan. 1992, p. 9.

<sup>61</sup> UNOS Financial Incentives for Organ Donation; a report of the UNOS ethics committee, payment subcommittee, June 30, 1993, p. 2.

<sup>62</sup> 42 USC 274e (1994) states: “it is unlawful for any person to knowingly acquire, receive or otherwise transfer any human organ for valuable consideration for use in human transplantation.”

<sup>63</sup> *Penn. Consolidated Stat.*, section 8622(b)(1).

<sup>64</sup> Phyllis Coleman, “Brother, can you spare a liver? Five ways to increase organ donation,” *Valparaiso Univ. L. Rev.*, vol. 31, no. 1, Fall 1996.

<sup>65</sup> *Ibid.*, p. 21.

If payment for a donor's hospital or other medical expenses were to be offered in Hawaii, the funds could be used to offset the donor's pre-consent medical costs, because under the ODCH's arrangement, once consent is given, the OPO picks up costs related to the organ donation. Alternatively, funds could be used for funeral costs.

In Georgia, the motor vehicle driver who consents to donating organs receives a reduction of the pertinent license fee cost to \$8 instead of \$15.<sup>66</sup>

### **Sell Organs**

The altruistic gift of donating an organ developed over time when transplantation was an unusual medical option during the 1960s and the number of transplants being performed were minimal. The federal prohibition against selling organs from deceased persons and the term "document of gift" in the UAGA indicate the intention that an organ is bestowed without expectation of payment. The proposal of outright sale of organs appears to be distasteful to many, but some writers view this policy as only perpetuating the organ shortage problem.

At least one author has proposed an examination of the concept of sale of organs to increase organ supply through a pilot project of giving a death benefit of \$1,000 to the family of an organ donor.<sup>67</sup> Peters suggests the pilot program as a way to determine citizen support. He argues that while most members of society espouse the established view of altruism at the time of donating a relative's organs, there may some members of our community for whom altruism is the last consideration. He cited as an example, the enthusiastic donation of a relative's organs because the next of kin did not like that patient and wanted to see the patient dead. Peters argued that a \$1,000 death benefit was not very much money to be considered coercive nor is it likely to poison the philosophy of altruism. He said that payment for organs might also increase the availability of minority organs which are in high demand and which would increase the chance of a good match being found for a minority recipient. He goes on to say that payment for organs is believed to be no different than the current practice of paying the doctor, the OPO, or the charter aircraft. On the other hand opponents to the payment proposal claim that payment places the interest of the family before that of the deceased. It is also feared that the poor would be likely to feel coerced into giving because they might not otherwise be able to afford to pay the hospital costs. Other questions raised by opponents include: (a) what is to prevent the payment price from going up so high that a black market develops in the sale of organs?; and (b) who should be the broker—the doctor, the OPO, or the hospital?<sup>68</sup>

At a recent unveiling of a commemorative stamp for the National Kidney Foundation, Governor Ben Cayetano suggested that the state government provide financial incentive to the

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<sup>66</sup> *Code of Georgia, Anno.*, section 40-5-25, Applications; fees.

<sup>67</sup> Thomas G. Peters, M.D., "Life or Death; the issue of payment in Cadaveric organ donation," *Commentaries, JAMA*, March 13, 1991, pp. 1302-1305.

<sup>68</sup> Edmund D. Pellegrino, M.D., "Life or Death; the issue of payment in Cadaveric organ donation," *Commentaries, JAMA*, March 13, 1991, pp. 1305-1306.



families of donors.<sup>69</sup> He said that people might be more inclined to donate organs if they knew their families would gain financially from such an act. Editorial comment in the *Honolulu Star Bulletin* said that suggestion “. . . has gone over with a deserved thud. . . . Although government payments even as tax credits to organ providers or their families might be deemed legal, they would encourage organ sharing for the wrong reason. . . . the best way to increase donations is through education.”

There has been no survey of Hawaii's citizens to determine whether public opinion in this state reflects the national sentiment about the sale of organs. Therefore, it is not clear whether the younger generation might feel differently about the sale of organs, or whether different cultures may find it more or less offensive.

### **Recognition For The Donor**

Another suggestion is public recognition of donors. The Organ Donor Center of Hawaii reported that an annual donor family memorial is held to remember and thank donors at a nondenominational event. Donor families are also informed about the transplant recipients who benefited from the donor's gift, without identifying the person(s) by name.<sup>70</sup> In this way donor families feel their loved one's life has meaning by giving another person a second chance.

Other suggestions for recognition include granting donors posthumous Congressional medals.<sup>71</sup>

### **Other Suggestions**

Some writers have suggested, but no state has adopted the proposal to give death row inmates the option to donate organs. There are, however, foreign countries in which organs have been retrieved from executed prisoners.<sup>72</sup> In a state which does not have the death penalty like Hawaii, the death row donation might be modified to allow a reduction in a inmate's

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<sup>69</sup> “Life Donors: Many die awaiting organ,” *Honolulu Star Bulletin*, August 31, 1998; “Cayetano suggests payments to encourage organ donation,” *The Honolulu Advertiser*, August 31, 1998; “Dollars for Organs,” (editorial) *Honolulu Star Bulletin*, September 1, 1998.

<sup>70</sup> For example, the donor's family might be informed that a 36-year-old mother of three received the donor's liver.

<sup>71</sup> Controversies in Organ Donation. National Kidney Foundation, New York, June 1993, p. 5.

<sup>72</sup> H. Hsieh, et al., “The Gift of Life from Prisoners Sentenced to Death, a Preliminary Report,” *Transplant Proceedings*, vol. 24, no. 4, Aug. 1992, pp. 1335-1336. In this report the researchers reported on prisoners in Taiwan who were executed by gunshot. The report compared the results of survival rates of recipients who received organs from executed prisoners and regular cadavers showed it was possible to use prisoner donated organs after execution.

sentence in exchange for the donation of a kidney.<sup>73</sup> Opponents of death row/prisoner organ donation usually raise the specter of diseased organs due to the high risk lifestyle engaged in by many criminals, usually drug or alcohol related. Proponents, however, point out that (at least for death row inmates) during the lengthy appeals process any incipient disease would reveal itself, or that the long period of incarceration would mean that drugs or alcohol would no longer be in that person's system, and that organ screening will also be performed before a donor is accepted.<sup>74</sup>

### **Require Hospitals To Report Deaths And Coordinate With Organ Procurement Organizations**

The UAGA requires hospitals to have a protocol in place routinely to request donation from a patient who might become a donor. However, having a "protocol in place" does not guarantee that requests are made of every potential donor. The problem has been noted that this provision provides for only administrative sanctions if the hospital with a protocol does not ask a patient about willingness to become a donor.<sup>75</sup> In many instances, the suitability of a patient to be a donor is determined by the physician. If the doctor has a personal bias against organ donation, or if the doctor believes that a patient's family is too upset and therefore unlikely to donate, or the circumstances too sensitive to ask, then the UAGA's required request language is ignored, the patient and family are not asked, and the option to donate is never revealed.

The Organ Donor Center of Hawaii reported to the Bureau that it has had fairly good response to voluntary routine request procedures from the seventeen acute care hospitals in this state, despite what the papers have reported to be poor donation rates in Hawaii.<sup>76</sup> Robyn Kaufman, Executive Director of ODCH, reported that about 56 per cent of deaths are reported from the acute care hospitals.<sup>77</sup> While the number of solid organ donors is admittedly small, if one includes the donors of eye, tissue, and bone, the donation rates are more respectable. For example, in 1997 there were 18 donors of solid organs but also 66 corneas and 25 tissue donors as well.

### **Required Referral Regulation From The Federal Government**

Under a recently published regulation (Federal Register June 18, 1998), hospitals that participate in Medicare and Medicaid reimbursement programs must do the following:

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<sup>73</sup> While donation of a solid organ means the donor has died, kidney (and in some cases, part of a liver) can be donated by a live donor. In the case of kidneys, a human being requires only one kidney to survive. Therefore, transplanting one kidney from a live donor would not cause the death of the donor.

<sup>74</sup> For more on death row organ donation, see: Phyllis Coleman, "Brother, can you spare a liver?", Five ways to increase organ donation," Valparaiso, Univ. L. Rev. vol. 31, no. 1, Fall 1996.

<sup>75</sup> *Hawaii Rev. Stat.*, section 327-5(f).

