

Approved: Feb. 10, 2000  
Date

MINUTES OF THE HOUSE TAXATION COMMITTEE.

The meeting was called to order by Chairperson Wagle at 9:00 a.m. on January 27, 2000 in Room 519-S of the Capitol.

All members were present except: Rep. Howell - excused  
Rep. Sharp - excused  
Rep. Johnston - excused  
Rep. Campbell - excused  
Rep. Gregory - excused  
Rep. Edmonds - excused

Committee staff present: Chris Courtwright, Legislative Research Department  
April Holman, Legislative Research Department  
Don Hayward, Revisor of Statutes  
Shirley Sicilian, Department of Revenue  
Ann Deitcher, Committee Secretary  
Edith Beaty, Taxation Secretary

Conferees appearing before the committee: Rep. Tom Sloan  
Fred Gatlin  
Prof. James Shanteau, Kansas State University  
Terri Roberts, Kansas State Nurse's Assoc.  
Orion Bell, Local Director of American Red Cross

The Chair introduced Representative Sloan who explained **HB 2613**. (Attachment 1). He pointed out that the bill did not violate any federal laws against paying for organs because it does not designate who should receive them.

Representative Gatewood asked if a family can donate their loved ones organs even though the deceased hadn't signed a donor card. Representative Sloan said they could.

Representative Sloan closed by saying if **HB 2613** isn't the answer, then someone must come up with one. He reminded the Committee there were 68 thousand people waiting and the National Organ Donor clearing house says that 5 thousand will die every year, so we're not doing enough. We must do more.

Representative Flora asked how the tax credit would work. Representative Sloan said that the process as he envisioned it to be, was when one goes to donate blood, the Red Cross gives you a form they've filled out with the necessary proof of your donation. When you file your income tax on April 15, you will attach this form.

Fred Gatlin spoke as a proponent for **HB 2613**. (Attachment 2). He told the Committee that he is on the waiting list for a kidney transplant due to the Polycystic Kidney Disease he suffers from. He presently has dialysis three times a week.

Next to appear in support of **HB 2613** was James Shanteau, Professor of Psychology, Kansas State University. He spoke to the Committee of his studies over the past 15 years of people's health care choices, (Attachment 3), and said that one common answer as to why there were so few organs donated was the lack of knowledge about the need for donors. However, their studies of over 800 residents of Kansas showed that almost 99% were aware of the shortage and were sympathetic to the plight of potential recipients. He said, in his view it was unstated motivations, subjective risks and unarticulated fears about donation. If these motivations, risk and fears could be addressed, then rates of donation would increase.

Appearing as an opponent of **HB 2613** was Teri Roberts, Executive Director of Kansas State Nurses Association. (Attachment 4).

## CONTINUATION SHEET

Ms. Roberts said that her organization knew that increased attention in this area would help with organ and tissue donations but they could not support **HB 2613** because they believe that the financial incentive comes very close to what is commonly referred to as retailing organs. She said that current federal law prohibits the sale of human organs and violators of the law can be fined a minimum of \$50 thousand and/or imprisonment for a maximum of five years.

Orion Bell, Director of the Kansas Capital Area Chapter of the American Red Cross in Topeka, testified as an opponent to **HB 2613**. (Attachment 5).

One of the things Mr. Bell stressed was the importance of not depending on your signature as a donor that is on your driver's license. Too many people have not had their wishes carried out because their family wasn't informed of those wishes and their driver's license was misplaced at the time of the person's death.

The Chair declared the hearing on **HB 2613** to be closed.

Representative Ray spoke to the Committee of a problem facing Black and Veatch regarding their High Performance Incentive Program Tax Credit. She said they have changed from a partnership to a corporation, and even though they are the same people and the same company, there is some question that they will not receive the tax credits they previously had received because they were told there were a different company. She did not believe this was the intent.

Representative Ray moved that a bill be adopted to clarify the intent of the Black and Veatch tax credit plan.. Representative Minor seconded the motion and it carried on a voice vote.

The meeting adjourned at 10:15 a.m. The next meeting is scheduled for Tuesday, February 1, 2000.

TOM SLOAN  
 REPRESENTATIVE, 45TH DISTRICT  
 DOUGLAS COUNTY

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## TESTIMONY ON HB2613 - CONCERNING TAX CREDITS

Madame Chairman, members of the committee, thank you for the opportunity to discuss this important issue of encouraging citizens to donate blood and organs.

Nationally, almost 69,000 Americans are on organ transplant waiting lists. The American Red Cross on January 10, 2000 issued a national appeal for blood donors and a Topeka radio station carried an appeal for local donors on January 18<sup>th</sup>. The National Red Cross media release states that only 5 percent of eligible Americans donate blood. The United Network for Organ Sharing stated in a December, 1999 media release that "more than 5,000 patients will die waiting for a transplant. Fewer than 50 percent of the patients added to the waiting list will ever receive a transplant."

Attached to my testimony is information about the national need for organ donors, donors and recipients in the Midwest and some numbers for Kansas.

HB2613 proposes a \$10 tax credit for each donation of blood and \$300 for each organ donated. Several questions have been raised about this bill and my sponsorship of it.

- 1) Yes, I am a blood donor and have signed the organ donor line on the back of my driver's license. No, I do not need a tax incentive to donate but if only 5 percent of eligible Americans donate blood and 69,000 organ donors are necessary to save lives, we clearly need to do more.
- 2) HB2613 does not violate federal laws against paying for organs because it does not designate who should receive the organs. HB2613 establishes that the State of Kansas believes that encouraging the donation of blood and organs is beneficial to the general public health and welfare.
- 3) Passage of this bill will not create a large financial loss to the State of Kansas, but it may help save lives - a frequent legislative objective.
- 4) There is a difference between blood (and bone marrow which I inadvertently left out of the bill) and organs. Blood and bone marrow are naturally replaced by the body. However, most

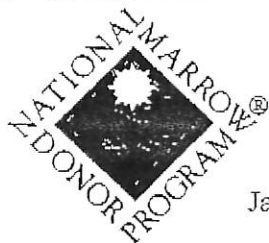
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donated organs are from deceased persons, their beneficiaries would benefit from the donation. Nothing in **HB2613** requires donations, the bill simply says state policy encourages people to help other people.

- 5) Passage of this bill will not establish a value for blood or organs. Persons who donate blood plasma already are paid by some collecting agencies. **HB2613** does not pay donors, it allows tax credits that may or may not be exercised by the donor or his/her beneficiaries. All persons who wish to donate will pass the rigid screening tests, that blood and organ centers already have in place. Those who fail will not receive the tax credits.
- 6) I envision a simple implementing process, if **HB2613** is enacted into law. The blood, bone marrow, and organ collection agencies will provide a Department of Revenue approved, signed form specifying the name of the donor, date of donation, amount of blood or specific organ donated, and the amount of tax credit for which the donor is eligible. The donor or executor files the forms with the income tax form and claims the appropriate credit.

