University of Pittsburgh
Medical Center

200 Lothrop Street
Pittsburgh, PA 15213-2582

COMMENTS SUBMITTED BY THE UNIVERSITY OF PITTSBURGH MEDICAL CENTER PURSUANT TO THE NOTICE OF HEARING ISSUED BY THE DEPARTMENT OF HEALTH & HUMAN SERVICES RELATING TO ORGAN ALLOCATION POLICIES

DECEMBER 12, 1996

The University of Pittsburgh Medical Center ("UPMC") respectfully submits to the Panel its comments pursuant to the Notice of Hearing dated November 13, 1996, relating to allocation and distribution of donated livers, alternative systems for allocating and distributing donated livers and increasing donation of human livers. UPMC is a 1,230 bed academic medical center comprised of Presbyterian University Hospital, Western Psychiatric Institute and Clinic, the School of Medicine, and the Pittsburgh Cancer Institute. UPMC provides primary and advanced specialty care to patients, performs biomedical and biotechnical research, and educates and trains health care professionals. UPMC is the largest transplant center in the United States and, along with its faculty and staff, has been internationally recognized for excellence in organ transplantation.

For almost six years, UPMC has argued to the Department of Health and Human Services (the "Department") and the United Network for Organ Sharing ("UNOS"), the contractor for operation of the Organ Procurement and Transplantation Network ("OPTN"), that the current system for allocation and distribution of donated livers is seriously flawed and should be changed. The essence of the proposal advanced by UPMC for those six years has been that donated livers should be allocated and distributed to the highest ranking patient on the liver waiting list, using established medical criteria, within the largest possible geographic area, limited only by the ischemic time for the donated organ. For those six years, UNOS has steadfastly refused to increase the size of the geographic area within which donated livers are shared. UNOS is a membership organization of 430 voting members of which 276 are transplant centers, 65 OPO's, other medical organizations and only 6 members of the general public. For the last four years, the Department has waited patiently for UNOS to recommend changes to increase organ sharing and improve the current system. This Panel has been convened because UNOS has been unwilling to adopt any changes which would increase organ sharing and improve the current system, so as to provide a fairer and more equitable system for transplant patients.

On December 7, 1994, UPMC submitted to the Department extensive comments pursuant to the Notice of Proposed Rule Making dated September 8, 1994. Copies of those comments are attached to this document as Exhibits "A" and "B". Many of the statements and observations included in those comments are as applicable today as they were two years ago. This set of comments will, based upon computer modeling and other research which has occurred in the interim, update the facts presented two years ago and further demonstrate the serious need for significant change and improvement to the current organ allocation and distribution system.

I. THE CURRENT SYSTEM AND THE UPMC PROPOSAL.

Under the current system, patients on the waiting list are assigned a medical priority status based upon their medical condition and life expectancy. Currently, the statuses are:

- Status 1 - in ICU with acute or chronic liver failure and a life expectancy of less than 7 days;

- Status 2 - ICU bound or continuously hospitalized;

- Status 3 - continuous medical care at home;

- Status 4 - at home and functioning normally;

- Status 7 - temporarily removed.

Patients move from one status to another and back again as their condition worsens or improves. Recently, UNOS voted to eliminate Status 4 and "grandfather" existing Status 4 patients into Status 3 and to move Status 1 patients with chronic liver failure to Status 2. The recent UNOS changes do not provide for any increase in geographic sharing for any patients.

Presently there are 65 local OPO's and 11 UNOS regions. The current system distributes livers to the patients as follows:

> Local OPO list Status 1, then Status 2, then Status 3 and 4; if not accepted, then UNOS Region list Status 1, then 2, then 3 and 4; and finally, if not accepted, National list Status 1, then 2, then 3 and 4.

UPMC has proposed that donated organs be distributed using the same medical priority status defined by UNOS, but in larger geographic areas, as follows;

- Local OPO list Status 1, then National list Status 1;

- Local OPO list Status 2; then National list Status 2;

- Local OPO list Status 3 and 4; then National list Status 3 and 4.

This system allows the physician to make the medical decision about a patient's proper medical status. Once that decision is made the UPMC proposal insures that higher priority patients are offered compatible organs, before such organs are offered to lower priority patients.

The UPMC proposal was rejected by UNOS. Likewise, UNOS rejected proposals by others which (1) offered organs to inpatients (Status 1 and 2) on the local/regional/national lists, before offering the organs to outpatients and (2) created modified regional distribution.

II. FUNDAMENTAL PRINCIPLES OF ORGAN ALLOCATION AND DISTRIBUTION.

UPMC believes that the following basic principles should be the foundation for any system of allocating and distributing donated organs in order to be fair and equitable to patients and to satisfy the provisions of NOTA:

(1) The system should focus on the transplant patients by providing a system which saves more patient lives, and thus results in the most patient life years saved.

(2) The system should be fair so that patients in similar medical conditions around the country have relatively equal waiting times and an equal opportunity to receive a compatible organ. In this way, the patients can have the greatest choice of where they receive medical care.

(3) The system should be a national system so that decisions are made without regard to geographic limitations, except where required by the ischemic time of the organ.

(4) The system should utilize fundamental medical principles to determine the most medically appropriate transplant candidate.

(5) The system should, to the greatest extent possible, increase the quality of organ transplantation.

(6) The system should promote and increase organ donation.

(7) The system should encourage and promote transplant centers which demonstrate above-average proficiency.

III. NATIONWIDE SHARING OF ORGANS BENEFITS PATIENTS AND DONATION.

With its emphasis on geographic limitations, the current liver allocation and distribution system has become an entitlement program for transplant centers with patients dying needlessly because donated livers are trapped by geography, depriving the sickest patients elsewhere in the country of life-saving transplants. Under this system, the location of a transplant center in relation to the location of a liver donor is more important, than the needs of patients on the waiting list. It is clear from reading the legislative history of NOTA that donated organs are considered a "national resource," that a national sharing system is required, and that the welfare of the patient is most important. The General Accounting Office Report of its review of the OPTN published in April, 1993, recognized that center interests were put ahead of patient interests and included the following statement on page 43:

> Favoring transplant centers over the needs of patients is contrary to federal law. Additionally, broadening the number of patients considered for an organ may result in selecting a patient who is better suited for the organ or has been waiting longer.

That observation was made about the system as it existed in 1993, but UNOS has not made any real changes in the system to correct these deficiencies.

Although the medical criteria adopted by UNOS specify that donated livers should be allocated and distributed to a Status 1 patient before a Status 2 patient and that a Status 2 patient should receive an organ before a Status 3 patient, the geographic limits imposed by the current system override those medical priorities. For example, when a liver becomes available in one OPO, that liver must be offered to all compatible patients (including Status 3 and 4) listed in that local area, before it may be offered to a compatible Status 1 patient listed nearby, but not in the local OPO.

Take as an example the story of Rex Voss which appeared on the front page of *The Wall Street Journal* on April 1, 1993. In early 1992, the 41 year old Mr. Voss, a father of four teenage boys, from Jackson, Mississippi contracted hepatitis C from an unknown source. Mr. Voss was evaluated and accepted as a liver transplant candidate at Baylor University Medical Center in Dallas and was

placed on the waiting list as what is now known as Status 3 (outpatient). In late 1992, Mr. Voss' condition deteriorated causing him to be hospitalized as a Status 2. Soon he was placed in intensive care, required a life support machine, and became a Status 1. A compatible liver became available in time to save Mr. Voss' life; however, it went to a healthier patient listed at a transplant center in Oklahoma City (40 minutes away from Mr. Voss by airplane), because that transplant center was in the local OPO where the organ was donated. Mr. Voss died on December 8, 1992, without receiving a transplant.

UNOS has admitted that this situation will repeat itself again and again under the current system. In the draft background materials provided to this Panel, UNOS states that "due to the local/regional/national distribution system, organs are not offered to all medically urgent patients before all less urgent patients: a local Status 3 patient may be transplanted before a regional Status 1." How is this justified when a Status 1 has a life expectancy of 7 days or less, and a Status 3 has a better chance of surviving one year without a transplant, than with one?

As a result of the unnecessary geographic limitations, the current system results in more patient deaths on the waiting list and overall and fewer lives saved among all patients than the allocation and distribution system proposed by UPMC and others which provide for wider geographic sharing of organs.