<sup>76</sup> "Many organ banks lag in transplants," *The Honolulu Advertiser*, September 8, 1998 and "Some organ banks better finding matches," *Honolulu Star Bulletin*, September 8, 1998.

<sup>77</sup> Telephone interview with Robyn Kaufman, Executive Director of ODCH, October 19, 1998.

1. Refer all deaths to the organ procurement organization (OPO) (in Hawaii this is the Organ Donor Center of Hawaii).
2. Determine who makes the request to potential donor families, and if not by OPO employees, then by OPO trained requestors.
3. Have an arrangement with an eye and tissue bank, with the OPO having first right of refusal regarding a referral.
4. Must work with OPOs in conducting medical record reviews (to determine the suitability of the organ and the recipient)

The national regulation concentrates on increasing consent from family members and ensuring that every possible donor is asked by having the OPO determine suitability of a potential donor. Under this regulation the doctor does not make the assessment of suitability and trained OPO personnel make the overture to the patient's family. The U.S. Department of Health and Human Services (DHHS) estimates a twenty percent increase of organ donors in two years for the nation under this regulation. There are similarities between the national regulation and the required request legislation described below for the state of Maryland.

In an effort to take on a more active role in the organ donation effort, the federal government has partnered with several organizations ranging from the health care community, law associations, educational organizations, religious organizations, donor and recipient groups, business groups, state organizations, and the media to target specific groups of people about donation. Among federal government agencies, the Office of Personnel Management and the Department of Defense have been working with the DHHS to develop ways to encourage their employees to donate organs.<sup>78</sup>

### **Required Referral Provisions In Maryland**

Maryland's required referral law requires all hospitals to report deaths to an appropriate organ, eye, or tissue OPO. This law ensures several things: first, by requiring that all deaths be reported to the local OPO, less discretion is granted to a physician who for a variety of reasons, may not present the option for an organ donation to a family. Second, the OPO has trained personnel to make the first request of organs, tissues, or corneas and can answer the donor family's questions about the need for organs and how the donation can help in specific ways. Maryland's law also requires the Secretary of Health and Mental Hygiene to publish guidelines about required referral and to assure that annual death record reviews are conducted so that there can be a comparison between the number of potential donors against the actual donors. This death record review is designed to help OPOs identify missed opportunities where they

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<sup>78</sup> HRSA News, Fact Sheet for the New Organ Donor Regulation, June 17, 1998 at [www.organdonor.gov](http://www.organdonor.gov).

should work to increase donations, and identify the hospitals which do a good job identifying potential donors.<sup>79</sup>

In Hawaii, under routine request (as provided for by the UAGA) only 56 percent of hospital deaths are being reported to the ODCH by the seventeen acute care hospitals in the State. In order to assure asking more donors for organs, required referral legislation might help to reaffirm the State's commitment to generating higher organ donation numbers. Required referral might successfully find additional donors from the 44 percent of hospital deaths that are not being reported to the ODCH.

### **Reduce Demand For Organs**

There are various causes for organ failure leading to the need for a transplant. Certain kinds of diseases, medications, congenital birth defects, and other reasons could result in kidney, liver, or heart disease. However, kidney failure often results from complications of diabetes; liver failure from excessive alcohol consumption; lung diseases from smoking, and so on. One of the ways to solve the organ shortage dilemma that is seldom addressed is how to reduce the demand for organs by increasing consumer awareness of the effects of unhealthy lifestyles on a person's organ functions.

While the medical community does its part to repair and treat diseased organs, government can help too by encouraging healthy lifestyles. In fact the evidence already exists that government has influenced some lifestyle changes in requiring the use of seatbelts, motorcycle crash helmets, and reduced highway speed limits. More recently, information regarding food labeling, new weight guidelines, and the new inverted food pyramid in educational articles and posters may contribute to healthy eating habits, which in turn can keep people healthy and their vital organs functioning properly.

Although it can be argued that the demand for organs will never be reduced to zero, it still behooves the government to promote healthy eating, exercise, and general living habits to reduce the likelihood of organ failure. It has also been pointed out that ironically, advances in medical technology and the crash worthiness of cars, use of seatbelts, and so on, may have reduced the availability of organs simply because more people survive car and motorcycle crashes that previously would have resulted in death.

### **Summary**

Hawaii's challenge will be to adopt and implement those suggestions that are culturally, religiously, and morally acceptable to most of Hawaii's citizens so that they are more willing to donate their own organs after death. In all efforts to increase donation, there should be no compromise of:

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<sup>79</sup> Information at [www.mdtransplant.org](http://www.mdtransplant.org), Sept. 25, 1998.

- (1) The safety of the organ transplant recipient;
- (2) The quality of the organ donated;
- (3) Consideration of the organ donor and family;
- (4) Continued vigilance of high medical standards;
- (5) Maintenance of hospital regulations that assure equity in organ allocation and distribution; and
- (6) Continued limitation of liability of parties involved in the transplantation process so that there will be no hesitation in performing these still risky though lifesaving, surgeries.

In the next chapter, the Bureau analyzes the consent issue and makes recommendations that will try to help the patients on the organ waiting list. Other proposals are intended to increase awareness about organ transplantation so that in the future more volunteers can be found to agree to organ donation. Like other public policies, this would require statutory amendments and public education before organ donation will be widely accepted.

## Chapter 5

### ANALYSIS AND RECOMMENDATIONS

If the legislature decides as a matter of state policy to intervene in the organ donation arena in order to both speed up and increase the rate of organ donations, there are many options available to it as the previous chapter indicated. Some states have emphasized public education to increase awareness about the need for organs. This method takes the long view because education of all citizens helps to insure that future generations know what organ transplantation is about and the value of donating. Most states aspire to having a wide pool of potential donors. The UAGA, which has been adopted by about twenty states, provide for ascertaining whether drivers would be willing to donate their organs by making some kind of indication through the driver licensing process. Many states refer to their driver licensing donor consent numbers as an indicator of success in increasing organ donation efforts. Some states use the donors' names from driver licensing forms to develop a register of known donors which is made accessible to organ procurement organizations (OPOs) and other authorized agencies. Other states do very little follow-up with these names. In Hawaii the number of drivers who have chosen to donate organs is totaled each month and this number is sent to the Organ Donor Center of Hawaii (ODCH) but not the names of these drivers. If any of these drivers returns a card requesting more information about organ donation then the ODCH will follow up as appropriate.<sup>1</sup>

Certainly education helps, but the need is more immediate for the individuals on the organ waiting list. Life hangs in the balance when a vital organ is failing. The percentage rate of drivers willing to donate organs could be 100 percent and a state still could have the same low numbers of actual donors, because the number of donors derived from the motor vehicle drivers form is almost immaterial until the promise to donate transforms into a real death and an actual donation.

This final chapter reviews some of the conclusions to be drawn from an analysis and review of the low rates of donation in Hawaii and the nation. The recommendations proposed here are designed to broaden the base of potential future donors, and to increase direct participation of organ donors from the pool of accident victims and others who for whatever reason, are about to die in the immediate future.

#### **The Need For Organs**

The numbers fluctuate, but there are about 170 to 200 persons in Hawaii currently awaiting a solid organ, such as heart, liver, lungs, or kidneys. There are other patients for whom bone tissue or corneas or heart valves would help improve their quality of life. What can be done immediately to help these people obtain the needed solid organ, tissue, or cornea? From most accounts, the immediate solution is to obtain consent for an organ donation—either from the dying themselves or their next of kin. Although the need for a solid organ has been the

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<sup>1</sup> Memorandum to Jean Mardfin from Robyn Kaufman, Executive Director of ODCH, October 16, 1998.

primary focus of this report, consent is still needed to retrieve tissue, bone, corneas, heart valves and other parts. The most efficient and publicly acceptable means of obtaining an organ would be without exception, to persuade every seriously injured and dying person or their families to consent to donate their organs. Determination of organ donation suitability can be made after the patient has agreed to donate.

### **The Odds Of Obtaining Consent**

A review of the local Hawaii data indicates that the current odds for obtaining consent at the time of death (or just prior to death) is poor—less than one percent, a far reach from the 26 percent of all motor vehicle drivers who have indicated they are willing to be donors when they die. But as will be described shortly, the shortage of donated organs can be explained as partly due to the necessity of seeking good, viable organs without relaxing rules for quality.