**HB2613** was introduced to address a legitimate public need - to increase the number of blood and organ donors, thereby saving lives.

I ask for your support for the concept espoused in **HB2613**.



January 21, 2000

National Marrow  
Donor Program®

Eastern Regional Office  
7910 Woodmont Avenue  
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Bethesda, Maryland 20814-3015  
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1-800-57-DONOR  
FAX: 301-951-5526

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**Laura Graves Award:**

The Honorable C. W. Bill Young  
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Claude Lenfant, M.D.

A collaborative effort of the:  
American Association  
of Blood Banks  
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America's Blood Centers

With federal funding from:  
Health Resources and Services  
Administration and  
Naval Medical Research and  
Development Command

Honorable Tom Sloan  
Statehouse  
300 SW 10<sup>th</sup> Ave.  
Topeka, KS 66612-1504

Dear Representative Sloan:

Thank you for inviting the National Marrow Donor Program® (NMDP) to make suggestions concerning your legislation to offer tax credits for individuals making blood or organ donations. By way of background, the NMDP has sought to make unrelated bone marrow donors available to as many patients requiring unrelated marrow transplantation as possible. As you may well imagine a decision by a volunteer to become available if needed to donate bone marrow to a complete stranger is a serious one. While we have been successful in our recruitment efforts, we can always use help.

As you consider this legislation, you might give some consideration to offering a tax credit to anyone qualified and volunteering to join the Registry who bears all or any part of the cost of Human Leukocyte Antigen (HLA) phenotype testing—blood testing. The amount of the credit might equal the amount of out-of-pocket expense assumed by the volunteer registrant at the time of entry onto the Registry.

Representative Sloan, the NMDP will never have sufficient resources to cover the costs of HLA typing for all of the altruistic individuals who want to join the donor Registry. Currently, the NMDP is able to provide some blood typing funding to donor centers and recruitment group staff working with volunteers in their communities around the nation. Unfortunately this funding is insufficient to meet all of the costs. A tax credit for individuals desiring to join the Registry, but who may have to pay some portion or all of the cost of blood typing would be very helpful to our recruitment efforts.

Sincerely,

Paul S. Egan  
Legislative Policy Representative

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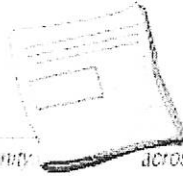
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## Red Cross Calls for Immediate Donations Blood Supplies Low Nationwide

### Holidays, Flu Outbreak Leave More Than Half of Red Cross Blood Services Regions Short of Type O Blood

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or  
Call 1-800-HELP-NOW

WASHINGTON, January 10, 2000--This season's flu outbreak following on the heels of the holiday season has dramatically impacted American Red Cross blood supplies nationwide. Donations are urgently needed as 27 of the organization's 37 Blood Services regions are at less than one day's supply of type O blood, the universal blood type. While all blood types are needed, type O blood donors are specifically asked to step forward because type O blood can be safely transfused in emergency situations to most patients.

"The top priority of the American Red Cross is to meet patient needs by providing a safe and adequate supply of blood," said Red Cross President and CEO Dr. Bernadine Healy. "We are committed to this as part of our mission, and we are asking for the support and help of all eligible blood donors."

Volunteer blood donations help patients being treated for accidents, routine surgeries, and serious diseases such as cancer, heart disease, and hemophilia. Despite the fact that giving blood is easy, safe, and takes less than one hour, only 5 percent of eligible Americans donate blood. To donate blood, one must be healthy, at least 17-years old, and weigh 110 pounds or more.

For more than 50 years, the American Red Cross has been the primary supplier of lifesaving blood and blood products in the United States. The Red Cross collects blood voluntarily donated by approximately 4.5 million donors, annually providing more than 6 million units of blood for patients nationwide. The Red Cross also enhances and saves the lives of thousands of patients each year by supplying one-quarter of the nation's tissue for transplantation, through its network of 15 tissue centers nationwide, and conducts advanced, highly sophisticated biomedical research that focuses on improving blood safety and developing potentially lifesaving products.

Note: Following is a list of Red Cross blood regions. **Asterisk (\*) indicates that the region has less than one-day supply of type O blood.**

**Connecticut Region** in Farmington, CT  
Lynn Townshend – 860-678-5421

\* **Northeastern Penn. Region** in Ashley, PA  
Molly Groody – 570-821-2407

\* **New York Penn. Region** in Rochester, NY

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## UNOS News Release

**For Immediate Release:**  
December 17, 1999

**Contact:** UNOS News Bureau  
E-mail: [news@unos.org](mailto:news@unos.org)  
Phone: (804) 327-1432

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### UNOS Statement on HR 1180

**Richmond, VA** - Today the President signed into law H.R. 1180, the Ticket to Work and Work Incentives Improvement Act of 1999. This bill contains a 90-day moratorium on the Department of Health and Human Services (HHS) Final Rule regarding organ allocation.

Continuing in the spirit of the November United Network for Organ Sharing (UNOS) Board of Directors meeting, in which HHS officials participated, UNOS is committed to working with the Department of Health and Human Services toward the mutual goal of providing the best possible care for patients.

The transplant community is currently examining the proposed regulation and will be prepared should it be implemented. We believe elements of the Final Rule could be improved and we will be providing our comments to the Secretary.

One potentially troublesome aspect of the Final Rule is a potential lowering of the current UNOS high quality standards for transplant centers and surgeons. The result of this regulation would enable any hospital or doctor to perform transplants, regardless of qualifications, and that would clearly not be in the best interest of patients. HHS has acknowledged our concerns and expressed a willingness to discuss them.

Tragically, no matter what is done through regulation or change in organ allocation policy, the sad fact still exists there is a critical shortage of donated organs. More than 5000 patients will die waiting for a transplant. Fewer than 50% of the patients added to the waiting list will ever receive a transplant. The medical community and the federal government will work together in coming up with a solution to significantly increase organ donation and thus save more lives.

UNOS maintains the U.S. organ transplant waiting list and brings together medical professionals, recipients and donor families to develop organ allocation policy under contract with the Department of Health and Human Services. UNOS collects, analyzes and publishes more data on a single field of medicine than any other organization.