- Fewer Patient Deaths and More Patient Life Years Saved

CONSAD Research Corporation of Pittsburgh, Pennsylvania, has prepared a computer model, based upon data received from UNOS and the Department which can evaluate alternative liver allocation and distribution proposals. Similarly, UNOS commissioned the Pritsker Corporation to prepare a computer model, which also evaluates various liver allocation and distribution systems. The current system, the UPMC proposal, and a number of other proposals providing for wider geographic sharing of organs have been evaluated on both the CONSAD model and the UNOS model. Both models are similar, but not identical. Expert reviewers at the Department found that both models are credible and that the results produced by each model for the various alternative proposals are consistent, but not identical.

The results of the CONSAD model are attached to these comments as Exhibit "C" and are a part of a report provided to the Panel by CONSAD. Those results demonstrate that allocating and distributing livers pursuant to the UPMC proposal would save 296 more lives at the end of three years than would be saved by allocating livers in accordance with the current system. UNOS model results for the UPMC proposal included in the materials given to the Panel reflected a savings of more than 120 lives over three years. In either event, the UPMC proposal results in fewer patient deaths, both pre- and post-transplant than the current system.

The same two models also evaluated the patient life years saved if livers are allocated using wider geographic sharing. The CONSAD results indicate that allocating and distributing livers pursuant to the UPMC proposal would result in 55,148 patient life years pre- and post- transplant saved over a three year period as opposed to 53,200 patient life years saved for the current policy. The results of the UNOS model also indicated that more patient life years are saved pre- and post-transplant by allocating livers pursuant to the UPMC proposal than the current system.

More patients die while waiting for a transplant under the current system because the current geographic limitations result in 30% to 40% of all donated livers being transplanted into Status 3 patients, as reflected in the results of both the UNOS model and the CONSAD model. Because Status 1 and Status 2 patients are near death, allocating a compatible organ to a Status 3 patient ahead of a Status 1 or a Status 2 patient usually results in the death of that sicker patient.

Furthermore, a recent UNOS study reported in the November, 1996, edition of *The UNOS Bulletin*, found that "liver patients who were transplanted in Status 3 did not appear to have any survival advantage over patients who continue to wait in Status 3. . . ." The report went on to state "[t]he cumulative survival rate for the waiting list group was higher than that of the transplant group for Status 3 patients during the first year after transplant." In the UNOS background materials given to this Panel, this choice to transplant a Status 3, before a sicker Status 1 and 2 patient, is justified by UNOS as a value judgment that the Status 3 patient has a better survival rate. Such reasoning is inappropriate. UNOS may attempt to justify the different treatment of acute vs. chronic Status 1 patients on the basis of survival rates, but neither UNOS nor the Department can justify elevating a Status 3 patient ahead of a Status 1 or 2 patient and allocating one-third of the available livers to those Status 3 patients ahead of Status 1 and Status 2 patients. The Status 3 patient has a better one year survival rate if he or she remains on the waiting list without a transplant, while virtually all Status 1 and 2 patients die within one year without a transplant. Liver transplantation is a life-threatening procedure and it should be undertaken because of a life-threatening event. A system which allows a Status 1 or Status 2 patient to die on the waiting list in order to transplant a Status 3 patient, thereby reducing that Status 3 patient's one year chance of survival, is not a system which focuses on the needs of the patients.

- Equal Opportunity and Equal Waiting Time for Patients.

Patients in similar medical circumstances, regardless of the transplant center at which they are listed, should have an equal opportunity to receive a compatible organ. That is not the case under the current system. UNOS, the Department, and most transplant professionals have admitted that there are substantially unequal waiting times for similarly situated patients in different parts of the country. This is true not only when you compare waiting times for all patients, but also when you compare waiting times for Status 1 and 2 patients, for which there are specific listing criteria so patients are not prematurely listed in these Statuses.

The time that patients spend waiting for an organ is an indicator of whether patients in different parts of the country have approximately the same opportunity to receive a donated organ. UNOS admits in the background materials provided to the Panel that there exist "substantial differences in waiting time to transplant" among transplant centers, OPOs and UNOS regions. The magnitude of those differences is shown in Tables 5 and 6 of those materials.

The CONSAD model evaluated the average waiting time until transplant, for all patients in the various UNOS regions, under the current system and showed a standard deviation among the regions of over 32 days. If livers are allocated pursuant to the UPMC proposal, however, the CONSAD results show that the standard deviation for the average waiting time until transplant, among the various regions, drops to 6.8 days. Similarly, the results produced by the UNOS model indicated that

allocation of livers under the UPMC proposal and others having wider geographic sharing, when compared to the current system, would reduce the inequity in waiting times for Status 1 and 2 patients by more than one-half, throughout the country.

Within a local OPO area, there is equal opportunity for comparable patients to receive an organ based upon the established criteria, i.e., local Status 1 patients receive a liver before local Status 2 patients, etc. This equal treatment ends, however, when one reaches the artificial geographic boundaries of the local OPO, because any compatible patient in the local OPO area, even if that patient has a lower medical priority, will be offered an organ from that area before that organ will be offered to a patient with a higher medical priority outside the local OPO area. If allocation of organs according to medical urgency status is fair and appropriate in the local OPO area, why is that system of allocation not fair and appropriate for the largest geographic area in which the organ can be safely transported?

UNOS and the transplant community have acknowledged that donated livers can be maintained outside the body for 12 to 18 hours and remain viable for transplantation. In the UNOS Policy Proposal Statement issued in 1990, the following statement was made:

> The distance factor is not relevant in the revised liver allocation policies (see Policy 3.6.7.1 below) because the current method of liver preservation (UW Solution) allows for long distance shipments. The committee believed that the donor livers available should be allocated to the most needy, irrespective of distance. (emphasis added).

The current UNOS system is totally contrary to this UNOS policy statement because it keeps a donated liver in a local area in order to transplant a Status 3 patient (if there are no compatible Status 1 or Status 2 patients in that local area), instead of allocating and distributing that donated liver to the "most needy, irrespective of distance."

- Negative Impact on Quality of Care.

Research has demonstrated that the current allocation system adversely affects the interrelated issues of patient mortality and quality of care. One result of the current system has been to promote significant increases in the number of very small transplant centers. The emphasis on "local" use of organs encourages the development of small transplant centers in some areas because they can be assured of a small, but steady, supply of organs.

For example, the number of approved liver transplant programs increased from 58 in 1988 to 112 in 1995. OPTN data show that in 1995 more than one-half (57) of those 112 centers performed 24 or fewer transplants and 33 programs performed 10 or fewer transplants. Of these 112 liver transplant programs reporting to UNOS in 1995, 71 centers (63%) performed fewer than 35 transplants.

The 1994 Report of Center Specific Graft and Patient Survival Rates shows that the mortality rates at small transplant centers are significantly higher than for larger centers. Based upon a review of 9,567 liver transplants, the study found the risk of patient death following transplant was 2.45 times higher at centers performing 10 or fewer transplants per year and 1.6 times higher at centers performing fewer than 35 transplants per year when compared with the risk of death at centers performing more than 35 transplants.

Although the studies should not be read to say that all small transplant programs are not qualified, they do point out serious problems inherent in small volume centers. Patients should not be forced by organ allocation policies to make decisions with life or death consequences between a low volume/high risk center with a shorter waiting list and a high volume/low risk center with longer waiting list.

- Effects on Organ Donation.

You may hear arguments that sharing organs over larger geographic areas will adversely affect donation rates. The empirical evidence, however, says the contrary. The Department first looked at this argument in 1990. The results of an OPTN survey were included in "The Distribution of Organs for Transplantation: Expectations and Practices" published in August 1990 by the Department's Office of the Inspector General. That report states "we found that in a national public opinion poll commissioned by the OPTN itself, over 75 percent of respondents disagreed with the statement that 'donor organs should go to someone in the area where the donor lived.'" (footnote omitted).

UNOS conducted another survey in early 1994, in which a number of questions were asked to 1,752 people, divided among 3 groups; the general public, transplant recipients and waiting patients. The results were consistent with the prior survey results:

- 60% of respondents across-the-board assigned the lowest priority to "keeping organs locally";

- more than half of the respondents gave the highest priority to "the most critically ill" patients;

- most importantly, of the non-donors surveyed, 66% would be more likely to donate to a national system of organ sharing, while only 19% would be more likely to donate if organs are kept locally.