According to the Organ Donor Center of Hawaii's estimates, about 56 percent of all deaths were reported to the ODCH in 1997 from the seventeen acute care hospitals in the State.<sup>2</sup> According to Executive Director Robyn Kaufman, a pilot project of routine referral that began in 1994 was applied statewide from 1995. Routine referral is a process provided by the UAGA whereby a hospital's medical personnel upon identifying a dying person who could be a suitable donor, notifies the ODCH and efforts are made to secure consent to retrieve that dying person's organs, tissue, or eyes.

Donor organs from deaths on neighbor islands can be brought to Honolulu on commercial flights or air ambulance when necessary. Tissue recovery is possible as long as an operating room is available.<sup>3</sup> The ODCH has five nurses who have been trained in how to approach families for donation. Hospital employees, including chaplains, social workers, and the like are also trained by ODCH personnel in the techniques of handling organ donation requests. Although recent news articles reported Hawaii at the bottom of the donation list among the 63 organ banks across the country,<sup>4</sup> a state by state comparison is not a fair comparison because on the mainland some OPOs may serve areas in several different but adjacent states. There are also five states with no transplant programs. Hawaii happens to have only one OPO and it serves the entire state of Hawaii. Only a few organs donated in Hawaii may be transported to a patient outside the state depending on the organs' viability and tissue match with the recipient.

According to the Organ Donor Center of Hawaii, the number of donors has remained between 12 to 15 annually since the establishment of the Center in 1987. In 1995 from about 7,500 deaths statewide, there were 11 solid organ donors; in 1996, from 7,800 deaths, there were

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<sup>2</sup> Not all deaths occur in acute care hospitals and for purposes of organ donation, the death must occur in a hospital, not in a nursing home, or at a private residence. The ODCH reported that about 50 percent of all deaths occur in a hospital setting.

<sup>3</sup> Telephone interview with Robyn Kaufman, Executive Director, and Felicia Wells-Williams, Professional Education Coordinator, Organ Donor Center of Hawaii, Oct. 9, 1998.

<sup>4</sup> "Many organ banks lag in transplants," *The Honolulu Advertiser*, Sept. 8, 1998 and "Some organ banks better finding matches," *Honolulu Star-Bulletin*, Sept. 8, 1998.

13 donors of solid organs; in 1997, from 8,000 deaths, in addition to 18 donors of solid organs, there were 66 eye and 25 tissue donors. In the first half of 1998, of 4,000 deaths, only 6 donors of solid organs have been found. Any reader would agree that this is not a record that would gladden the heart of a person on the transplant waiting list. But realistically, the ODCH estimates that of 8,000 deaths statewide, only about 100 (1.25 percent) would be able to provide suitable solid organs. There are many reasons for the small number of suitable donors. First, a death must occur in an acute care hospital for organs to be properly maintained for transplantation. Second, there are diseases that may eliminate a donor, such as hepatitis, AIDS, and the like. Third, organs from persons over 70 years old may be eliminated as over age (although other parts such as corneas may still be recovered). Therefore, even under ideal conditions this State would probably still have patients on the waiting list for organs.

While this appears to be dismal news, Hawaii is one of many states trying to find ways to increase organ donation. The nationwide shortage of solid organs can be explained by the growth of transplantation overall. In the United States since 1986 “. . . the number of organ donors has increased by only 33 percent, while the transplant waiting list has grown by 250 percent. As of June 3, 1998, 56,222 individuals were on the waiting list for a transplant, but the number of organs transplanted from cadaveric donors in 1997 numbered only 17,032. Preliminary 1997 data compiled by the Organ Procurement and Transplantation Network contractor indicates that the number of donors (5,475 in 1997) increased by only 54 donors or by less than one percent over the 5,421 donors in 1996.”<sup>5</sup> This shortage of suitable donors for transplant recipients extends to foreign countries as well.

If there is any consolation for transplant patients on the Hawaii waiting list, it is that no state has reached a level of surplus organs and that Hawaii's experience is not unique. Unfortunately, awareness of the national need for organs puts Hawaii's needs in perspective, but does not help to reduce demand for organs locally nor does it reduce the desperate condition of some ill individuals that can only be alleviated with a suitable organ match.

## **Analysis**

### **The Principal Participants In The Organ Donation Equation**

An analysis of organ donation reveals these major participants:

- (1) The public, or more specifically the donor and the donor's next of kin who can consent to provide the needed organs or tissue;

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<sup>5</sup> U.S., Dept. of Health and Human Services, Federal Register, June 22, 1998, Final Rule on Medicare and Medicaid Programs; Hospital Conditions of Participation; Identification of Potential Organ, Tissue, and Eye Donors and Transplant Hospitals' Provision of Transplant-Related Data, p. 33857.



- (2) The seventeen acute care hospitals in the state and the medical professionals who help to identify the potential donors or perform the organ retrieval;<sup>6</sup>
- (3) The organ procurement organization, like the Organ Donor Center of Hawaii which through its trained staff, makes the request for organs and manages the donors for recovery of parts; and
- (4) The government, both state and federal, which for the past thirty or so years have played a limited role by providing the legal structure within which the organ transplant process can occur.

### **Are Potential Donors Being Asked?**

The cause of the low rates of donation is often described with the phrase, “didn’t know, didn’t ask.” In other words, if the potential donor does not know about the option to donate and is not asked, donation will not occur. Given the very low rate of donation in Hawaii, it is likely that if 56 percent of deaths from acute care hospitals are being reported to the local OPO, many potential donors are not being asked. Alternatively, even if asked, perhaps potential donors are not asked in a manner that generates giving, which may indicate a need for further training of designated requesters as well as medical personnel who must first recognize that a dying person might be a suitable donor. Other reasons for donor unwillingness to consent may be due to religious convictions or misconceptions about organ retrieval, death, or medical services in general.

### **Reasons For The Current Review Of Organ Donation Policies**

The continuing shortage of donated organs from consenting individuals has spurred the several governments to reevaluate current assumptions about the UAGA. When the UAGA was proposed and adopted by various states, it was anticipated that the law would facilitate organ donation by: (1) defining when death had occurred; (2) providing a mechanism for indicating on a driver’s license willingness to donate organs at a future time; (3) limiting liability for transplant physicians; (4) requesting hospitals cooperate by developing organ donation protocols; and (5) other steps. In the meantime science and medical technology continued to improve the methodology for organ transplantation so that more and more patients are added to the transplant list because of its potential to extend and improve life. Today, transplantation has become a real option to consider when a patient’s organ, tissue, cornea, or bone needs replacement. However, demand continues to outstrip supply and the current law is viewed as insufficient or inadequate to address these needs.

Unless there is an increase in the donation figures, patients on the organ transplant waiting list will continue to increase in number and with donations remaining steady, more of the

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<sup>6</sup> Organ retrieval can occur in any of the seventeen acute care hospitals but transplantation itself is conducted at the St. Francis Medical Center.

donees will die waiting. The state government could take on a larger role in order to elevate the urgency of the need to a wider audience in order to generate more donations. The government could participate by funding educational programs that increase public awareness of organ donations and can amend the law to require referral of all hospital deaths to the OPO to increase the probability of obtaining consent from more donors.

### **The Donor's Consent**

Central to all participants who are associated with organ transplantation is the issue of consent. First and foremost, the donor must give consent before organs can be evaluated for suitability and then retrieved for transplantation. There are several aspects of giving consent, including whether the donor understands what transplantation is, appreciates the need for solid organs, and whether there are emotional, religious, intellectual, or other barriers that prevent giving consent to organ donation. The traditional suggested solution to obtaining the donor's consent is education in the belief that education brings knowledge and with this knowledge, the donor is more willing to give consent.

The donor himself may indicate consent while alive and well, on his driver's license, will, or other document. Where a donor has made no indication of organ donation wishes, Hawaii's UAGA provides for asking a relative (in order of priority) for consent. A problem often cited as a reason for low donation rates is the anecdotal evidence that the medical professional will ask a family of the deceased to give consent, despite the evidence of a document of gift such as a donor card or driver's license indicating the person is an organ donor. At this point the relative could veto the wishes of the deceased. In Hawaii's UAGA, section 327-2(h), *Hawaii Revised Statutes*, provides that an anatomical gift that is not revoked by the donor before death is irrevocable and does not require the consent or concurrence of any person after the donor's death. (Emphasis added.)

The custom of asking a relative for consent appears to have developed historically before transplantation became an almost routine medical procedure, because a relative traditionally has had control over decisions regarding disposition of the deceased's body. The practice continues because of consideration for the feelings of the survivors by the hospital and medical personnel and also because the sensitive handling of survivors avoids bad publicity, lawsuits, and the like. For this reason, many organ donation awareness programs emphasize the need to discuss one's wishes with the family before the request to donate becomes an issue. There is evidence that a family member is more likely to consent to the donation of a relative's organs if that family member knows that the patient wished to be a donor.