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## Organ & Tissue Donation

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### Waiting List

The UNOS National patient waiting list for organ transplant contains over 68,600 registrations. On July 14,1999 There were:

44,457	Registrations for a kidney transplant.
13,601	Registrations for a liver transplant.
483	Registrations for a pancreas transplant.
121	Registrations for a pancreas islet cell.
1,963	Registrations for a kidney-pancreas transplant.
115	Registrations for a intestine transplant.
4,328	Registrations for a heart transplant.
231	Registrations for a heart-lung transplant.
3,386	Registrations for a lung transplant.
<b>68,685</b>	<b>TOTAL</b>

NOTE: UNOS policies allow patients to be listed with more than one transplant center (multiple-listing), and thus the number of registrations may be greater than actual number of patients.

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VI. Transplants at programs associated with: Midwest Organ Bank

Transplant Center Name	Transplants performed in 1998						
	Kidney	Liver	Pancreas	Heart	Lung	Heart-Lung	Kidney-Pan
Children's Mercy Hospital	9	2					
Research Medical Center	34						
St Luke's Hospital	49			18			
University of Kansas Medical Center	37	38					
University of Missouri Hospital & Clinic	39			9			
Via Christi Regional Medical Center	41			8			

Based on UNOS OPTN and Scientific Registry data as of May 27, 1999

<http://207.239.150.13/tpd/olap/BuildTables.asp>

**VII. Cadaveric transplant donors and transplanted organs recovered by organ procurement organization: Midwest Organ Bank**

This table contains information about the number of cadaveric transplant donors and number of organs transplanted from cadaveric donors that were recovered by this OPO.

	During 1997	During 1998
Total transplant donors	96	122
Kidneys Transplanted	171	216
Livers Transplanted	81	104
Pancreases Transplanted	14	25
Hearts Transplanted	38	50
Lungs Transplanted	18	35

This table contains information about the number of cadaveric transplant donors and number of organs transplanted from cadaveric donors that were recovered by this OPO.

Please note that the organs recovered by this OPO may or may not have been transplanted at transplant centers within the OPO. Additionally, multiple organs may have been transplanted simultaneously (e.g., a double-lung transplant) so the number of organs transplanted may not equal the number of transplants performed.

Based on UNOS OPTN and Scientific Registry data as of May 27, 1999

## Results for Kidney for the state of Kansas

[← Back](#)[Technical Guide](#)

Please select a center:

KSFW - Via Christi Regional Medical Center

### I. Activity on cadaveric Kidney waiting list for the state of Kansas.

	Number on waiting list	
	1/1/1998 - 12/31/1998	1/1/1999 - 3/31/1999
Number Waiting At Start of Period	111	108
Number Added to the Waiting List	74	28
Number Transplanted	61	11
Number Died on Waiting List	4	1
Number Removed For Other Reasons	12	13
Number on Waiting List at end of period	108	111

This table shows: (1) the number of patient registrations on the waiting list at the beginning of both 1998 and 1999; and (2) the activity on the waiting list during the year.  
Based on UNOS OPTN data as of May 30, 1999

## Results for Heart for the state of Kansas

[← Back](#)[Technical Guide](#)

Please select a center:

KSFW - Via Christi Regional Medical Center

### I. Activity on cadaveric Heart waiting list for the state of Kansas.

	Number on waiting list	
	1/1/1998 - 12/31/1998	1/1/1999 - 3/31/1999
Number Waiting At Start of Period	74	73
Number Added to the Waiting List	19	1
Number Transplanted	8	1
Number Died on Waiting List	7	3
Number Removed For Other Reasons	5	2
Number on Waiting List at end of period	73	68

This table shows: (1) the number of patient registrations on the waiting list at the beginning of both 1998 and 1999; and (2) the activity on the waiting list during the year.  
Based on UNOS OPTN data as of May 30, 1999

## Results for Liver for the state of Kansas

Please select a center:

### I. Activity on cadaveric Liver waiting list for the state of Kansas.

	Number on waiting list	
	1/1/1998 - 12/31/1998	1/1/1999 - 3/31/1999
Number Waiting At Start of Period	14	6
Number Added to the Waiting List	34	7
Number Transplanted	38	7
Number Died on Waiting List		
Number Removed For Other Reasons	4	
Number on Waiting List at end of period	6	6

This table shows: (1) the number of patient registrations on the waiting list at the beginning of both 1998 and 1999; and (2) the activity on the waiting list during the year. Based on UNOS OPTN data as of May 30, 1999

### Number of Transplants Performed January — December 1998\*

853	Kidney-Pancreas transplants
11,470	Kidney alone transplants ( 3,712 from living donors)
208	Pancreas alone transplants
4,165	Liver transplants
2,292	Heart transplants
62	Heart-lung transplants
928	Lung transplants
67	Intestine transplants
<b>20,045</b>	<b>TOTAL</b>

\* Based on UNOS Scientific Registry data as of January 4, 1999  
Double kidney, double lung and heart-lung transplants are counted as one transplant.

# TESTIMONY ON HB 2613

## Before House Taxation Committee

By Fred Gatlin

January 27, 2000

Madame Chairwoman and members of the Taxation Committee. I appear before you today as a private citizen. I am in fact a state employee. However, I am here today as Fred Gatlin resident of Topeka who is waiting for a kidney transplant. In 1983 my mother was not feeling well. She went to the doctor and he ordered a sonogram after finding no obvious cause for her condition. In 1960 my Grandmother, my mothers mother, became ill. She was taken to KU Med Center and died. My mother accompanied her mother and was told that her illness was Polycystic Kidney Disease. They told my mother the disease was autosomal dominant and she had a 50% chance of inheriting it. My mother chose to ignore this possibility until 1983. A week after my mother was diagnosed, I found out I also had Polycystic Kidney Disease. My kidney function decreased steadily and in July 1998 my kidney function had declined to the point that I was eligible for the transplant list. On October 31, 1998, I began dialysis.

Dialysis allows me to continue to work. Fortunately, I have an understanding and supportive boss. Dialysis is confining. I presently have dialysis on Monday, Wednesday and Friday at 3:30 in the afternoon. Each session lasts 3.5 hours plus time before and after the treatment. If I travel, it is necessary to plan times to be gone and find sites to do the dialysis and arrange time to do it. If I am more than four hours from Kansas City I must go off the list until I return. The 10.5 hours plus needed weekly to do dialysis limit work, restrict family time and make social and community activity more difficult. While dialysis is a far better choice than no dialysis. I am convinced I would feel better, have more energy and be more productive if I had a new kidney.

Do we currently have enough organ donors? The answer is clearly No. In my view we would have enough organs when there is no significant waiting list or we have organs that can not be used because there are no qualified recipients. You will hear today that this bill is bad legislation because it is a financial inducement to donate and will lead to unqualified donors motivated by money. I am a two gallon blood donor. However, I do not wish to comment on that part of the bill. My interest and comments are on organ transplant. I struggle to understand the logic that a \$300. tax credit is an improper financial inducement to donate. In living donors of a kidney, I find it difficult to understand what would motivate anyone to donate an organ for mercenary reasons. HB 2613 proposes a tax credit. In order to use a tax credit one must have enough income to use it. Donating a kidney is major surgery. In fact donating a kidney is a longer recovery time than receiving a kidney. For most organ donors the credit will be to the estate of the donor. I have heard numerous stories of how organ donation was one ray of sunshine in an untimely death. If we can offer a tax credit to that estate, I think that is good public policy.