These survey results are very much what one would expect from persons who choose to donate organs. Generally families who agree to donate a deceased loved one's vital organs do so with the hope of helping critically ill patients live. It makes no difference to them where the recipient lives; the important factor is that the recipient is saved from imminent death. The family's grief is helped by the thought that a another person is saved from death and the recipient's family can avoid similar grief.

Notwithstanding these survey results, UNOS continues to propose a liver allocation and distribution system which, according to the results of the UNOS model (1) keeps 78% of donated organs locally, (2) transplants 35% to 40% of donated livers into Status 3 and 4 patients (the least critically ill), and (3) shares only 4% of donated livers on a national basis. If the two survey results are to be believed, the current system of liver allocation and distribution is one reason that liver donation rates are not improving.

You will also hear arguments that by increasing organ donation rates across the country, the allocation and distribution problems can be eliminated. By itself, such statements are accurate, but

they avoid the issue. The real questions are "how do you increase donation rates," "how long will it take to reach the needed levels," and "how do you save lives in the interim." According to the two UNOS survey results, one answer to the question "how to increase donation rates" is to change the allocation and distribution system so that (1) more critically ill patients receive donated organs, and (2) more donated organs are shared nationally.

If donation rates increase significantly in 3 or 4 or 5 years, any allocation and distribution system will work reasonably well for patients. But what happens before the donation rates rise to the necessary levels? UPMC believes that we should change the allocation and distribution system, so that more patients per year are saved while we work to improve donation rates.

- Effect on Patients.

You will also hear arguments that larger geographic sharing of donated livers will result in establishing a few large volume, regional centers which will cause patients to travel great distances to receive a transplant, thereby disadvantaging the poor. Such statements are pure speculation. It is likely that some liver transplant programs will close, but some transplant programs close or suspend operations every year. For example, in 1995, nine registered liver programs did not perform any transplants. Usually, programs close because their quality of care is low and they cannot attract patients or they lose their transplant surgeon. If transplant programs begin to close, the most likely reason is not more organ sharing, but rather the programs' poor post transplant survival rates. Patients are better served by not being transplanted at centers with very high mortality rates.

The transplant community recognizes that some areas are overserved with liver transplant programs. For example, Ohio has six transplant programs and a surgeon from Ohio who testified at the hearing indicated that area may not truly need that many programs. In states like Kansas, Alabama, New Mexico, South Carolina, New Jersey, the District of Columbia and Iowa with only one liver transplant program each, patient demand for those programs would not be so low that the programs would cease operating. On the other hand, it is possible that one or more programs in states like Texas (with 9), Missouri (with 6), California (with 11), Pennsylvania (with 7) and Louisiana (with 5) may cease operation due to lack of patient demand.

Wider geographic sharing should increase patient choice and quality of care. With wider geographic sharing, patients can choose a center based on such factors as location, mortality risk, special programs to treat special diseases and other important factors without having to worry about size of the waiting list. With wider geographic sharing and the existing medical status definitions, a patient can be assured that he or she will be offered an organ from a large geographic area when he or she is the most appropriate and sickest patient in that large area. In other words, length of the waiting list and waiting times becomes almost a non-factor in the patient's decision. For example, a patient with a rare or unusual diagnosis who cannot be treated at a local center can go to a center where the disease can be treated effectively without fear of a long waiting list. Likewise, a patient living near a center in an urban area with a long waiting list can go to the local center without fear of the length of the list.

CONCLUSION

The UPMC proposal before this Panel is one that has been formulated based on the best interests of the patients. That premise is the basis for NOTA, the OPTN and all transplant programs. The UPMC proposal does not change the medical criteria which have been established by the transplant community. It simply removes the artificial geographic limitations to the distribution of organs based on the medical criteria. When an organ can be safely transported from Oklahoma City to Dallas and transplanted in a Status 1 patient (Rex Voss), it should not be first offered to a Status 4 or Status 3 patient in Oklahoma City. Such a system is unfair to patients and adversely affects donation.

The fundamental question is:

> If the allocation of organs according to medical urgency status is fair and appropriate in the local OPO area, why should that system not be used for the largest geographic area in which the organ can be safely transported and transplanted?

Not one person has testified that wider geographic sharing of organs according to medical status is not the fairest method for patients. The testimony from opponents has been either that we ought to move toward the goal more slowly or that the goal of more sharing will hurt "my center." To those who say move slowly, UPMC says that UNOS has been looking at the issue for six years. How much more slowly can we go? To those who say more sharing may harm "my center," the answer should be that benefit to patients comes before benefit to centers.

HOGAN & HARTSON
L.L.P.

COLUMBIA SQUARE
555 THIRTEENTH STREET, NW
WASHINGTON, DC 20004-1109
TEL (202) 637-5600
FAX (202) 637-5910

ISABEL P. DUNST
PARTNER
DIRECT DIAL (202) 637-5616

January 10, 1997

Dr. Philip R. Lee
Assistant Secretary for Health
Department of Health and Human Services
200 Independence Avenue, SW
716-G Hubert Humphrey Building
Washington, DC 20201

Dr. Bruce C. Vladeck, Jr.
Administrator
Health Care Financing Administration
200 Independence Avenue, SW
314-G Hubert Humphrey Building
Washington, DC 20201

Dr. Ciro V. Sumaya
Administrator
Health Resources and Services Administration
5600 Fishers Lane, Room 14-05
Rockville, MD 20857

Dr. Phillip Gorden
Director
NIDDK, NIH
31 Center Drive, MSC -2560
Building, 31, Room 9A52
Bethesda, MD 20892-32560

RE: Varying Medicaid Rules Regarding Liver Transplantation

Dear Gentlemen:

At the recent hearings convened by the Department of Health and Human Services on the issues of organ donation and allocating donated livers, members of the hearing panel raised questions concerning state Medicaid rules for liver transplantation. The focus of the questions seemed to be access to transplantation and what effect, if any, a change in liver allocation policy would have on the ability of Medicaid patients to receive a transplant.

At the conclusion of the hearings, my client, the University of Pittsburgh Medical Center ("UPMC"), together with an independent consulting firm, CONSAD Research Corporation, undertook to gather as much information as possible on these issues. As you know from Dr. Mark Joensen's testimony at the hearing, CONSAD is very knowledgeable in this policy arena. The purpose of this letter is to share that information with you.

Based on contacts with Medicaid offices in each state, UPMC and CONSAD found that all states will cover liver transplants for qualified Medicaid recipients at an in-state or out-of-state transplant center. Six states cover liver transplantation only for juvenile Medicaid patients. As you may know, fourteen states have no approved in-state liver transplant programs, so naturally Medicaid recipients from those states must go out of state. A number of states such as Alabama, Arkansas, Delaware, Kentucky, Massachusetts, New Hampshire, West Virginia and Maine, allow Medicaid patients to be transplanted at any facility to which they are referred by their physician as long as that facility meets the states' standards and will accept the offered payment, even if there are also in-state liver transplant programs. In all of the states, the costs to be paid by Medicaid include transportation costs. Often, per diem expenses for the patient and a companion are also covered on a case-by-case basis. Some additional results of the survey of Medicaid programs appears in Attachment 1.

Although there are some variations, particularly in states where there is significant penetration of HMOs into the Medicaid market, the states appear to apply similar criteria for evaluating transplant centers for Medicaid patients. States look at such factors as Medicare approval, number of transplants and survival rates, reputation of the center and location in or near the state. Although some states appear to have formal Medicaid certification processes, most do not; instead they handle both in-state and out-of-state transplants under either a formal or informal agreement. In states such as Delaware, Illinois, Tennessee, Massachusetts, Utah and New York, which have large portions of their Medicaid recipients in HMOs, the HMOs contract with transplant centers that meet the HMO's criteria and are willing to accept their terms. In all, 28 states currently cover at least some of their Medicaid population through managed care providers. Thirteen additional states are in the early states of developing a formal managed care program for Medicaid patients.