### **Attempts To Limit Or Eliminate Relative's Consent**

The difficulty of obtaining consent from relatives has led to various proposals for laws which relax the requirement for consent in ways that limit, influence, or eliminate the family from the donation equation by adopting other options, like presumed consent, or by proposing financial incentives for donating an organ, short of outright sale. When Pennsylvania in 1993

proposed a presumed consent bill for organ donations, it was defeated. However, Pennsylvania provides for up to \$3,000 to be paid to a donor's funeral home, hospital, or other service provider for incidental expenses incurred by the donor's family in connection with the organ donation. Debate continues across the country about financial incentives because it appears that many people are uncomfortable about moving away from the altruistic donation of an organ. Meanwhile waiting transplant patients pay the price for the low rate of donation.

One modification to the consent issue that should be considered in this state according to the ODCH, is to allow hospitals to retrieve organs from a willing donor (someone with an existing document of gift) when no relatives can be located. At present, not even the existence of a document of gift will persuade a hospital to retrieve organs from a patient who appears to have no relatives.<sup>7</sup> Texas has addressed this issue by allowing organ retrieval when relatives cannot be located for four hours after death.

### **Consent And The Hospital**

Under the provisions of the UAGA, hospitals must have a protocol for routinely requesting organ donation of patients and many in Hawaii do so. The hospital's medical personnel (along with the OPO) seek to identify the persons from whom to obtain consent. This can involve not only a determination of which dying person might make a suitable donor, but also an evaluation of whether the survivors would assent to making a donation of their dying relative's organs.

Because the hospitals make the initial contact with the patient, it is the hospital through its functionaries like doctors, nurses, social workers -- not the OPO -- that determines whether or not to seek consent from a patient for an organ donation. Depending upon the exigencies of the medical emergency, the family circumstances, and so on, the medical professionals might choose not to ask for organ donation. Under the UAGA scenario the OPO must wait until it is invited by the hospital to participate in the request from the patient or family if and when the hospital staff determine donor suitability. Some opportunities for asking may therefore be missed.

It is for this reason that some states like Maryland and Pennsylvania created the required referral program to assure that every potential donor's family is informed about the option to donate. The concept of required referral is described later in this chapter.

### **Consent And The OPO**

Third, the OPO helps to obtain consent by among other things, answering a donor's questions and educating the public to make consent more likely. The OPO trains professionals in the best techniques for requesting donations of organs.

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<sup>7</sup> Telephone interview with Robyn Kaufman and Felicia Wells-Williams, Oct. 9, 1998.

Researchers have examined the various aspects of asking a donor for consent to donate organs, whether to ask, who asks, when and where the donor is asked, and the manner of asking. Their findings indicate that the grieving family first should be given the chance to accept the death, before being asked for an organ donation; that the requester should be one who has been trained in this process; that a cooperative effort by a requester from the hospital and someone from the organ procurement organization results in greater likelihood of a yes answer, that the setting of the request should be in a quiet room, out of the hospital corridors and waiting areas.

Training requesters, combined with a wider educational effort of the population as a whole may be necessary to assure that families who are asked to donate a relative's organs receive the most sensitive, caring attention.

The ODCH wears many hats, because it is one of sixty-three federally certified organ procurement organizations in the United States. The ODCH plays an active role in evaluating donors for organ, tissue, and eye recovery; obtaining proper authorization from next of kin, managing donors for surgical recovery of donated parts and distributing the parts according to an established allocation method. The ODCH helps to educate hospital personnel and assists a hospital in its preparation of policies and procedures relating to organ, tissue, and eye donation. The ODCH also reimburses the hospital for reasonable charges related to the evaluation, management, and recovery of donated organs, tissue, and eyes.<sup>8</sup> For all OPOs, consent is critical to its ability to continue to provide services. The ODCH along with special interest groups involved with kidney transplants, eye bank, and others, appears to have a cooperative relationship and all work toward educating the public about organ, tissue, bone, and corneal transplants.

There may be good reasons for asking family members for consent having to do with determining the suitability of the patient's organs for donation. According to the ODCH after consent is received from the donor or donor's family, organ recovery requires among other things, a determination of the donor's medical social history and this information may be best provided by the relative. Some infectious diseases may not be in the donor's medical history (say, from recent foreign travels) but could have been acquired in the period just before death and not manifested medically. Alternatively, certain health risk behaviors such as drug use may be known to the relative but not recorded in the donor's medical file. Reliable medical social history information is easier to obtain from a consenting family member.

### **Consent And The Government's Role**

In the 1990s some states re-examined their role regarding organ donations to become more active proponents in this area. These states like Maryland, Pennsylvania, Texas (and more recently the federal government in its required referral regulation for hospitals participating in Medicare and Medicaid programs) realized that a major stumbling block to obtaining organs is assuring that consent is sought from every possible available donor. If every death is approached with a request for organ donation, there is hope for increasing the number of organ donors. As

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<sup>8</sup> From (sample) "Organ, Tissue, and Eye donation services agreement," provided by the ODCH.

described earlier, Texas is the only state that has tried to tackle the issue of consent through its “quasi-presumed consent” statute whereby a four-hour window is tolerated for locating next of kin. In 1993 when Pennsylvania’s legislature proposed presumed consent language, it was defeated. States like Illinois have also sought to improve the consent rate by stepping up its educational efforts about organ donation and transplantation through public awareness programs. The problem is that education, while serving its purpose, does not affect consent to donate until the willing organ donor actually dies.

Obtaining consent from all patients soon to die is the best way to ensure helping the patients on the waiting list. Since the statutory language providing that relatives do not have to give further consent when a valid document of gift exists does not seem to work in the ways that the original framers of the UAGA intended, required referral legislation has been adopted by a few states and a similar regulation adopted by the federal government to increase the number of deaths being reported to the OPO.

### **The Required Referral**

In order to increase the chances for obtaining consent from more dying patients, Maryland, Pennsylvania, and six other states require referral of all deaths to the OPO.<sup>9</sup> Required referral means that the hospitals are required to refer every death to the OPO without making an initial assessment of medical suitability for organ donation. The OPO then works with the hospital to connect with the affected family, make the request for donation, assess the suitability of the donor, and so on.<sup>10</sup> It has been reported that since Pennsylvania adopted the required

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<sup>9</sup> Similar to Maryland’s and Pennsylvania’s required referral law is the federal regulation issued on June 22, 1998 by the U.S. Department of Health and Human Services requiring hospitals participating in the Medicare program to report all deaths to OPOs.

<sup>10</sup> Section 19-310, Amoss Organ and Tissue Act of 1998. In Maryland, the required referral language provides generally:

- (1) On or before the occurrence of each death in a hospital, the hospital shall contact an appropriate organ, tissue, or eye recovery agency in order to determine the patient’s suitability for organ, tissue, or eye donation;
- (2) The contact and its disposition shall be noted in the patient’s medical record;
- (3) The appropriate organ, tissue, or eye recovery agency, in consultation with the patient’s attending physician or the physician’s designee, shall determine the patient’s suitability for organ, tissue, or eye donation; and
- (4) If the organ, tissue, or eye recovery agency in consultation with the patient’s attending physician determines that the patient is not a suitable candidate for donation based on established medical criteria, this determination shall be noted by the hospital personnel in the patient’s medical record and no further action is necessary.

If the patient is a suitable candidate, a representative of the appropriate organ, tissue, or eye recovery agency or a designated requestor shall initiate a request with sensitivity, in the order of stated priority, (spouse, adult child, parent, sibling, and so on) that the individual’s representative consent to the donation of all or any of the decedent’s organs or tissues as an anatomical donation if suitable.

referral law in 1995, one of the OPOs serving southeast Pennsylvania, Delaware, and south New Jersey has had a 40 percent increase in organ donation.<sup>11</sup>

Maryland law also requires the Secretary of Health and Mental Hygiene to publish guidelines:

- (1) Requiring that at or near the time of each individual death in a hospital, the hospital contact by telephone an appropriate organ, tissue, or eye recovery agency to determine the suitability of the individual for organ, tissue, or eye donation;
- (2) Requiring that each hospital designate a person to make the contact; and
- (3) Identifying the information that the person designated by the hospital shall have available before making the contact.