I encourage this committee to give this bill serious consideration. I would ask that you consider dividing the issue. I think the donation of blood and the donation of organs are very different and should be looked at separately. I encourage you to then move ahead at least with the organ transplant portion of the bill. I also ask that you make the tax credit to estates a refundable credit. This will allow more estates use is credit. With the above mentioned changes I urge you to approve HB 2613.

House Taxation  
Date 1/27/00  
Attachment # 2

**House Bill No. 2613 (An Act providing for tax credits for certain anatomical donations)**  
**Introduced by Representative Sloan**

Testimony by James Shanteau, Ph.D.  
Professor of Psychology, Kansas State University

**Background:** Over the past 15 years, I have studied on how people make health-care choices generally and organ-donation decisions specifically. Based on these studies, I have authored a book (*Organ Donation and Transplantation: Psychological and Behavioral Factors* published by the American Psychological Association), written a dozen papers, and given over 20 talks on organ donation behavior. I have also received several grants and coordinated an international conference (held at KSU) on organ donation. Last July, I wrote a piece for *USAToday* on the unintended behavioral consequences of a proposed change in Federal Regulations concerning organ distribution. I have been interviewed often by both print and media reporters about the behavior of organ donation. Thus, I am knowledgeable about many aspects of this topic.

**The Problem:** Organ donation is one of the marvels of modern medicine. Organs such as kidneys are routinely transplanted with success rates approaching 90%. Moreover, the success rates for more difficult transplants, such as hearts and livers, have been steadily rising. Thus, the technology of transplantation has developed rapidly as a lifesaving procedure with promises of even more success in the future. A major roadblock, however, has been the inability to deliver the miracle of transplantation to many patients in need. This is not due to lack of skilled surgeons or hospital facilities. Rather, it is due to a persistent shortage of organs. The shortfall is due, in part, to better medical technology and improved immunosuppressant drugs. However, the biggest reason for the shortage is simply the lack of donors.

**Some Numbers:** The United Network for Organ Sharing (UNOS) reports that there are over 66,000 people on the waiting list for transplants today <[http://www.unos.org/Newsroom/critdata\\_main.htm](http://www.unos.org/Newsroom/critdata_main.htm)>. Most are waiting for kidneys (44,000), livers (14,500), and hearts (4,000). UNOS estimates that one new name is added to the transplant waiting list every 16 minutes. Of these, fewer than 50% will ever receive an organ. In 1997, over 4,300 died waiting for an organ (up from 1,400 in 1988). As the attached chart shows, the waiting list for kidneys has grown steadily while the number of donors has remained nearly constant.

**Where are the Donors?** These shortages are not due to lack of potential organs suitable for transplan-

tation. One estimate (by the Midwest Organ Bank in Kansas City) concluded that only about 3,000 out of a potential 23,000 donors in fact donated organs. Even a modest increase in the rate of donation would go a long way toward reducing the shortage. The central question is why are there so few organs donated? One common answer in the medical literature is that lack of knowledge about the need for donors is the reason. However, our studies of over 800 residents of Kansas show that almost 99% were aware of the shortage. Moreover, most were quite sympathetic to the plight of potential recipients. Therefore, the shortage does not appear to be due to a lack of knowledge or an absence of empathy. My view is that the reluctance to be a donor is due to unstated motivations, subjective risks, and unarticulated fears about donation. If these motivations, risk, and fears can be addressed, then rates of donation will increase.

**Prior Efforts to Increase Donations:** There have been many previous attempts to solve the organ donation problem. Some of these efforts involve education, public service announcements, national organ donor awareness days, and media events. Most states let citizens indicate their willingness to be a donor on their driver's licenses. There have been proposals to offer financial incentives, eg, to pay for the donor's funeral expenses. In addition, a number of legal mandates are in place, eg, hospital personnel are now required to ask patients about organ donation. Despite these efforts, the gap between supply and demand continues to grow. (See the attached chart for the kidney transplant waiting list.)

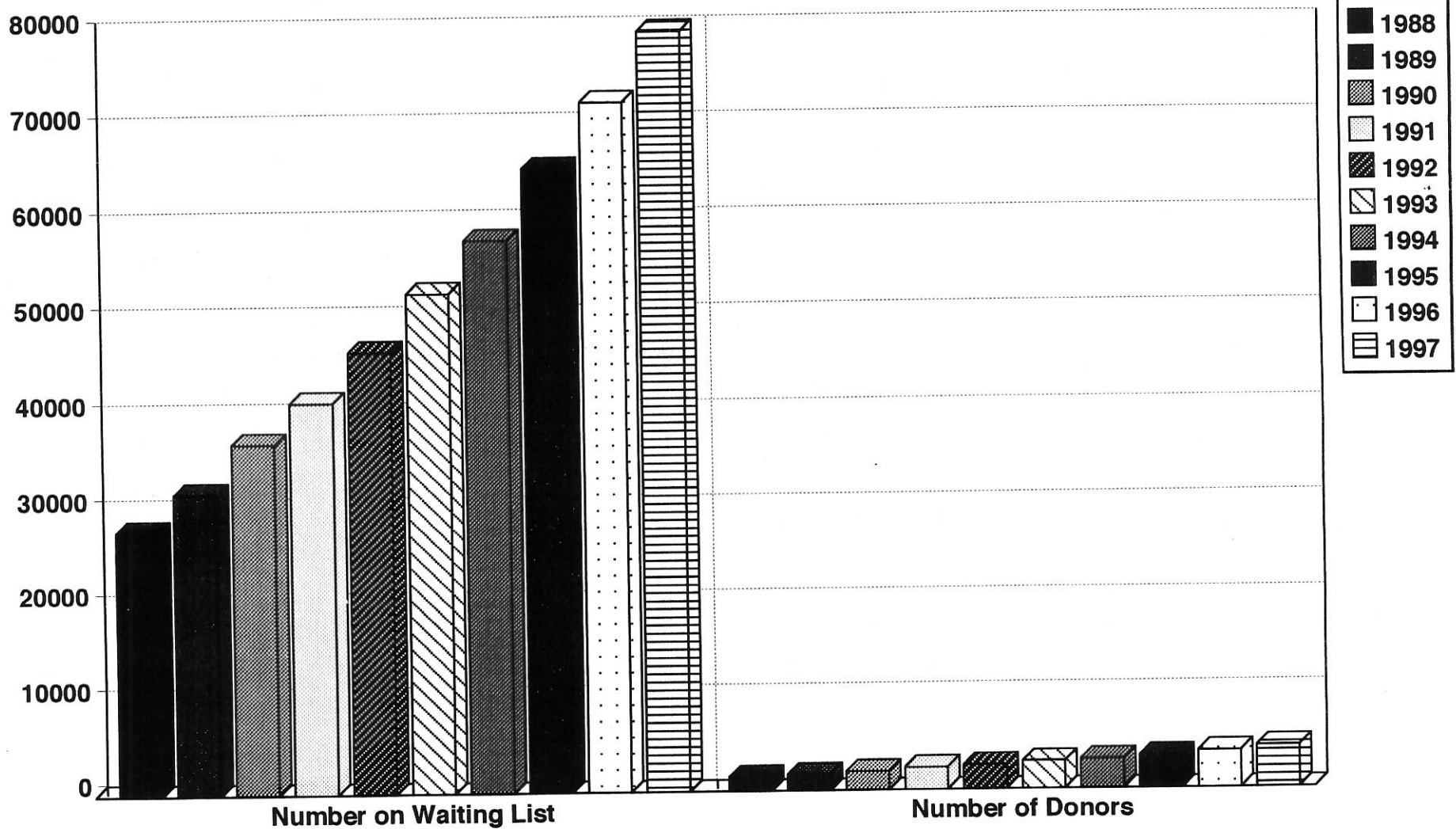
**Proposed Legislation:** Federal law clearly prohibits the sale of organs. However, the proposed bill takes a different approach since the state (not the recipient) is involved. Also, tax incentives have been used to reduce perceived risk in other areas (eg, economic development). At this time, no one knows whether such a tax credit will help. (It is possible, however, to conduct behavioral research on this issue.) Still, it is hard to see how the proposal could hurt the rates of donation. For instance, it clearly places the State in the position of sanctioning organ donation. One other question: How are people going to find out about the tax credit? Obviously, no measure (no matter how generous) will have any impact if no one knows about it. Perhaps this information could be added to drivers' license applications.