In addition to contacting the various Medicaid offices, UPMC also collected data from several of the larger urban liver transplant centers concerning the number of transplants that they performed for Medicaid patients in the last few years, as well as the number of in-state and out-of-

state Medicaid patients on their waiting lists in November, 1996. These results suggest that the larger transplant centers are transplanting substantial numbers of Medicaid patients from outside their local areas. These patients come from states with no transplant centers, as well as from states where the in-state transplant centers are not able to list the patient because the centers lack appropriate expertise. Many children fall into this category.

One of the reasons that these centers treat significant Medicaid populations is obvious, that is, their geographic proximity to locations with large Medicaid populations. Others are not so obvious. Generally, these large centers have the expertise to transplant the most difficult cases and these programs have some of the best risk-adjusted survival rates in the country. Also, most of these centers have policies like the policy at UPMC. UPMC will accept and transplant a patient utilizing Medicaid coverage, so long as the patient's state approves, even if UPMC has no extant contract with the state or if the state's reimbursement rate is below that of Pennsylvania.

The core concept of wider geographic sharing of organs is that the sickest patient in a wide geographic area will be offered a compatible organ before it is offered to a less sick patient. Based upon the above findings and the computer modeling results of both CONSAD and UNOS, UPMC believes that access to liver transplants for Medicaid patients will not be adversely affected and, in many cases, will be improved if there is broader geographic sharing of donated livers.

As a background matter, it is important to note that when one looks at the UNOS map of the geographic distribution of transplant centers, the 39 transplant centers which performed 35 or more transplants in 1995 are located in or near the largest population areas of the country. They are also located in or near the cities with the largest number and concentration of Medicaid recipients. These centers are in cities such as Boston, New York, Chicago, Pittsburgh, Baltimore, Miami, Atlanta, Dallas, St. Louis, Los Angeles, San Francisco, and Cleveland. As reflected in the data from these programs, these centers accept referrals from and serve a large number of Medicaid recipients. Many of these Medicaid patients are from the local areas served by those centers, but a portion of each center's Medicaid patients are referrals from outside areas.

Under an allocation system calling for broader geographic sharing of livers, it is probable that some of the small transplant programs which have the poorest survival outcomes will close, since the artificial incentive to choose those centers because of shorter waiting times would be negated. Generally, but not in all cases, those centers performing 12 or fewer

transplants per year have the worst survival rates. Since most state Medicaid programs already utilize Medicare approval as a measure of quality in seeking care for their Medicaid beneficiaries, it is unlikely that such small centers serve a large Medicaid population.

Some witnesses at the hearing (such as those from Tennessee, Alabama, South Carolina and Colorado) raised concerns that most small and medium-sized transplant centers, including theirs, would close and leave only a few regional mega-centers for all transplants if wider geographic sharing of organs is implemented. That scenario is unrealistic. It is unlikely that programs in states like Kansas, Nebraska, Utah, Alabama, South Carolina, New Jersey, or Iowa (states with only one in-state program) will be adversely affected by wider geographic sharing of organs. Each of these programs performed 25 or more liver transplants in 1995 and has survival rates and reputations that attract patient referrals, including referrals of Medicaid patients. In Tennessee, the two non-pediatric programs each perform more than 25 transplants per year and attract patients from Tennessee and from other states. In Colorado, one center performed 62 transplants in 1995, while the other center performed one each in 1994 and 1995. The large center is well known and draws patients from several states, including Medicaid patients from Wyoming.

We would note that the current UNOS local-regional-national system does not necessarily benefit Medicaid patients in states where there are approved in-state transplant centers. A good example of this is Wisconsin. Medicaid patients in northern Wisconsin, unless medically necessary to do otherwise, list at transplant centers in Minnesota. Under the current local-regional-national system, a compatible liver donated in Wisconsin will be offered to a patient on a waiting list at one of the three Wisconsin transplant centers before being offered to patients in Region 7 which includes the Wisconsin Medicaid patient listed in Minnesota, even if the Medicaid patient is more medically urgent.

Patients in some fourteen states with no in-state liver transplant program will not be adversely affected by wider sharing of livers because they will continue to go out of state. In fact, some patients may have improved access with wider geographic sharing. For example, Arkansas Medicaid patients often seek liver transplantation in Memphis, Tennessee, since Arkansas has no in-state program. Arkansas is in UNOS Region 3 while Tennessee is in Region 11. Under the current local-regional-national system, a liver donated in Arkansas will more likely go to a patient at a center in Region 3 (maybe Alabama, Georgia or Florida) rather than to the nearby Medicaid patient in Memphis, who may be more medically urgent. Broader geographic sharing will more effectively allocate organs to the more medically urgent patients.

Moreover, as you are aware, more and more states are utilizing managed care in their Medicaid programs. In many of these states, the HMO contracts with transplant centers outside the state. Tennessee is a good example. There are eleven HMOs that serve Tennessee Medicaid recipients. At least two of the HMOs contract with large liver transplant centers throughout the country, as well as in Tennessee. Two of the three transplant programs in Tennessee are not participants in some of the HMO networks. For Medicaid programs using HMOs with out-of-state transplant networks, Medicaid pays for transplants wherever they are performed. In the event of a closure of any transplant program it is reasonable to believe that HMO networks would establish new agreements in order to continue to provide access to liver transplantation for all the HMO patients, both Medicaid and non-Medicaid.

Finally, concern was also expressed at the hearing about pediatric transplant patients. Such patients, whether their transplants are paid for by Medicaid or otherwise, have more equitable access to donated organs under a system with wider geographic sharing than under the current system. In several states, such as Hawaii, Virginia, South Dakota, Montana, Oklahoma and Wyoming, Medicaid will only pay for liver transplants for patients under ages 18 or 21. As was brought out in the testimony to your panel, there are a limited number of programs which will perform pediatric transplants due to the complex surgery. UNOS reported in the summer of 1996 that their computer model showed that more livers would be offered for pediatric transplants under alternative policies with broader geographic sharing than under the current system. Thus, for this segment of Medicaid patients, broader geographic sharing increases their access to organ transplantation.

As reflected in the computer model analyses, CONSAD and UNOS results show that all patients, including Medicaid patients, have a more equitable chance to receive a donated organ under a system that uses larger geographic sharing. The real access problem for Medicaid recipients, as for all liver transplant patients, is equal access to available organs. The average waiting times calculated by the CONSAD computer model demonstrate that there are significant disparities in the times that patients (including Medicaid patients) must wait for a liver transplant in different parts of the country. The shortest average waiting times are in UNOS Regions 3 (southeast U.S.), 6 (northwest U.S.), and 11 (mid-Atlantic), three areas with few large population centers and relatively small Medicaid populations. The longest average waiting times are in Regions 7 (upper mid-west), 9 (New York state), 5 (California and southwest), and 2 (upper mid-Atlantic), four areas having several large population centers and relatively large Medicaid populations. If organs are shared throughout larger

geographic areas, Medicaid recipients, and all patients on the waiting list will have more equal access to available organs. Data presented in Attachment 2 indicate that currently more Medicaid recipients live in geographic areas with longer average waiting times than in areas with shorter waiting times.

Under the current liver allocation system, a significant number of Medicaid-eligible patients, i.e. those living in large urban areas containing major transplant centers, are faced with the undesirable choice of listing with a hospital close to home where there is likely to be a long (perhaps too long) waiting list or to list at a smaller, higher-risk center with less favorable patient outcomes farther from home just to be assured of getting a liver in time. Much of the discussion pertaining to alternative national allocation policies has focused on the impact of alternative policies on small centers. Data presented in Attachment 2 indicate that the Medicaid population that resides in the vicinity of small centers comprises only four percent of the total Medicaid population. Many more Medicaid recipients (40 percent) live in the vicinity of large centers. Moreover, 46 percent of the Medicaid population do not live near a transplant center. These patients are more likely to travel to large centers than to small centers. Simply stated, wider sharing of donor livers will equalize this access and will benefit Medicaid recipients, not harm them.

I hope this information is useful as you continue your deliberations.

Sincerely,

Isabel P. Dunst

Attachments

Attachment 1: Summary of Results From Survey of State Medicaid Offices[1]

Medicaid programs that	Number of States
Permit Medicaid recipients to go to an out-of-state liver transplant centers	50
Cover travel expenses out-of-state	50
Contract only with small volume medical centers	1
Cover a sizeable portion of Medicaid patients through managed care programs	16
Cover some portion of Medicaid patients through managed care programs	26

Source: CONSAD Research Corporation

[1] Survey responses were obtained from all fifty states.