Maryland<sup>12</sup> and Pennsylvania<sup>13</sup> require the conduct of an annual death record review at each hospital to determine the hospital's compliance with the provisions of required referral. The requirement for review of death records means that at a later time analysis can be made of the level of compliance from hospitals. Fines can also be imposed for lack of compliance. The value of death record review is ascertaining verifiable compliance with the required referral program.

There is language under the required referral states like Maryland or Pennsylvania that clearly state that the evidence of a legitimate donor card (document of gift) shall not be revoked by a family member. As recently as August 24, 1998, New Jersey amended its UAGA to specify that “. . .the intent of a decedent to give all or any part of his body as a gift shall not be revoked by any person nor shall the consent of (designated relatives in order of priority) be necessary to render the gift valid and effective.”<sup>14</sup>

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The Pennsylvania law (Section 8617(a)) provides: “On or before the occurrence of each death in an acute care general hospital, the hospital shall make contact with the regional organ procurement organization in order to determine the suitability for organ, tissue and eye donation for any purpose specified. . . . This contact and disposition shall be noted on the patient's medical record.”

<sup>11</sup> U.S., Dept. of Health and Human Services, Federal Register, June 22, 1998, Final Rule on Medicare and Medicaid Programs; Hospital Conditions of Participation; Identification of Potential Organ, Tissue, and Eye Donors and Transplant Hospitals' Provision of Transplant-Related Data, p. 33869.

<sup>12</sup> Section 19-310(L) provides that Maryland's Department of Health and Mental Hygiene conduct annual death record reviews at each hospital to determine the hospital's compliance with the provisions of required referral.

<sup>13</sup> Pennsylvania, Section 8617(g) requires the department of health to make annual death record reviews at acute care general hospitals to determine compliance with required referral. Noncompliance can result in a fine of \$500 for each instance of noncompliance. Fines are placed in the organ donation awareness trust fund.

<sup>14</sup> Section 4 of P.L. 1969, c. 161 (C.26:6-60), approved August 24, 1998 session laws of New Jersey.

## Federal Regulation On Required Referral

On June 22, 1998 the Health Care Financing Administration (HCFA) of the U.S. Department of Health and Human Services issued its final rule regarding several requirements a hospital that participates in the Medicare program must meet to increase organ donation. In this section the Bureau presents HCFA's reasoning for adopting the new regulation that resembles the required referral process found in Maryland, Pennsylvania, and other states. HCFA pointed out that (as to organ donation) "the current hospital conditions of participation have not produced the results which were anticipated."<sup>15</sup> Further, the data on low donations demonstrated that some hospitals need more than encouragement to meet the requirements (of the Medicare program) which mandates that hospitals identify potential organ donors and assure that families of organ donors are informed of their donation options.

HCFA proposed these rules on December 19, 1997, to "extensively revise the current conditions of participation for hospitals . . . in response to a critical shortage of organs available for transplantation. . . . Every day an estimated 10 individuals in the United States die because organs are not available to save their lives. This fact gave particular urgency to publication of a final rule covering the provisions of the proposed rule designed to increase donation and transplantation."<sup>16</sup> HCFA pointed out that:<sup>17</sup>

Referring all deaths is a better approach because it creates a clear standard for hospitals to follow, it ensures that hospitals will not erroneously assume that a potential donor should be excluded, it allows early intervention by the OPO to guide the organ and tissue procurement process to ensure a successful outcome, and will make it easier to standardize transplantation waiting time.

After HCFA published its proposed regulation in December 1997, it received many comments for and against its proposal. HCFA addressed these concerns when it presented its final regulation in June 1998. This final regulation which takes up only one page is supported by 18 pages of supplementary information from HCFA. In Hawaii seventeen acute care Hawaii hospitals, which are Medicare, and Medicaid eligible will be required to comply with the regulation.<sup>18</sup> Federal regulation would supersede state law and rules to the extent that they conflict with state provisions. The following discussion can be found in more detail in HCFA's Final Rule, published in the Federal Register, June 22, 1998.

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<sup>15</sup> U.S., Department of Health and Human Services, Federal Register, June 22, 1998, Final Rule on Medicare and Medicaid Programs; Hospital Conditions of Participation; Identification of Potential Organ, Tissue, and Eye Donors and Transplant Hospitals' Provision of Transplant-Related Data, pp. 33857 to 33863, at 33861.

<sup>16</sup> *Ibid.*, pp. 33857 to 33863, at 33857.

<sup>17</sup> *Ibid.*, pp. 33857 to 33863, at 33873.

<sup>18</sup> U.S., Department of Health and Human Services, Federal Register, June 22, 1998, Final Rule on Medicare and Medicaid Programs; Hospital Conditions of Participation; Identification of Potential Organ, Tissue, and Eye Donors and Transplant Hospitals' Provision of Transplant-Related Data.

### HCFA's Justification For Required Referral

HCFA argued for the adoption of the regulation because “... referral of all deaths is the single most critical factor in increasing organ donation rates. Referral of all deaths assures that determination of medical suitability is made by the OPOs, because OPOs are the entities with knowledge of transplant hospitals’ donor suitability.”<sup>19</sup> (Emphasis added.)

HCFA agreed with a 1988 commentary published in the Journal of the American Medical Association which states that the cooperation of the medical professions is the primary factor limiting the supply of transplantable organs. The author (of the 1988 commentary) suggested that routine referral “would not solve all the problems of professional cooperation, but it would ameliorate a key one and open the bottleneck that presently constrains the supply of organs.”<sup>20</sup> (Emphasis added.)

HCFA said that required referral is “. . .workable and will increase organ donation” because it establishes a clear standard for hospitals regarding when referrals must be made to the OPO. HCFA said, “Referral of all deaths, with no exclusions eliminates the need for OPOs and hospitals to rewrite referral protocols and reeducate hospital staff whenever transplant hospitals’ donor suitability criteria change. It is also less difficult for HCFA to monitor hospital compliance if there are no exclusions.”

“By making the pool of potential donors so large, OPOs ensure that no medically suitable donors are missed. However, many, if not most, of the potential donors in this large pool will not be medically suitable to be actual donors.”<sup>21</sup> (Emphasis added.)

In addition to increasing the donor pool for solid organs, “many OPOs will be screening donors for tissue and eye donation, and tissue and eye banks often have criteria for donation that differ significantly from the criteria for organ donation. For example, in 1997, only 6.4 percent of organ donors were over the age of 65. The Eye Bank Association of America reports however, that more than 28 percent of all eye donors in 1997 were over the age of 70.”<sup>22</sup>

HCFA went on to say that “Some OPOs for example, the Louisiana Organ Procurement Agency, have experimented with expanded criteria for determining medically suitable donors, with good results. However, transplant hospitals vary in their willingness and ability to transplant organs from potential donors who are past a certain age. At one time, most organ donors were age 45 or younger; now some transplant hospitals are transplanting livers from 80-year old donors. According to the Organ Procurement and Transplantation Network contractor,

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<sup>19</sup> *Ibid.*, pp. 33857 to 33863 at 33859.

<sup>20</sup> Citing, J. Prottas, “Shifting Responsibilities in Organ Procurement: A plan for routine referral.” Journal of the American Medical Association. 1988: 260:6.

<sup>21</sup> U.S., Department of Health and Human Services, Federal Register, June 22, 1998 Final Rule on Medicare and Medicaid Programs; Hospital Conditions of Participation; Identification of Potential Organ, Tissue, and Eye Donors and Transplant Hospitals’ Provision of Transplant-Related Data, pp. 33857 to 33863 at 33859.

<sup>22</sup> *Ibid.*



the 33 percent increase in cadaveric donors between 1988 and 1996 is primarily due to the increase in donors ages 50 and over. Cadaveric donors age 50 and over increased from 12 percent in 1988 of all cadaveric donors to 27 percent in 1996.”<sup>23</sup>

Thus HCFA argued that required referral allows early intervention by the OPO to guide the organ and tissue process to ensure a successful outcome so that a hospital will not erroneously assume that a potential donor is too old or has a medical condition that precludes donation. This in turn removes from hospitals the burden of keeping abreast of changing standards for donor screening and suitability criteria. By asking more dying persons or their families for organ donation, the chance of obtaining consent is increased.

Other reasons HCFA expects the new regulation to help in the organ transplant effort include: (1) minimization of regional differences in organ procurement and transplant waiting times; and (2) facilitation of compliance by hospital systems whose member hospitals are served by more than one OPO. These last two reasons are not expected to impact Hawaii's organ procurement procedures in the immediate future, as this State is served by only one OPO.