House Taxation

Date 1/27/00

Attachment # 3

# Number of People on Waiting List versus Number of Donors



Data from United Network for Organ Sharing (UNOS) *Annual Report for 1998*.

House Bill No. 2613 (An Act providing for tax credits for certain anatomical donations)  
Introduced by Representative Sloan

Testimony by James Shanteau, Ph.D.  
Professor of Psychology, Kansas State University

**Background:** Over the past 15 years, I have studied on how people make health-care choices generally and organ-donation decisions specifically. Based on these studies, I have authored a book (*Organ Donation and Transplantation: Psychological and Behavioral Factors* published by the American Psychological Association), written a dozen papers, and given over 20 talks on organ donation behavior. I have also received several grants and coordinated an international conference (held at KSU) on organ donation. Last July, I wrote a piece for *USAToday* on the unintended behavioral consequences of a proposed change in Federal Regulations concerning organ distribution. I have been interviewed often by both print and media reporters about the behavior of organ donation. Thus, I am knowledgeable about many aspects of this topic.

**The Problem:** Organ donation is one of the marvels of modern medicine. Organs such as kidneys are routinely transplanted with success rates approaching 90%. Moreover, the success rates for more difficult transplants, such as hearts and livers, have been steadily rising. Thus, the technology of transplantation has developed rapidly as a lifesaving procedure with promises of even more success in the future. A major roadblock, however, has been the inability to deliver the miracle of transplantation to many patients in need. This is not due to lack of skilled surgeons or hospital facilities. Rather, it is due to a persistent shortage of organs. The shortfall is due, in part, to better medical technology and improved immunosuppressant drugs. However, the biggest reason for the shortage is simply the lack of donors.

**Some Numbers:** The United Network for Organ Sharing (UNOS) reports that there are over 66,000 people on the waiting list for transplants today <[http://www.unos.org/Newsroom/critdata\\_main.htm](http://www.unos.org/Newsroom/critdata_main.htm)>. Most are waiting for kidneys (44,000), livers (14,500), and hearts (4,000). UNOS estimates that one new name is added to the transplant waiting list every 16 minutes. Of these, fewer than 50% will ever receive an organ. In 1997, over 4,300 died waiting for an organ (up from 1,400 in 1988). As the attached chart shows, the waiting list for kidneys has grown steadily while the number of donors has remained nearly constant.

**Where are the Donors?** These shortages are not due to lack of potential organs suitable for transplan-

tation. One estimate (by the Midwest Organ Bank in Kansas City) concluded that only about 3,000 out of a potential 23,000 donors in fact donated organs. Even a modest increase in the rate of donation would go a long way toward reducing the shortage. The central question is why are there so few organs donated? One common answer in the medical literature is that lack of knowledge about the need for donors is the reason. However, our studies of over 800 residents of Kansas show that almost 99% were aware of the shortage. Moreover, most were quite sympathetic to the plight of potential recipients. Therefore, the shortage does not appear to be due to a lack of knowledge or an absence of empathy. My view is that the reluctance to be a donor is due to unstated motivations, subjective risks, and unarticulated fears about donation. If these motivations, risk, and fears can be addressed, then rates of donation will increase.

**Prior Efforts to Increase Donations:** There have been many previous attempts to solve the organ donation problem. Some of these efforts involve education, public service announcements, national organ donor awareness days, and media events. Most states let citizens indicate their willingness to be a donor on their driver's licenses. There have been proposals to offer financial incentives, eg. to pay for the donor's funeral expenses. In addition, a number of legal mandates are in place, eg. hospital personnel are now required to ask patients about organ donation. Despite these efforts, the gap between supply and demand continues to grow. (See the attached chart for the kidney transplant waiting list.)