Attachment 2: Proportion of Medicaid Population Residing in Communities With Liver Transplant Programs with Different Annual Volumes and Waiting Times

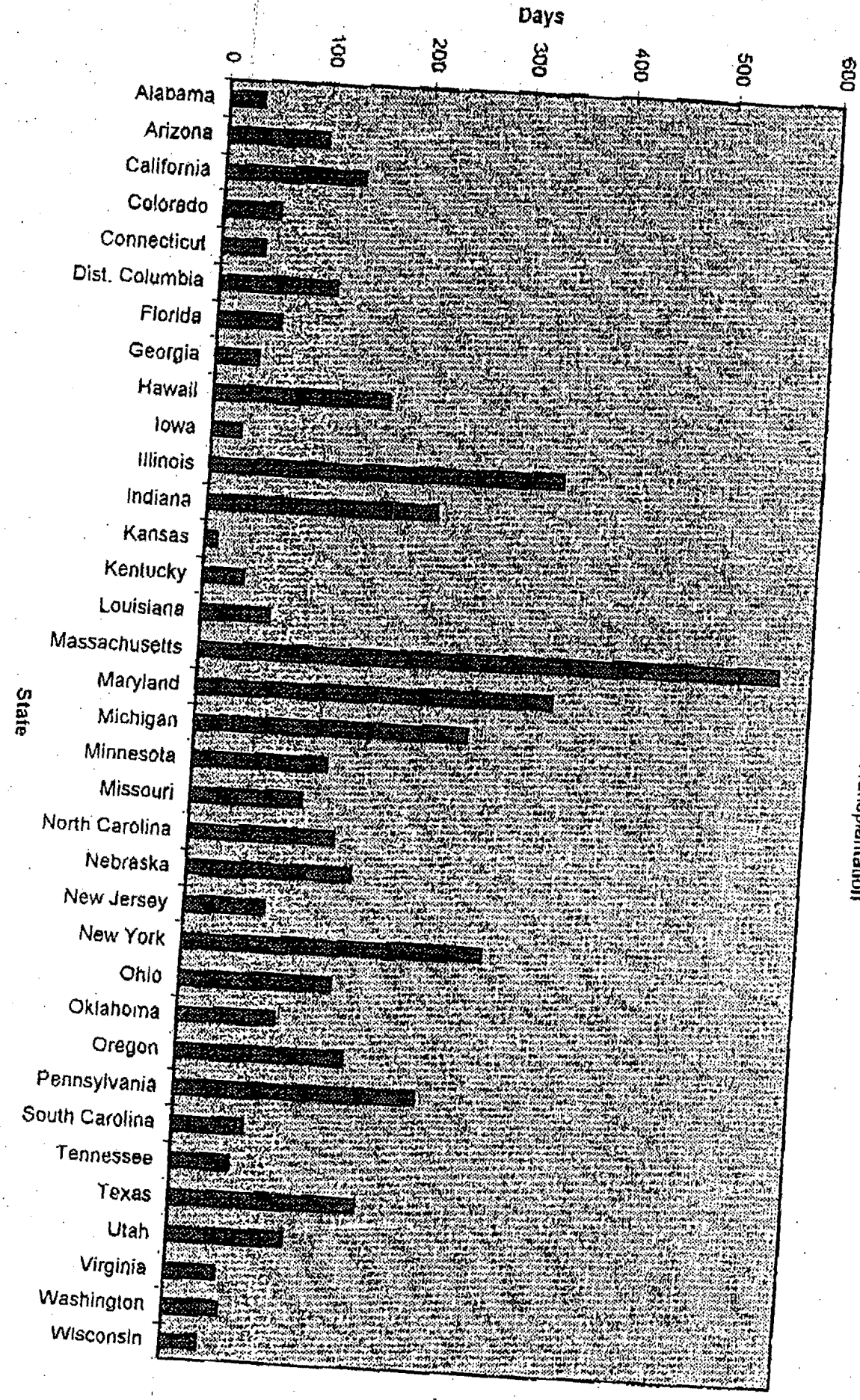
	Percent of All Medicaid Recipients
MSAs with large-volume liver transplant centers	40%
MSAs with medium-volume liver transplant centers (and no large-volume centers)	10%
MSAs with only small-volume centers	4%
Areas with no transplant centers	46%
UNOS Regions with average waiting times that are **shorter** than the national average	45%
UNOS Regions with average waiting times that are **longer** than the national average	55%
UNOS Regions with average waiting times that are at least 20 percent **shorter** than the national average	17%
UNOS Regions with average waiting times that are at least 20 percent **longer** than the national average	37%

Source: Current Population Study, U.S. Bureau of the Census

MSA - Metropolitan Statistical Area

Large-volume centers perform 35 or more transplants annually.
Medium-volume centers perform 12 to 34 transplants annually.
Small-volume centers perform les than 12 transplants annually.

State	Median Waiting Time Until Transplantation
Alabama	33
Arizona	98
California	136
Colorado	55
Connecticut	42
Dist. Columbia	115
Florida	82
Georgia	41
Hawaii	173
Iowa	28
Illinois	349
Indiana	226
Kansas	12
Kentucky	40
Louisiana	67
Massachusetts	569
Maryland	351
Michigan	269
Minnesota	132
Missouri	109
North Carolina	143
Nebraska	162
New Jersey	78
New York	298
Ohio	148
Oklahoma	95
Oregon	164
Pennsylvania	237
South Carolina	69
Tennessee	57
Texas	183
Utah	114
Virginia	50
Washington	55
Wisconsin	36
Total	146


Days
0
100
200
300
400
500
600
Alabama
Arizona
California
Colorado
Connecticut
Dist. Columbia
Florida
Georgia
Hawaii
Iowa
Illinois
Indiana
Kansas
Kentucky
Louisiana
Massachusetts
Maryland
Michigan
Minnesota
Missouri
North Carolina
Nebraska
New Jersey
New York
Ohio
Oklahoma
Oregon
Pennsylvania
South Carolina
Tennessee
Texas
Utah
Virginia
Washington
Wisconsin
State
Median Waiting Time Until Transplantation

UNOS
Network
for
Organ
Sharing

1100 Boulders Parkway
Suite 500
P.O. Box 13770
Richmond, Virginia 23225-8770
804-330-8500
Fax 804-330-8517

Executive Director
Walter K. Graham

MEMORANDUM

To: The United States Transplant Community

From: James F. Burdick, UNOS President

Subject: DHHS/Liver Allocation

Date: November 11, 1996

Please read the attached letter from Assistant Secretary for Health, Phil Lee, MD and the accompanying Federal Register notice. This may well be the single most significant communication UNOS has ever received from DHHS.

We understand that the decisions announced in Dr. Lee's letter resulted most directly from discussions at the highest levels of DHHS over the past few weeks relating to certain correspondence alleged to have been sent to the President by a financial contributor who is reportedly not involved in transplantation personally. UNOS was not consulted regarding these decisions, nor were we privy to the discussions. Despite repeated requests, we have been unable to obtain a copy of the letter, and we were informed that DHHS staff were not free to discuss the meetings. We have been told verbally that neither the letter nor the personal note from the President to Secretary Shalala accompanying the letter and requesting a response are subject to release under the Freedom of Information Act even though the letter has had an obvious and profound impact on DHHS's position.

This is a critical time in the history of the OPTN -- the transplant community's ability to determine the policies and standards for the field is at stake. The National Organ Transplant Act states clearly that it is the private sector OPTN, *not* the Government, which has the legal responsibility for developing OPTN membership standards and medical criteria for organ allocation. Nevertheless, Dr. Lee's letter states DHHS's intention for Secretary Shalala to determine "which of the liver allocation policies promises the best result for the patients of America" and to then "submit to OMB the text for a final rule that embodies the Secretary's decision regarding liver allocation."

I strongly urge you to avail yourself of every possible opportunity to make your voice heard as effectively as possible in this matter. Many in the transplant community have already contacted their elected representatives, and you may want to consider such an action.