### **Conclusions About Required Referral**

The federal government has concluded that the application of organ donation laws for the past two generations have not sufficiently aroused public attention or concern to generate enough organs for patients who need them. By following the practices of a few states like Pennsylvania and Maryland, the HCFA regulation strengthened the need to ask for organ donation by requiring the hospital to refer every death to the OPO. The regulation assures that the asking is done in a manner designed to obtain consent because the OPO and the hospital must work collaboratively in this task and the designated requester must have completed a course in the best methods for approaching potential donor families and asking for the donation of organs. The additional requirement of conducting a review of death records can help to improve donations by identifying the areas that need more attention, perhaps in training requesters or allocating resources, in order to increase the donor potential of a hospital.

### **Required Referral As A Proposal For Hawaii**

Implementation of required referral in Hawaii would be an extension of the current program that began as the statewide routine request in 1995 under the UAGA. It would generate more potential donors being referred to the local OPO. The ODCH reported to the Bureau that that agency could double its present workload without adding more staff. Even if 8,000 deaths occurred statewide, ODCH reported that about 50 percent would be non-hospital deaths. Other deaths may be eliminated outright for reasons described earlier, such as overage, infectious disease, or poor condition. Therefore, a required referral program where every death would be reported to the ODCH would not unduly overburden the local OPO. Since the level of

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<sup>23</sup>Citing, UNOS 1997 Scientific Registry and Organ Procurement and Transplantation Network Annual Report.

cooperation between the ODCH and hospitals is reportedly a good one, and there are collaborative efforts already ongoing between the ODCH, the Kidney Foundation, and the local Eye Bank, a required referral program would be an excellent way to assure more people are asked to donate.

### **Education Function Of Government**

Education remains an important component of increasing the chance of obtaining consent from future donors and expanding the pool of potential donors. Since the government has limited experience and expertise in the technical and medical aspects of organ donation evaluation, those tasks should remain with the OPO. However, the OPO could advise the state government in ways the government could help in the organ awareness and education areas. MOTTEP, the ODCH's program that seeks more minority donors, can also assist and advise government agencies to spread the word to Hawaii's minority groups.

Examples of educational programs in Illinois point to the advantages of authorizing a single high profile executive, in that case the Secretary of State, the responsibility for bringing the organ donor issue to the people of the state. That office can send follow-up letters to the licensees who sign the donor form, or informational pamphlets to those who do not, in the hope of changing their minds. The presence of the Secretary of State at other events like community fairs brings an official stamp of approval to the program. In Hawaii, the Lieutenant Governor generally handles the functions of the Secretary of State, and could comparably be authorized to head the organ donor education awareness programs for Hawaii.

Other projects such as children's poster contests draw attention to the need for family discussion of organ donations and involve all age groups. Educational programs targeting minorities, children, and other special groups expand the potential pool of donors and may make consent easier to obtain.

The main advantage of a government spokesperson for organ donation is to focus attention to a public need. If government assumes some of the public education effort, the OPO could concentrate on educating hospital personnel and using its expertise in medical matters such as donor evaluation and maintenance.

### **Developing A Funding Mechanism**

Another area in which government intervention can help is by creating a fund that can be filled with the proceeds received from adding \$1 to driver license application fees or tax returns, or from voluntary donations at other entry points. This fund can then be used for educational programs and other purposes as described in the earlier chapter.

Pennsylvania's Organ Donation Awareness Trust Fund is funded by voluntary contributions made at the time drivers apply or renew drivers' licenses, register a motor vehicle, or pay taxes. Illinois has a Live and Learn Fund, funded by monthly transfers from the state

treasury of \$1,700,000, part of which is used for an organ awareness or education program (a larger portion of this fund is used for library grants). Kentucky has a provision to allow driver license applicants to voluntarily donate \$1 to a fund for the purpose of promoting an organ donation program.<sup>24</sup>

A similar program if established for Hawaii could create a fund from the 733,000 drivers' licenses.<sup>25</sup> A \$1 fee added on vehicle registration charges already exists in Hawaii in the form of a \$1 for the highway beautification program.<sup>26</sup> Whether this organ donation education fund is used for educational awareness programs or for gifts to pay for a portion of the donor's funeral costs or hospital expenses, the ultimate goal is directed towards increasing consent rates for organ donation.

### **Inter-Relatedness Of All Efforts**

As may be evident from the above discussion, all efforts relate to each other. Education and awareness programs increase the chances of obtaining consent because an informed public can understand the reason for the request; required referral increases the number of people asked to donate organs. Required training of designated requesters assure the hospital personnel and the donor's family that the request for donation will be made in a sensitive, caring manner that fully explains the benefits of donating. Finally, compliance with reporting hospital deaths can be verified with an annual death records review.

### **Recommendations**

- The Bureau recommends the adoption of a required referral system in which all acute care hospitals are required to report every death to the Organ Donor Center of Hawaii (ODCH), the local organ procurement organization (OPO). This would affirm the State's commitment to increasing organ donations, despite the fact that these efforts very likely already have been implemented voluntarily under the UAGA required request provisions. Required referral legislation is designed to increase the number of deaths reported to the ODCH. Required referral would help the patients on the transplant waiting list because every dying person (or their relative) would be offered the opportunity to donate organs, tissue, or eyes, for transplantation. It is important to ask and offer the option of donating to any dying person. (See suggested legislation, section 2, §327-A.)
- As part of the required referral system, the Bureau also recommends the following provisions: (1) that the request is made by a trained, designated requester; (2) that an annual review of death records be conducted by the OPO and hospitals; and (3) that a fine be assessed for noncompliance with the required referral system. The use of a trained

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<sup>24</sup> *Kentucky Rev. Stat.*, section 186.531(2)(g).

<sup>25</sup> As of December 31, 1996.

<sup>26</sup> *Hawaii Rev. Stat.*, section 286-51.

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designated requester will assure the consistent, caring, and sensitive approach to the family and increasing the chances of getting consent. An annual review of death records can identify what kind of improvements if any need to be added to the request process to assure more donations. Assessing a fine for noncompliance would provide sanctions which do not now occur. (See suggested legislation, section 2, §327-A.)

- The Bureau recommends giving the Lieutenant Governor the responsibility for increasing visibility about organ donation through education and public awareness projects. (See suggested legislation, section 2, §327-B.)
- The Bureau recommends the creation of an advisory committee on organ donation to report progress and suggest new projects in this area to the Legislature. The input from many participants involved in the transplantation program can improve publicity, education, and other types of awareness in organ donation. (See suggested legislation, section 2, §327-B.)
- The Bureau recommends the creation of a funding source to help pay for educational programs that utilizes cooperative efforts from established organ donor groups. This fund could also offset costs for educating hospital staff, training designated requesters, and other matters as appropriate. (See suggested legislation, section 2, §327-A.)

### **Suggested Legislation**

The Bureau suggests the following bill to implement the above recommendations. The Legislature could choose to incorporate some points but not others as it sees fit.

**Digest.** Amends Hawaii's Uniform Anatomical Gift Act in various ways. Requires all acute care hospitals in Hawaii at or near the time of every individual death, to report to the organ procurement organization (OPO) by telephone to determine suitability for organ, tissue, or eye donation of the individual in question. Requires the OPO and hospital representatives to cooperatively develop protocols for presenting the option to donate to the individual or the individual's family, as the case may be. Prohibits family members from overriding the donor's wishes when evidenced by a document of gift. Limits liability of any person who relies in good faith on the document of gift, except for gross negligence, recklessness, or intentional misconduct. Requires the OPO and hospital representatives to conduct an annual death record review. Authorizes the assessment of a fine for noncompliance with the required referral of all deaths occurring in acute care hospitals. Establishes a state organ donation advisory committee made up of representatives of organ, tissue, and eye donation, transplant recipients, donor families, government, and health professionals. Authorizes the LG to actively promote organ, tissue, and other anatomical gift efforts.

## A BILL FOR AN ACT

### RELATING TO ANATOMICAL GIFTS.

SECTION 1. **Findings and purpose.** The legislature finds that there exists in the State a shortage of organ and tissue donors to provide the organs and tissue that could save lives or enhance the quality of life for many persons. There are many more patients on the waiting list for a kidney, liver, heart, lung, or other solid organs than there are donated organs. As a result many patients die before they can be given a second chance at life.