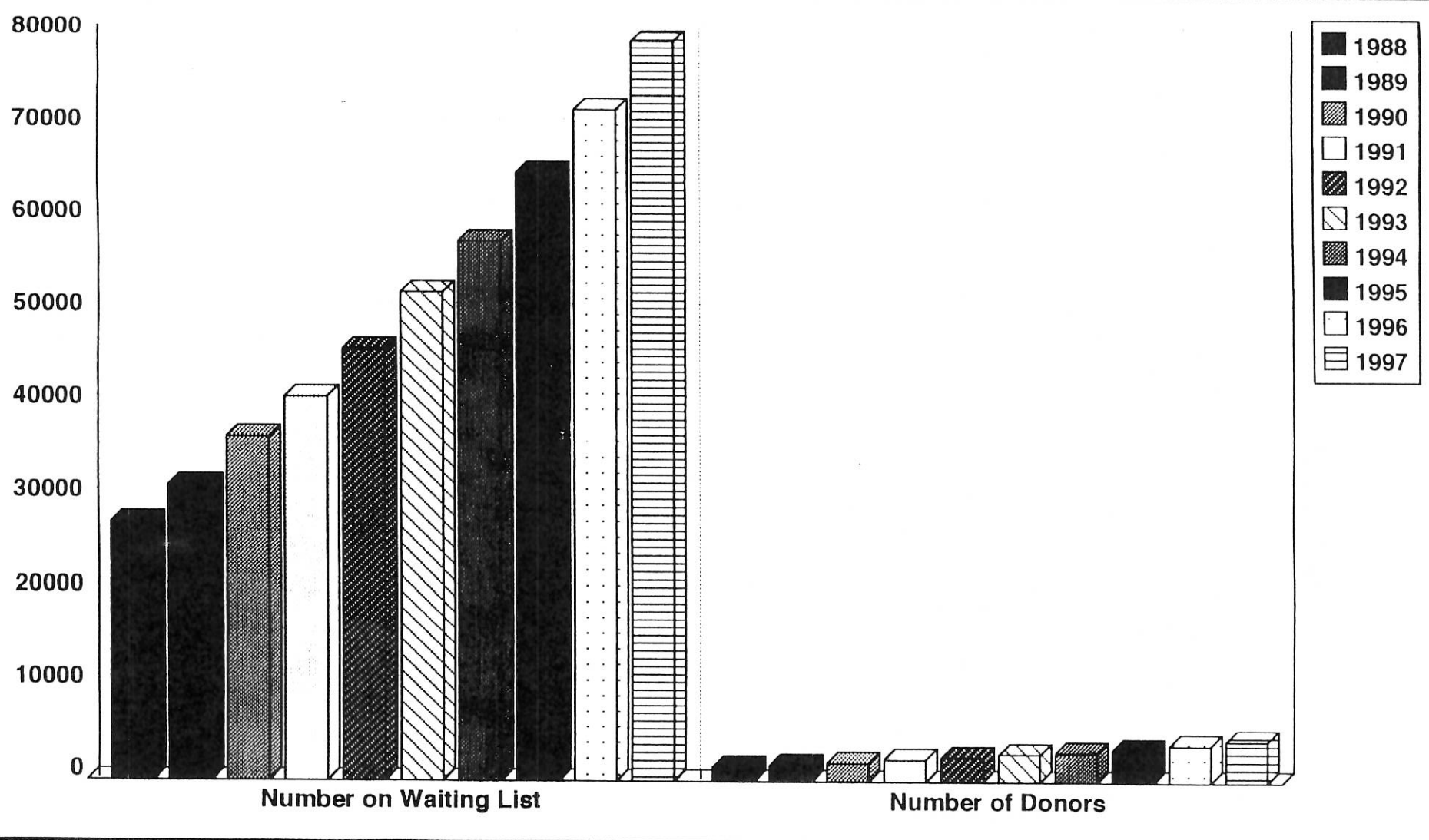
**Proposed Legislation:** Federal law clearly prohibits the sale of organs. However, the proposed bill takes a different approach since the state (not the recipient) is involved. Also, tax incentives have been used to reduce perceived risk in other areas (eg. economic development). At this time, no one knows whether such a tax credit will help. (It is possible, however, to conduct behavioral research on this issue.) Still, it is hard to see how the proposal could hurt the rates of donation. For instance, it clearly places the State in the position of sanctioning organ donation. One other question: How are people going to find out about the tax credit? Obviously, no measure (no matter how generous) will have any impact if no one knows about it. Perhaps this information could be added to drivers' license applications.

January 27, 2000

House Testimony  
Attach. 3-3

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# Number of People on Waiting List versus Number of Donors



Data from United Network for Organ Sharing (UNOS) Annual Report for 1998.





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the Voice of Nursing in Kansas

Emma Doherty, M.A., R.N.  
President

Terri Roberts, J.D., R.N.  
Executive Director

January 27, 2000

## H.B. 2613 Organ/Tissue and Blood Donation Tax Credits

Chairwoman Wagle and members of the House Taxation Committee, I am Terri Roberts, a registered nurse here today speaking on behalf of the KANSAS STATE NURSES ASSOCIATION.

The intent on this bill is to increase the number of available organs, tissue, and blood available to use in the U.S. healthcare system that has made tremendous gains through advances in surgical techniques, tissue typing, and the development of powerful immunosuppressive drugs--which has made it possible to transplant both a larger number and an increasing variety of organs. Organs being transplanted from cadavers include: kidneys, hearts, lungs, liver, bone marrow, skin corneas, and pancreases.

Since the passage of H.B. 3157 in 1986 Kansas registered nurses, physicians and hospital personnel have implemented in Kansas hospitals guidelines or protocols for identifying and informing potential organ and tissue donors and their families. The Kansas law was passed in concert with a nationwide movement towards increasing awareness of the need for organ and tissue donation through better dialogue and education provided by health professionals--we refer to this law as the "required request" provision for organ donation.

In December 1997 Donna Shalala and Vice-President Al Gore spearheaded a nationwide effort the National Organ and Tissue Donation Initiative, to increase organ donations, and I have attached a copy of that campaign and its outcomes--which increased donations 5.6%. Despite all of these efforts, there is still more to do, and we know that increased attention in this area will help spread the word about the waiting lists for organ transplantation.

Unfortunately, at this time we are unable to support the proposed legislation which provides tax credits for blood and organ/tissue donation. This financial incentive comes very close to what is commonly called referred to as "retailing organs". Current federal law implementing The National Organ Transplant Act (Public Law 98-507) prohibits the sale of human organs. Violators of this provision of law can be fined a maximum of \$50,000 and/or imprisoned for a maximum of five years. We believe that the spirit of this federal law is to support the "voluntary" and "non-commercial" nature of organ and tissue procurement in the U.S. and in the interest of maintaining this system, despite its shortages, we ask that you do not recommend this H.B. 2613 favorably.

Thank You.

The mission of the Kansas State Nurses Association is to promote professional nursing, to provide a unified voice for nursing in Kansas and to advocate for the health and well-being of all people.