This issue is simple: will the transplant community ultimately decide policy? An arbitrary, poorly considered, or politically expedient decision by Government staff could be a tragedy for transplant patients. It is imperative that the extensive work and insight achieved over the past several years by the transplant community working through UNOS not be lost. I encourage you to take appropriate supportive action to ensure that the UNOS process be preserved. If you need scientific data or information regarding UNOS policy, please call the UNOS staff for assistance. The UNOS Board of Directors will discuss this matter at its meeting November 13-14 in Boston, and we will report any new developments to you as soon as possible.

UNOS

804-330-8500

Fax 804-330-8517

Executive Director
Walter K. Graham

November 22, 1996

Dear Transplant Colleague,

I need your help. The important privilege and responsibility we in the transplant community have had for the past ten years to collectively develop transplant standards and policy through UNOS is in serious jeopardy of being lost. This is not about liver allocation; it is about who makes the policies - - all policies for all organs.

Please send me a letter addressed to Donna Shalala, Secretary of Health and Human Services, 200 Independence Ave, S.W., Room 615F, Washington D.C. 02201, on your institution's letterhead stating your opposition to DHHS moving this policy and standard-setting function into the Government. Please do it today. I need to receive your letter by December 3, 1996, 12:00 p.m., eastern time. I am asking everyone in the transplant community to write letters, which I will personally deliver to DHHS as a demonstration of our desire to keep the responsibility for deciding the medical criteria for organ allocation in the OPTN.

It appears that DHHS's decision to take the policy-making role into the Government so that Secretary Shalala could determine which liver allocation policy should be imposed on the transplant community was based, in part, on the erroneous impression that a substantial number in the transplant community support such a move. Our own recent member survey shows that more than 95% favor keeping this function in the private sector transplant community, something I want to demonstrate conclusively at the Government's hearings on December 10 and 11.

I also strongly encourage you to convey this message to your elected representatives, and my strong advice regarding the upcoming hearings is that you request to be heard on this issue. This is the first time in the ten-year history of the OPTN that DHHS has taken this position regarding the respective roles of the Government and UNOS. Therefore, this may be the only opportunity to effectively convey your opposition to this fundamental change in how transplant policy is made.

It is surely true that there are many different opinions in the transplant community about the best way to allocate organs. However, the existence of such differences, which are often voiced vigorously should not be taken as evidence the community desires the Government to subsume responsibility for choosing which allocation system to put into place.

Please fax your letter to one of the following fax numbers at the UNOS office and mail the original immediately:

(804) 330-8507
(804) 330-8517
(804) 330-8593
(804) 327-1449

Sincerely,

James F. Burdick, MD
President

UNOS

United Network for Organ Sharing

1100 Boulders Parkway
Suite 500
P.O. Box 13770
Richmond, Virginia 23225-8770
804-330-8500
Fax 804-330-8517

Executive Director
Walter K. Graham

To: UNOS Board of Directors,
UNOS Committee Chairs, UNOS Past Presidents

From: Walter K. Graham, Executive Director

Subject: DHHS Hearings Update

Date: December 6, 1996 CONFIDENTIAL

Dr. Lee called earlier this week to inform us that the hearings are still on. The hearings schedule is attached for your reference. Dr. Lee said the Department is still considering our request to confirm what Dr. Sumaya said to the UNOS Board at the June 26, 1996, meeting, and that the purpose of the hearings is to receive comments on the OPTN's performance, not to decide liver allocation policy. Dr. Lee said he had personally recommended the hearings be postponed, and he felt the Department should not make the policy decision - - it should be done by the OPTN. However, he said others in the Department disagreed. Dr. Burdick spoke with Dr. Lee later in the week to reiterate our desire that the Department clarify these issues before the hearings next week.

I accompanied Watson Bell, the UNOS Patient Affairs Committee Chair, and his wife Jean Ann who is a liver transplant recipient, to the White House this past Monday. We met with Ms. Carol Rasco, Domestic Policy Advisor to the President and Mr. Chris Jennings, Special Assistant to the President for Health Policy Development. I felt the meeting was constructive for the simple reason that Mr. Jennings had been given the impression that the Department's decision was something we should have expected. He seemed genuinely surprised that we had no forewarning. A copy of my follow up letter to him is attached. We were given very firm assurance that the letter to the President from David Matter had been forwarded to the Department as a routine referral, and that there was no pressure from the White House regarding the issue. Watson, Jean Ann and I also met with Senator Bumpers of Arkansas who is looking into these issues on Watson's request.

This coming Monday, your fellow board member, Dr. Phil Berry, along with Bill Lawrence and I, will visit with the Senate Majority Leader, Senator Trent Lott. Dr. Berry who is a liver transplant recipient, is personally acquainted with Senator Lott. Senator Lott is from Mississippi, and the UNOS members there have contacted him to voice their support for UNOS. We want to brief Senator Lott and ask his advice. We will join our Mississippi members in asking him to sign the attached letter, which is now being circulated among members of Congress for signature. This letter was initiated by several members of Congress, including Senator DeWine of Ohio who spoke to our Board this past June about his experience as a donor father. Several Senators and Congressmen have already agreed to sign the letter. I would encourage you to contact your Congressman or Congresswoman and your Senators to request that they also sign it. They can contact Senator DeWine's office (Ms Saira Sultan at 202 224-2315).

We have been in contact with numerous members of Congress, including our Richmond, VA Congressman, Mr. Bliley who chairs the House Commerce Committee, which has jurisdiction over NOTA. We have been flooded with information from our members about contacts they have made. Please let us know of your own activities so we do not "cross our wires."

We have received 517 letters from members in response to Dr. Burdick's November 22 call for action. So far, 81% of centers, 58% of OPOs, and 41% of histocompatibility labs have responded with letters, and your fellow Board members who are Regional Councillors are making follow up calls. We recently released the results of our membership survey conducted earlier this year in which 95% of physicians and surgeons polled said they favored UNOS, not the Government, making OPTN policy decisions. We want to present these demonstrations of support to the hearing panel next week.

At the hearing itself, Dr. Burdick will lead a delegation from UNOS in presenting background for how the policy was developed and stressing the importance of keeping the policy-making function within the private sector. Dr. Cass Franklin, UNOS Minority Affairs Committee Chairman, will also speak, as will your fellow Board members, Mr. Donald Streater who is a liver transplant recipient, and Mrs. Lynn Slabaugh who is a donor family member. Mr. Watson Bell who chairs the UNOS Patient Affairs Committee will speak on the second day, and Dr. Bruce Lucas, UNOS Immediate Past President, will speak on the third day. At the end of the session, Dr. Burdick will present closing remarks. We are hopeful that Dr. Margaret Allen who preceded Dr. Lucas as UNOS President, will be able to join Dr. Burdick in that presentation.

We expect the press to give this event full coverage. In anticipation of that situation, we recently engaged a Washington based public relations firm to provide advice and assistance for this story. Also, we are asking Dr. Andy Klein, Chair of the UNOS Liver/Intestine Committee to be in attendance at the meetings to assist in briefing the press or responding to the Government regarding policy issues.

We will provide you with a further update following the hearings. Please do not hesitate to call me if you need any further information.

WKG/

Enclosures

Cleveland Plain Dealer
Sunday, February 2, 1997

Waiting for the right person to die

First of five articles

By TED WENDLING,
JOAN MAZZOLINI
and DAVE DAVIS
PLAIN DEALER REPORTERS

For 99 days, Linda Robinson had been waiting for someone to die.

On the night of Aug. 26, as Linda went about the monotony of tidying up her room on the ninth floor of the Cleveland Clinic and preparing for bed, a representative of LifeBanc was phoning Teresa Duke, the Clinic's thoracic organ coordinator. A 44-year-old woman in Columbus had died of a stroke and her family had agreed to donate her organs.

In an act of pure altruism by grieving strangers, a heart, matching Linda's in blood type and size, was being offered to the Clinic for transplantation. The heart was the first match the Clinic had been offered for Linda since her hospitalization May 20.

Although Linda's wait had been shorter than many Clinic heart transplant patients', the uncertainty had become nerve-wracking.

Just three days earlier, doctors had to shock her heart to stabilize her erratic heartbeat. The jolt left scars on her chest and back. It also left an indelible psychological scar, driving home the realization that, after two open-heart surgeries, her 37-year-old heart was not going to last much longer.