The legislature further finds that particular difficulties exist in making members of various minority groups aware of the need for anatomical gifts. For various reasons minorities appear to be at increased risk to suffer illnesses such as diabetes, that destroy healthy organs and require replacement. The chances of finding a good organ match is increased if the donor is of the same ethnic group as the transplant recipient. Minority ethnic groups must be educated in the great need among their own people for anatomical gifts. The legislature finds that more education and discussion among families are necessary to encourage organ donation.

The purpose of this Act is to increase the number of patients being asked to donate organs, to expand educational efforts across all ethnic, religious, and age groups, and to increase the supply of organs for waiting transplant recipients.

SECTION 2. Chapter 327, Hawaii Revised Statutes, is amended by adding three new sections to be appropriately designated and to read as follows:

**“§327-A Required referral.** (a) On or before the occurrence of each death in an acute care hospital, the hospital shall report to the appropriate organ, tissue, or eye recovery agency in order to determine the suitability of the individual for organ, tissue, and eye donation. This contact shall be noted on the patient’s medical record.

(b) If the hospital administrator or designee has received actual notice of opposition from any of the persons named in section 327-3 and the decedent was not in possession of a valid document of gift, the gift of all of any part of the decedent’s body shall not be requested.

(c) Each acute care hospital shall develop within one year of the effective date of this Act with the concurrence of the hospital medical staff, a protocol for identifying potential organ and tissue donors. The protocol shall require that at or near the time of every individual death,

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an acute care hospital shall contact by telephone the local organ procurement organization to determine suitability for organ, tissue, and eye donation of the individual in question. Each hospital shall designate a person to contact the organ procurement organization along with the appropriate data about each affected individual necessary to begin assessment for suitability for recovery of anatomical gifts. The acute care hospital's protocol shall specify the kind of information that shall be available prior to making the contact, including but not limited to the patient's age and cause of death. The organ procurement organization in consultation with the patient's attending physician, or designee, shall determine the suitability for donation. If the organ procurement organization in consultation with the patient's attending physician or designee determines that donation is not appropriate based on established medical criteria, this shall be noted by the hospital personnel on the patient's record, and no further action shall be necessary. If the organ procurement organization in consultation with the patient's attending physician or designee determines that the patient is a suitable candidate for anatomical donation, the acute care hospital and the organ procurement organization, separately or together, shall initiate a request by a designated requester who shall be a person trained by the organ procurement organization. The protocol shall encourage discretion and sensitivity to family circumstances in all discussions regarding donations of tissue or organs. The protocol shall take into account the deceased individual's religious beliefs or nonsuitability for organ and tissue donation. As used in this section, "designated requester" means a person who has completed a course offered by an organ procurement organization on how to approach families and request organ or tissue donation.

(d) The department of health shall conduct annual death record reviews at each acute care hospital to determine the hospital's compliance with this section. The department may delegate its duty to conduct annual death record reviews to the local organ procurement organization. There shall be no cost assessed against a hospital for a review of death records pursuant to this subsection.

The department of health may impose an administrative fine of up to \$500 for each instance of noncompliance. For purposes of this section, noncompliance means any failure on the part of an acute care hospital to contact an organ procurement organization at or near the death of each individual.

**§327-B Advisory committee on anatomical gifts.** (a) There is established within the department of health for administrative purposes the advisory committee on anatomical gifts consisting of at least fifteen members appointed by the governor as provided in section 26-34. Members shall serve without compensation but shall be reimbursed for expenses, including travel expenses, necessary for the performance of their duties. Members shall be selected from among transplant recipients, donor families, health care providers, clergy, and organ, tissue, and eye procurement organizations. Additional members shall be selected from the department of education, the department of health, and department of commerce and consumer affairs. Professional associations of attorneys, health care providers, teachers, and nurses, as well as organ, tissue, and eye transplant donors, recipients, and the public may be consulted for nominees to the advisory committee. Every effort shall be made to select members from every island and from rural and urban areas for maximum geographic representation. Members shall serve for four years and may be removed for incompetence or misconduct. A majority of the members then serving shall constitute a quorum. Members shall select their own chairperson who shall serve for two years.

(b) The committee shall meet at least semiannually or at the call of the chairperson to:

- (1) Evaluate current donation rates and suggest methods to increase anatomical gifts;
- (2) Propose legislative, regulatory, or other policy changes to increase anatomical gifts;
- (3) Cooperate with the lieutenant governor and the local organ procurement organization to promote educational programs to increase awareness of organ donation needs; and
- (4) Engage in any other informational, educational, and promotional efforts that will help to increase organ, tissue, and eye donations.

(c) The lieutenant governor shall be the primary government official to promote organ donation awareness and shall serve in an ex officio member of the advisory committee. The lieutenant governor shall assist in any way to promote educational programs to promote organ donation.

**§327-C Organ and tissue education special fund.** The Hawaii organ and tissue education special fund is established in the state treasury and shall be administered by the office of the lieutenant governor. The fund shall be used for educational purposes to promote organ,

tissue, and eye donation programs, in schools and other public places including motor vehicle registration offices, busses, libraries, and government offices.”

SECTION 3. Chapter 286, Hawaii Revised Statutes, is amended by adding a new section to be appropriately designated and to read as follows:

“§286-A Organ and tissue education fee. Notwithstanding any other law to the contrary, an additional fee of \$1 for each certificate of registration or driver's license application or renewal shall be collected annually by the director of finance of each county, to be deposited into the organ and tissue education special fund pursuant to section 327-C.”

SECTION 4. Chapter 327, Hawaii Revised Statutes is amended as follows:

1. By amending subsection (h) of section 327-2 to read:

“(h) An anatomical gift that is not revoked by the donor before death is irrevocable and [does not require the consent or concurrence of any person after the donor's death.] the intent of a decedent to give all or any part of the decedent's body as a gift pursuant to this chapter as evidenced by the possession of a donor card, donor designation on a driver's license, advance directive, on other document of gift, shall not be revoked by any person, nor shall the consent of any other person be necessary to render that gift valid and effective.

Any person, hospital, or organization that relies on the document of gift and acts in good faith in accordance with the provisions of this chapter shall not be subject to criminal or civil liability from any action taken under this chapter. The immunity provided by this subsection shall not extend to persons if damages result from the gross negligence, recklessness, or intentional misconduct to the decedent.”

2. By repealing section 327-5.

[“§327-5 Routine inquiry and required request; search and notification. (a) On or before admission to a hospital, or as soon as possible thereafter, a person designated by the hospital shall ask each patient who is at least eighteen years of age: "Are you an organ or tissue donor?" If the answer is affirmative the person shall request a copy of the document of gift. The person designated shall make available basic information regarding the option to make or refuse to make an anatomical gift. The answer to the question, an available copy of any document of gift or refusal, if any, to make an anatomical gift, and any other relevant information, shall be placed in the patient's medical record.



(b) If, at or near the time of death of a patient, there is no medical record that the patient has made or refused to make an anatomical gift, the hospital administrator or a representative designated by the administrator shall discuss the option to make or refuse to make an anatomical gift and request the making of an anatomical gift pursuant to section 327-3. The request shall be made with reasonable discretion and sensitivity to the circumstances of the family including a reciprocal beneficiary. A request is not required if the gift is not suitable, based upon accepted medical standards, for a purpose specified in section 327-6. An entry shall be made in the medical record of the patient, stating the name and affiliation of the individual making the request, and of the name, response, and relationship to the patient of the person to whom the request was made. The director of health may adopt rules to implement this subsection.

(c) The following persons shall, at the person's discretion and if time and resources permit, and if doing so would be inoffensive to anyone in the vicinity of the body, make a reasonable search of the person and the person's immediate personal effects for a document of gift or other information identifying the bearer as a donor or as an individual who has refused to make an anatomical gift:

- (1) A law enforcement officer, firefighter, paramedic, or other emergency rescuer attending an individual who the searcher believes to be dead or near death; and
- (2) A hospital, upon the admission of an individual at or near the time of death, if there is not immediately available any other source of that information.

(d) If a document of gift or evidence of refusal to make an anatomical gift is located by the search required by subsection (c)(1), and the individual or body to whom it relates is taken to a hospital, the hospital shall be notified of the contents and the document or other evidence shall be sent to the hospital.