Constituent of The American Nurses Association

Attach. 3  
4

# HHS FACT SHEET

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

April 16, 1999

Contact: HRSA Press Office  
(301) 443-3376

## National Organ and Tissue Donation Initiative

**Overview:** *In December 1997, Vice President Al Gore and HHS Secretary Donna E. Shalala launched the National Organ and Tissue Donation Initiative. In 1998, the first full year of the Initiative, organ donation increased 5.6 percent, the first substantial increase since 1995. Several actions by HHS and its partners in the National Initiative contributed to the year-one success:*

- *During 1998, HHS issued a new regulation to ensure that hospitals work collaboratively with organ procurement organizations in identifying potential donors and approaching families. Hospitals are now required to notify organ procurement organizations (OPOs) of all deaths and imminent deaths. This helps ensure that opportunities for donation are not overlooked.*
- *HHS conducted a national conference aimed at identifying most effective evaluation strategies for activities to increase donation and transplantation. HHS also funded research on why families consent, or refuse to consent, to the donation of organs of a loved one.*
- *Working with dozens of partner organizations in the private and volunteer sectors, HHS worked to increase awareness of the need for organ and tissue donation. Awareness efforts centered on informing individuals that once they make the decision in favor of organ donation, they need to share their decision with their families since families are usually asked to give consent.*

*Today about 62,000 patients nationwide await organ transplants, and some 12 die each day while waiting. Less than one-third - about 20,000 - receive transplants each year. While the number of cadaveric donors rose in 1998 to nearly 5,800, with about three organs recovered from each donor, it still falls far short of the substantial and growing need. Most Americans say they support donation and would carry out their loved one's wishes if they knew them, but only about half of families asked give consent. If families discuss and share their decision to donate, many more lives could be saved.*

### Three Elements of the National Initiative

#### ***Building Partnerships and Increasing Family Discussion***

Sharing life means sharing your decision. A new groundbreaking study funded by HHS' Agency for Health Care Policy and Research (AHCPR) and the latest Gallup survey on donation both confirm that nearly all Americans would consent to donation if they knew that their loved one had requested it. However, only half or fewer would consent if they were unaware of these wishes.

The AHCPR study, conducted by researchers at Case Western Reserve University and the University of Pittsburgh, examined families who had faced real-life decisions about donation and found that only 43 percent of them had ever discussed donation with their loved ones. Less than 25 percent knew if their loved ones carried

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HHS serves as a catalyst for the field by emphasizing and encouraging carefully designed and rigorous evaluation components and research projects to ascertain effective interventions for increasing donation. In fiscal year 1999, HRSA is providing up to \$5 million for projects through a peer-reviewed, competitively awarded extramural support program. The goals of this program are to implement, evaluate, and disseminate model interventions with the greatest potential for yielding a verifiable, demonstrable impact on donation and which are replicable, transferable and feasible in practice. The program will fund pilot and replication studies.

Other HHS agencies, especially the National Institutes of Health and AHCPR, are supporting research to improve donation and transplantation. At NIH, this research includes basic, pre-clinical, and clinical research on immune system functioning, graft acceptance and rejection, avoiding the need for re-transplantation, organ matching in diverse populations, methods to improve organ and tissue retrieval and preservation, and improving the quality of life for transplant patients. In addition, NIH's National Institute of Allergy and Infectious Diseases is supporting the development and evaluation of a statewide donor registry and education program by the Louisiana Organ Procurement Agency. The AHCPR study of donor and non-donor families is described above.

### National Initiative Partners

Public Awareness Partners: HHS has teamed up with the **Coalition on Donation**, whose members include national and local organizations, to deliver a consistent, unified message on the importance of family discussion. With the **Advertising Council**, the Coalition on Donation has implemented a multi-year, national public awareness campaign.

Health Care Organizations: Health care organizations are uniquely positioned to educate their members, who in turn educate their patients, about the need for organ donation. The **American Medical Association**, the **American Academy of Family Physicians**, the **American Nurses Association**, the **American Association of Health Plans**, and the **National Medical Association** provide their members with organ donation educational materials. Other health organization partners include the **American Association of Neurological Surgeons** and the **Congress of Neurological Surgeons**.

Law Associations: Attorneys, especially those involved in estate planning, are in strategic positions to encourage and help Americans make end-of-life decisions, including donation decisions. The **American Bar Association**, through its Real Property, Probate and Trust Section, in partnership with HHS, will encourage attorneys to educate clients on organ donation.

Educational Organizations: Educators are key to teaching the nation's children and young adults about the need for donors. HRSA is partnering with the **American College Health Association**, the **University of Rhode Island** and **TransWeb University** (<http://www.transweb.org/journey>) to reach young people with the donation message.

Faith Organizations: Many Americans turn to religious leaders for guidance about organ and tissue donation and other end-of-life decisions. A number of faith and interfaith organizations are educating their members about the gift of life and helping HHS to promote the annual observance of **National Donor Sabbath**, a Friday-to-Sunday period two weekends before Thanksgiving. These organizations include: the **Congress of National Black Churches**, the **General Conference of the Seventh-day Adventist Church**, the **Interfaith Conference of Metropolitan Washington**, the **National Interfaith Coalition on Aging**, the **National Spiritual Assembly of the Baha'is**, the **Presbyterian Church USA**, the **Rabbinical Assembly**, the **Rabbinical Council of America**, the **Shepherd's Centers of America**, and the **Union of American Hebrew Congregations**.

Donor and Recipient Groups: The **National Kidney Foundation's National Donor Family Council** and HHS

donor call. Families who were undecided when asked to donate were only half as likely to consent as those who were initially inclined to donate. Overall, less than half (47.5 percent) of the families consented to donate, yet the overwhelming majority (95 percent) of the families indicated that knowledge of their loved one's wishes would have had substantial influence on their final decisions.

Partners respond by encouraging Americans to donate. Dozens of health care, business, minority, religious, educational and government organizations have joined this initiative to encourage all Americans to discuss and share their decision to donate with their families before the occasion to donate arises. They are reaching out to their employees, members, and the public to encourage donation, and thanks to HHS' partnership with the Coalition on Donation, they are using the same message as the national public awareness campaign developed by the Coalition and the Advertising Council, "Share your life. Share your decision."

### *Expanding Opportunities for Families to Donate*

HHS' Health Care Financing Administration (HCFA) revised its Hospital Conditions of Participation for Organ, Tissue and Eye Donation (June 22, 1998, 63 Fed. Reg. 33856) effective August 21, 1998, to maximize opportunities to donate by requiring Medicaid- and Medicare-participating hospitals to notify OPOs of all deaths and imminent deaths so potential donors are identified and families are asked about donation. Hospitals now will refer 2.1 million hospital deaths annually to the nation's 62 OPOs or to a third party designated by the OPOs to handle the referrals. Hospitals also will work with the OPO to ensure that the family of every potential donor knows about its option to donate organs or tissues. Hospitals also will have agreements with at least one tissue bank and one eye bank to preserve and distribute tissues and eyes, as long as these agreements do not interfere with organ donation.

To ensure that individuals who approach families demonstrate discretion and sensitivity, hospitals must select an OPO representative or others who have completed a training course offered or approved by the OPO. Hospitals also must work with OPOs and the eye and tissue banks to educate hospital staff on donation issues and review death records to make sure potential donors were correctly identified.