She urgently needed a transplant. And although she was not in the habit of wishing ill on others, that meant someone had to die. Soon.

Blind trust

Thirty years after South African surgeon Christiaan Barnard prolonged the life of a 55-year-old man for 18 days by performing the first heart transplant, the American public is as ambivalent as ever about the social, moral and psychological implications of transplanting the living organs of one person into another.

While the wizardry of modern medicine allows doctors to seemingly confer immortality on those whose vital organs have begun to fail, many people — often because of the distrust, ignorance or sheer grief of their survivors — continue to take those organs to their graves.

But while donations have remained relatively stagnant, the number of hospitals performing transplants has more than doubled since 1988. Because transplants have become so commonplace, the number of people who have died waiting for organs has doubled, too.

Hospitals, striving to remain competitive, raise their profiles in their communities and claim a piece of the multibillion-dollar transplant market, have spent millions of dollars to start transplant programs.

SEE LINDA/12-A

LINDA FROM 1-A

Eight years ago, 118 hospitals were doing heart transplants. Today, there are 166. For liver transplantation, the number of programs has grown from 70 in 1988 to 118 today.

Likewise, the number of people waiting for an organ transplant has tripled, topping 50,000 last month.

Like Linda, most of those patients know virtually nothing about the hospitals, surgeons and national organ-allocation system charged with saving their lives, relying simply on blind trust.

"It's amazing to me," said Judith B. Braslow, director of the U.S. Department of Health and Human Services' Division of Organ Transplantation. "You hear people say, 'I heard he was a big doctor.' What's a 'big doctor?' It doesn't mean anything, but the average person doesn't want to know much.

"The average patient wants to go, get their transplant, get better and get off the list. They have one goal."

That's certainly true of Linda. When she entered the Clinic, she didn't know how many heart transplants the Clinic had done, what its survival rate was or how its waiting time compared to other transplant centers.

She also knew nothing about a troubling issue that centers don't discuss with patients: The number of hearts turned down, for medical or nonmedical reasons, that were later transplanted into patients at other centers.

"I just know it's something I've got to do to get out of here," Linda said. "I just want to make sure it's a good match."

Luckily for Linda, her insurance company, Travelers, has a contract with the Clinic's heart transplant program as one of its "centers of excellence." The Clinic has one of the top cardiac programs in the country, and its doctors performed 66 heart transplants in 1995, more than all but three other centers. The national average was 14.

Compared to the other programs, the Clinic also has a better one-year survival rate (89 percent vs. 82 percent), and a reasonable median waiting time (149 days), and turns down almost no organs for nonmedical reasons.

'It's time'

It was 1:20 a.m. on Aug. 27 when a nurse flipped the light switch in Linda's room, rousing her from a deep sleep. A Clinic heart procurement team would be flying to Columbus to take a look at the 44-year-old stroke victim's heart, which had been matched for Linda through the United Network for Organ Sharing. UNOS, an organ databank in Richmond, Va., has the federal contract to distribute organs nationwide.

"I can't believe it! I'm not ready!" Linda stammered as she tried to remember the phone numbers of the people she had promised to call. "I'm so scared. I can't believe it."

There was, of course, her husband, George, who was back in Tyrone, the small central Pennsylvania town in which she had grown up.

Also her mom, Rita Miller, who was staying at the Ronald McDonald House on Euclid Ave.

"George, it's time," Linda said, her voice quivering.

"Are you sure?" he answered, shaking himself awake. He began to cry.

"Please drive careful," Linda said. "I love you. I'll see you when I wake up."

George, 36, a self-avowed "old hillbilly," used to be a long-distance trucker. He quit after Linda was hospitalized, taking a local construction job so that he wouldn't be on the road if something happened.

Being a trucker, George had spent plenty of nights driving in the fast lane. But even making good time, the trip to Cleveland would be 4½ hours. He couldn't be expected to arrive before 6:30 a.m.

In Rita's room, the beeper the Clinic had given her finally went off. By the time a Clinic police officer delivered her to the hospital, she was frantic.

"I know we were waiting all this time, but I'm so scared," she said. "I'm just hoping this heart likes her as much as she likes it."

Even though the hour was late, the ninth floor was abuzz with activity as the nursing staff prepared to move Linda to the cardiac intensive-care unit on the fifth floor.

"I'm hoping it all goes well because she's really a special person," said nurse Jennifer Ullman. "I don't know how I would tolerate being here day after day. She deserves to have a life. She's young."

Marion Grimaldi, another nurse, was beaming.

"For me, it's a really exciting time when somebody gets a heart," she said. "It's like you feel like they're going to have a baby or something. The hair goes up on my arms."

As Linda was being wheeled down the hall, her mind was racing. One foreboding thought lingered: What if this turns out to be a dry run?

A dry run is the ordeal of getting prepped for surgery, only to find out that the organ is unsuitable for transplant. Roughly one-fifth of the trips Clinic heart procurement teams make to inspect donor hearts turn out to be dry runs — the judgment call being made that, upon close inspection, the organ is too marginal to accept.

That's what had happened to Linda's friend, Nancy Vigneau. On Aug. 15, as Nancy, 46, was being prepped for a heart transplant, the Clinic's procurement team leader called from Columbus to inform Nancy's surgeon that the donor heart was damaged.

The psychological effect on Nancy had been devastating. Four days later, the Brooklyn woman suffered a heart attack. She subsequently underwent open-heart surgery in which she received a HeartMate, a mechanical device that temporarily aids the weakened heart in the absence of a donor.

"I wish she'd have got her heart, God love her," Linda said. "I just hope that doesn't happen to me."

The death watch

While the ICU nurses and an anesthesiologist prepped Linda, Rita sat alone in the waiting room, clutching a box of Kleenex.

The clock read 3:10 a.m. A "Taxi" rerun played on the overhead TV set as Rita dabbed at her eyes.

Watching her daughter struggle to live for so many years had taken its toll on Rita. Linda, the eldest of Rita's five children, had been stricken with undiagnosed rheumatic fever as a child and underwent open-heart surgery to replace a valve in 1972, when she was just 13. She subsequently suffered a stroke.

She recovered, but when she had another stroke in 1988, followed again by open-heart surgery and replacement of the same valve, it became apparent to Rita that if Linda was going to outlive her, she would need a new heart.

Linda has viral cardiomyopathy, an enlarging of the heart. It is the most common diagnosis among heart transplant patients, afflicting a little more than half of those who receive transplants.

Worrying about Linda had been enough of a burden, but Rita, who is 55 years old and divorced, also had her own health problems, having recently been diagnosed with cancer of the breast and lymph nodes. That required her to drive the 250 miles back to Altoona, Pa., for her chemotherapy treatments, after which she would return to Cleveland to be by Linda's side.

"This time, I really felt bad," she said of her latest chemo session. "I had to lie down when I got here. Two nurses up there [on Linda's floor] got me a bed."

Since Linda's hospitalization, Rita has been haunted by helicopters, wondering every time she hears the distinctive *whap whap whap* of the Metro Life-Flight chopper whether it carries "Linda's heart."

For some who wait, the death watch becomes a topic of gallows humor, said Teresa Duke, the Clinic's thoracic organ coordinator. A few patients cope with their fear and guilt, she said, by "joking around about sitting at their windows with binoculars, looking for motorcyclists" to crash.

The call

At 5:03 a.m., the phone rang in the ICU. Dr. James McCarthy, the surgeon who had flown to Columbus for the procurement, had bad news. The stroke victim's heart was no good.

In an instant, all the hope, excitement and expectancy of a night of magic were replaced by a sorrow so profound it seemed as though everyone in the room had died at once.

"You're kidding," Rita said as she began to sob. "Oh baby girl, baby girl...."

Linda, the color drained from her face, stared straight ahead. "I've had bad luck for so long, I don't need any more," she said.

As she tried to comfort her mother, Linda thought of George, racing down Interstate 80 in the early-morning darkness, worrying about whether he was going to be late.

"He drove so far for nothing," Linda said. "I don't look forward to telling him. He's going to be so upset."

Room with a view

From the ninth floor of the Clinic's "G" Tower, home to those awaiting heart transplants, patients can contemplate the treetops and rooftops of the city's East Side and watch the traffic on busy Euclid Ave.