(e) If, at or near the time of death of a patient, a hospital knows that an anatomical gift has been made pursuant to section 327-3 or a release and removal of a part has been permitted pursuant to section 327-4, or that a patient or an individual identified as in transit to the hospital is a donor, the hospital shall notify the donee if one is named and known to the hospital; if not, it shall notify an appropriate procurement organization. The hospital shall cooperate in the implementation of the anatomical gift or release and removal of a part.

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(f) A person who fails to discharge the duties imposed by this section is not subject to criminal or civil liability but is subject to appropriate administrative sanctions.”]

SECTION 5. In codifying the new sections added to chapter 327, Hawaii Revised Statutes, by section 2 of this Act, the revisor of statutes shall substitute appropriate section numbers for the letters used in the new sections' designations in this Act.

SECTION 6. Statutory material to be repealed is bracketed. New statutory material is underscored.

SECTION 7. This Act shall take effect upon its approval.

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# HOUSE RESOLUTION

REQUESTING THE LEGISLATIVE REFERENCE BUREAU TO STUDY WAYS TO  
ENCOURAGE AND FACILITATE ORGAN DONATION IN HAWAII.

1 WHEREAS, according to the United States Department of  
2 Health and Human Services, as a result of medical advances, two  
3 thousand Americans, or about fifty-five persons a day were able  
4 to receive organ transplants in **1996** that either saved or  
5 enhanced their lives; however, approximately four thousand  
6 people died while waiting for transplants because not enough  
7 organs were available; and

8  
9 WHEREAS, according to the United Network for Organ  
10 Sharing, as of December 31, **1996**, about two hundred, Hawaii  
11 residents were waitlisted on the national transplant waiting  
12 list; and

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14 WHEREAS, although most Americans approve of organ and  
15 tissue donation, only half of families asked to donate actually  
16 give their consent; and

17  
18 WHEREAS, a third of potential donor families are never  
19 asked to donate organs; and

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21 WHEREAS, the United States Department of Health and Human  
22 Services is developing a national initiative to address the  
23 critical need for increased organ and tissue donation in the  
24 United States and is willing to provide states with promotional  
25 materials, data analyses, technical and policy support, and  
26 linkage with a strong network of nonprofit and voluntary  
27 organizations to provide speakers and grassroots support; and

28  
29 WHEREAS, several problems and potential solutions have  
30 been identified, including:

31  
32 (1) Lost opportunities for families to donate because  
33 hospitals have not identified and reported potential  
34 donors to organ procurement organizations; and

35  
36 (2) Low rates of family consent to donation;

37  
38 and

1           WHEREAS, a Pennsylvania law (Act 102, 1994) requires  
2 hospitals to notify organ procurement organizations of every  
3 death, which has resulted in a twenty-six percent increase in  
4 donors and a thirty-six percent increase in transplants two  
5 years after the law became effective; and  
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7           WHEREAS, Tennessee has enacted a new law effective June,  
8 1997, modeled on Pennsylvania's law; and  
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10           WHEREAS, Arizona revised its Anatomical Gift Act in 1996  
11 to require hospital donor protocols to include referrals to  
12 organ procurement organizations, hospital staff training, and  
13 measures to make obtaining consent easier, which has resulted  
14 in a sixty-two percent increase in tissue donation; and  
15

16           WHEREAS, participation in donor registries has increased  
17 seventy-seven percent in Illinois since the passage of its  
18 State's "Live and Learn" law in 1993 (a public education  
19 program) while organ donation has increased fifty-two percent;  
20 and  
21

22           WHEREAS, since Kentucky passed a "Trust for Life" law in  
23 1993 which allowed residents to make a \$1 contribution to an  
24 organ donor awareness fund, organ donors have increased by  
25 fifty percent; and  
26

27           WHEREAS, organ donation nationwide has not kept up with  
28 the need for donations for transplants, and there appears to be  
29 several examples in other states that have generated some  
30 success in increasing the rate of organ donations and public  
31 awareness and acceptance of organ donation that may benefit the  
32 residents of Hawaii who, each year, wait futilely for a needed  
33 transplant; now, therefore,  
34

35           BE IT RESOLVED by the House of Representatives of the  
36 Nineteenth Legislature of the State of Hawaii, Regular Session  
37 of 1998, that the Legislative Reference Bureau is requested to  
38 study ways to encourage and facilitate organ donation in  
39 Hawaii; and  
40

41           BE IT FURTHER RESOLVED that the study examine at least the  
42 statutes and culturally appropriate approaches taken by  
43 Pennsylvania, Tennessee, Arizona, Illinois, and Kentucky; and

1           BE IT FURTHER RESOLVED that the Legislative Reference  
2 Bureau is requested to report its findings and recommendations,  
3 including any necessary proposed legislation, to the  
4 Legislature not later than twenty days prior to the convening  
5 of the Regular Session of 1999; and  
6

7           BE IT FURTHER RESOLVED that certified copies of this  
8 Resolution be transmitted to the Acting Director of the  
9 Legislative Reference Bureau and the Executive Director of the  
10 Minority Organ Tissue Transplant Education Program of Honolulu.

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SENATE CONCURRENT  
RESOLUTION

REQUESTING THE HAWAII STATE BAR ASSOCIATION TO INCLUDE IN ITS CONTINUING EDUCATION PROGRAMS, INFORMATION ABOUT ORGAN DONATION.

1           WHEREAS, there are many patients in the State of Hawaii  
2 who suffer from End Stage Renal Disease and other terminal  
3 illnesses due to organ failure such as liver disease, heart  
4 disease, and so on; and

5  
6           WHEREAS, there are about 200 patients on the waiting list  
7 for new organs, and many die waiting for a suitable organ to  
8 become available; and

9  
10          WHEREAS, of the 4,000 or so persons who died in the first  
11 six months only six persons donated solid organs in the first  
12 half of 1998; and

13  
14          WHEREAS, the Hawaii State Bar Association serves as a  
15 unified bar of all licensed attorneys in the State; and

16  
17          WHEREAS, the Hawaii State Bar Association often conducts  
18 continuing education classes in wills, trusts, and probate for  
19 attorneys; and

20  
21          WHEREAS, many attorneys who deal with clients who need  
22 advice and other documentation for end of life decisions can  
23 provide useful information to these clients about organ  
24 donation at the time of providing service for drafting wills or  
25 trusts; and

26  
27          WHEREAS, the Organ Donor Center of Hawaii serves as a  
28 federally certified organ procurement organization for Hawaii  
29 and can provide informational brochures to the Hawaii Bar  
30 Association regarding organ donation; now, therefore,  
31

1 BE IT RESOLVED by the Senate of the Twentieth Legislature  
2 of the State of Hawaii, Regular Session of 1999, the House of  
3 Representatives concurring, that the Hawaii State Bar  
4 Association is requested to include, in its continuing  
5 education programs, information regarding becoming an organ  
6 donor; and  
7

8 BE IT FURTHER RESOLVED that the Hawaii State Bar  
9 Association solicit advice and information from the Organ Donor  
10 Center of Hawaii for suitable materials, including questions  
11 and answers about becoming an organ donor; and  
12

13 BE IT FURTHER RESOLVED that certified copies of this  
14 Concurrent Resolution be transmitted to the Executive Director  
15 of the Hawaii State Bar Association and the Executive Director  
16 of the Organ Donor Center of Hawaii.  
17  
18  
19  
20

OFFERED BY: \_\_\_\_\_

## Appendix C

### REQUIRED REQUEST FORM (Sample)

The donation of organs and tissues has the potential for saving thousands of lives each year. Are you willing to have your organs and tissues used after your death, without cost to you or your estate?

I hereby make this anatomical gift if medically acceptable for use in transplantation, therapy, medical research, or education, to take effect upon my death.

I give any needed organs or tissues for transplantation

or

only the following organs for tissues for transplantation:

- eyes
- kidneys
- pancreas
- liver
- lungs
- heart
- bone and tissue
- other, please specify \_\_\_\_\_

my body for anatomical study.

I do not make this anatomical gift.

I do not want any of my organs used.

I want my next of kin or designated surrogate to decide whether after my death my organs or tissues are used.

Signature \_\_\_\_\_

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The Required Response Form has the advantage of collecting information already collected by forms used by the states and, by its flexibility, gives the applicant three options: (i) donation, (ii) no donation, or (iii) delegation of the consent decision to the donor's family. The completed Form would have to be submitted to the DMV for a successful driver's license application to be processed. The Subcommittee has yet to address how the information on this Form would be merged with identifying information (eng., name, date of birth, Social Security Number) in the construction of a central data file.