To support these activities, HCFA and HHS' Health Resources and Services Administration (HRSA) will co-sponsor a June workshop to develop a resource guide to assist in educating and training hospital staff. In addition, they will co-host a conference in September to exchange information on successful strategies for increasing donation, including effective referral, consent, education and monitoring practices. Finally, the Joint Commission on Accreditation of Healthcare Organizations, which reviews the performance of most of the nation's hospitals, has incorporated the revised hospital conditions into its standards for accreditation.

HHS estimates that the revised hospital conditions can increase organ donation by 20 percent within the first two years. In addition to preliminary data indicating a 5.6 percent increase in organ donors in 1998, data collected from tissue banks by the Musculoskeletal Transplant Foundation suggests that tissue donation overall has increased about 52 percent since the new provisions took effect.

Finally, HCFA will continue to hold OPOs responsible for meeting performance standards. On a regular basis, OPOs are evaluated against their peers on five specific performance standards. HCFA will work with the Association of Organ Procurement Organizations (AOPO) toward stronger performance by OPOs.

In 1995, organ donation results for the nation's then 66 OPOs ranged from a high of 34.3 organs donated per million population to a low of 2.4 donors per million. (In 1996, two OPOs were terminated from Medicare and Medicaid participation because they did not meet current performance standards. In early 1997, two OPOs consolidated into one.)

*\* Learning More About What Works to Improve Donation and Transplantation*

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have teamed up to implement a new Web site at <http://www.kidney.org/recips/donor> to provide information and bereavement support for donor families. In addition, HRSA, the National Donor Family Council, <http://www.kidney.org/recips/donor> to provide information and bereavement support for donor families. In addition, HRSA, the National Donor Family Council, and other national donor, recip

**Business Organizations:** The **U.S. Chamber of Commerce** and the **Washington Business Group on Health**, representing many large and small businesses, are helping members conduct employee education campaigns. **The Home Depot** also has made donation information materials available to its nationwide network of stores.

**Media:** Another HHS partner, the **James Redford Institute for Transplant Awareness**, is reaching out to national media organizations and schools, to promote public awareness. HHS worked with producers of the CBS special "Nicholas' Gift" to develop and air a 10-second post-program public service announcement featuring the Vice President and Mrs. Gore encouraging donation.

**Minority Organizations:** The **National Minority Organ/Tissue Transplant Education Program (MOTTEP)**, with the support of NIH's Office of Research on Minority Health and the National Institute of Diabetes and Digestive and Kidney Diseases, is the first national program to empower minority communities to promote minority donation and transplantation as well as good health habits. In turn, this effort should improve the chances for a well-matched organ amongst minorities waiting for transplants. Now in 15 sites across the country, MOTTEP's target populations include African Americans, Hispanic/Latinos, Native Americans, Asians, Pacific Islanders and Alaskan Natives. HHS is a national sponsor of **National Minority Donor Awareness Day 1999** (August 1) hosted by MOTTEP, **American's Blood Centers Foundation** and **The Marrow Foundation** in 22 cities nationwide.

**State Organizations:** HHS works with the **National Governors' Association**, the **National Conference of State Legislatures**, the **Council of State Governments** and the **Association of State and Territorial Health Officials** to encourage state efforts to increase donation. With the encouragement of the Department of Transportation's **National Highway Traffic Safety Administration**, the **National Association of State Emergency Medical Directors** passed a resolution for automated statewide donor registries linked to state motor vehicle departments.

**Federal Partners:** The federal government is educating its own about donation, hoping to serve as a model for other employers. For example, with assistance from the **Office of Personnel Management**, HHS has provided donation materials to federal agencies for employees, including donation messages on pay stubs and full-page donation ads in the federal health plan catalog for the past two years. The **Department of Defense**, which routinely asks patients in its health care system to consider donation, is making donation information materials available in its treatment facilities.

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For more information on the National Organ and Tissue Donation Initiative, visit the U.S. Department of Health and Human Services' Web site at <http://www.organdonor.gov>, or contact: Health Resources and Services Administration, Division of Transplantation, 5600 Fishers Lane, Room 4-81, Rockville, MD 20857, 301-443-7577 (telephone), 301-594-6095. (fax)

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Note: HHS fact sheets releases are available on the World Wide Web at: <http://www.hhs.gov>.



**American Red Cross**

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### **Position Statement on House Bill 2613**

The **American Red Cross** is the nation's leading supplier of voluntarily donated blood and blood products, supplying nearly half of the blood used by patients in hospitals across the United States. In addition, Red Cross Tissue Services is a leading supplier of connective tissue, bone tissue, heart valves and skin grafts. The **Central Plains Blood Region** provides blood for more than 110 public, private, veterans and military hospitals in Kansas. The American Red Cross **Southern Plains Area Tissue Services** contracts with 44 Kansas hospitals for the procurement of voluntarily-donated human tissue, and also provides bereavement services and after-care for the donor family. Local Red Cross Chapters across the state are actively involved in donor recruitment efforts and public awareness campaigns to raise the level of participation in blood and tissue donation.

We are keenly aware of the need to increase the amount of biomedical donations of blood and tissue. Each year, thousands of people with healthy tissue die without indicating their willingness to donate their tissue. In fact, fewer than 5% of the available donors will actually give. Across the country, 50,000 people are on waiting lists for organs. We know that only five percent of the population donates blood. Therefore, we applaud Rep. Sloan's efforts to increase donations of these lifesaving resources. Despite this, **we must express our opposition to House Bill 2613.**

The American Red Cross **opposes** any legislative or regulatory proposal at the federal, state or local level that would provide remuneration for donating blood, blood components, or tissue. We oppose remuneration, not only in the form of direct financial payments, but also as indent payments, tax credits or preferential treatment.

Remuneration for a donation of blood or tissue is contrary to the spirit of volunteerism and may be a threat to the public health. The Red Cross believes that such donations should be motivated by the desire of individuals to help their neighbors. We are concerned that some incentives may cause donors to be untruthful about their health histories, or donate when they should defer themselves or their families.

The collection, preparation and transfusion or transplantation of human blood, tissue and organs is a highly regulated industry. The Food and Drug Administration, as well as the nation's blood, tissue and organ banks believes that a volunteer donor is one of the most critical elements of the safety of the United States' supply of biomedical products. Regulatory procedures designed to maintain this voluntary supply might be adversely impacted by the implementation of the tax incentives proposed in this bill.

We encourage everyone who is in good health to be a blood donor, and to support the availability of organs and tissue for transplant by signing a donor card and making their wishes to be a donor known to their loved ones. However, our concerns over the potential threat to public health this bill presents outweigh its noble intention. We therefore express our opposition to its passage.

*House Jax  
1-27-2000  
Attach. 5*



A United Way Agency