The perspective can be frustrating, but for patients who are tethered to IVs and rolling heart monitors, it offers a reprieve from television and the obsessive attention they must pay to their huge daily doses of medication.

But that's not true for Linda, who with help from her mom, transformed the spartan hospital room into a makeshift home. Hundreds of get-well cards, drawings and photographs warmed the walls of G90-26.

"I got that 3-D puzzle," Linda had said on Day 90, pointing to her Cinderella's castle puzzle, one of many she had finished. "I told myself when I finish that puzzle, that night I'll get my heart. Well, that's been finished for a week, and I still don't have my heart."

Improvements in transplantation — new medications and ventricular assist devices, which keep failing hearts beating — have increased the short-term survival rate. Considered little more than experiments 15 years ago, heart transplants are routine enough today that their average $250,000 cost is covered by Medicare, Medicaid and private insurance.

But with donor organs being so scarce, the rapid medical advances have brought with them bigger waiting lists, longer waiting times and a greater chance of dying while waiting for an organ.

Eight years ago, four people died every day waiting for an organ. By 1992, that number was seven. Today, it is above nine.

Currently, more than 3,700 people are waiting for a heart transplant. Only 2,361 received one in 1995, and 770 people died waiting.

'I'm on my way'

Aug. 30 was a sweltering day in Tyrone, and George Robinson couldn't move from the living room couch. He had been thinking about mowing the lawn, but he couldn't snap out of his depression. All he felt like doing was lying around.

Since Linda's hospitalization, her doctors had been forced to shock her heart seven times to keep it going. "The nurses down there said they had never brought somebody back to life that many times," she had told George matter-of-factly.

George was still confident that Linda was in good hands, but she had been waiting in the hospital for a new heart for more than three months nov. What if she died waiting? He would be alone.

George and Linda didn't have children. Linda had learned the hard way that she would never be a mother, having been told only after a miscarriage at age 21 that the blood-thinning medication she had taken made it impossible.

George was getting another ice tea when the phone rang. It was 2:30 p.m.

"Honey, it's time," Linda said, trying to conceal her fear. "Now don't get too excited. Remember what happened last time. They've got another heart, but they have to check it out."

The clock was running. Four-and-a-half hours stood between them, so George didn't waste words.

"I'm on my way," he said. "I love you."

First, George had to pick up Rita. To save time, he decided to take the route that went by Ty-

rone Area High School. But it was Friday, and the school was playing its arch-rival, Bellwood, in football. It was a big event in the small town, and hundreds of people already had clogged the streets by 3 p.m.

"I told her that when I got the call, I'd be there before they took her in," George said, recalling his late arrival the morning of Linda's dry run. "No matter what, I'd be there."

Code Blue

Farley Lee was filling out paperwork at the Clinic's ninth-floor nursing station when Linda's heart monitor sounded. Linda had been working on another jigsaw puzzle — the same one she had been noodling over for two weeks — when she learned that a heart had been offered for her. Initially, she had taken the news calmly, but within minutes her heart was racing out of control.

Lee reached the room first, finding Linda on the phone.

"I don't feel good," Linda said.

"Get back in bed," the nurse ordered.

Linda's normal heart rate was about 90 beats a minute, but as the Clinic staff rushed into her room, they could see it was at 120 and rising. They put her on oxygen, started an EKG and called a "Code Blue." It was 3:05 p.m.

The nurses knew Linda was in trouble. They also knew there would be no transplant that night if they couldn't slow her heartbeat.

When Linda's heartbeat reached 150, the paddles were brought out to shock her.

"It's the same rhythm you did last week on us," said Dr. Matthew G. Deedy. "You feeling OK?"

"Yep," Linda said weakly, the oxygen mask muffling her voice.

Linda was anxious, but she also was alert and responsive. Deedy decided to give her heart time to slow itself, rather than shock her or administer drugs. Either one of those measures could jeopardize her chances of undergoing a transplant.

By 4 p.m., Linda's heart rate had dropped to 119. It was a go.

Point of no return

Shortly after 6:30 p.m., the organ procurement team boarded Life-Flight, bound for Youngstown. The team was led by McCarthy, the surgeon who had decided that the heart offered for Linda three days earlier was unacceptable.

In the ICU, doctors and nurses once again began inserting an IV tube into Linda's jugular vein. Linda was awake during the procedure.

"Ben, if the heart's no good, will they electric-shock me again?" she asked Ben Meola, one of her nurses. "I don't want to be shocked."

"They'll make that decision then," he answered gently. "Think positively."

Dr. Robert W. Stewart, head of the Clinic's heart transplant program and the doctor scheduled to perform Linda's surgery, came in to introduce himself and tell Linda a little bit about what to expect.

Transplants are exercises in medical precision — from the seemingly interminable poking and prodding patients endure to the almost military-style police escorts procurement team members receive until the moment they enter the surgery room.

"You try to coordinate everything else so that the minute they're walking in with the [new] heart, we're taking the old one out so that there's an exchange at that time," Stewart said.

"The critical decision is really made by the person who goes to get the heart," he added. "I'm very fortunate to have highly experienced guys like Jim McCarthy. I have no idea how many transplant runs he's been on. He can spot a bad heart at 20 feet. He also knows a good heart. And he knows the heart that isn't perfect, but is going to be good enough for us."

Linda was beginning to get groggy from the medication. Her eyes were slits, but she could still talk.

"I hope they wake me tonight," she said, her voice barely audible through the oxygen mask. "I want to wake up later and have this whole thing be over."

Denise E. Brainard, a transplant nurse who follows patients after surgery, tried to comfort her.

"I talked to Dr. Stewart and he said it looks like a real good heart," the nurse said.

"I don't want a bad heart," Linda told Brainard.

"Oh, we won't give you a bad heart. That's why there are dry runs. When we give you a heart, it'll be a good one."

"They said that other one was from a 44-year-old woman," Linda added. "I don't want a heart from a 44-year-old woman. After going through all this, I want a young heart. I don't want a 44-year-old heart."

"Well, even if we give you a 44-year-old heart, you can be sure that it will be a good one. You should have a good weekend. What a nice [Labor Day] holiday present."

It was shortly before 8 p.m. when the staff assembled in the ICU to take Linda to the operating room. As they were preparing to move her, George and Rita arrived at the fifth-floor waiting room.

"They're wheeling her to the elevator," a nurse told him. "You can catch her there."

The reunion was brief and frenzied.

This was it, George thought. These were the people who were going to perform a miracle by giving Linda a new heart.

His own heart was in his throat.

"I got to see her for two minutes," he said. "That's all I wanted — just to let her know that we were there, that we love her."

Night owls

. The heady success the Clinic's heart transplant program has enjoyed since its inception in 1984 has conferred godlike status on its three surgeons — Stewart, Nicholas Smedira and Patrick M. McCarthy. But it is the tireless and nerve-jangling efforts of Katherine J. Hoercher, the cardiac transplant coordinator; Duke, the thoracic organ coordinator; and the Clinic's organ procurement teams that are perhaps even more impressive.

One of the grim realities of organ donation is that many organ donors die at night, often from homicides or traffic fatalities. That requires Duke, Hoercher and the procurement teams to be available around the clock.

As a result, they learn to take power naps, sometimes aboard Life-Flight.

"Transplants aren't really any fun because they're often in the middle of the night," said Hoercher. "But we're very aggressive. We take a lot of hearts that other programs turn down."

Stewart said the Clinic is acutely aware of the balance of risk factors.

"I will transplant a high-risk recipient," he said. "I will also use a donor that is borderline. But I won't use a borderline heart in a high-risk recipient. Risk is cumulative. And we can neutralize one risk factor by having everything else lined up very nicely."

Patients don't realize it, but even the nation's top transplant centers turn down more than 80 percent of the hearts they are offered, usually because the recipient is too ill or for any of more than a dozen other reasons involving the health and social history of the donor.

The determining factors in who gets transplanted are blood and tissue type, length of time on the waiting list, medical urgency and the distance the procurement team has to travel to obtain the organ.

Hoercher said the Clinic had traveled as far as northern Florida to pick up a heart. Because of the Clinic's willingness to accept hearts that other transplant centers turn down, 60 percent of its hearts come from outside the region.

The Clinic also transplants patients who are on its waiting list but are hospitalized out of state, bringing them in by helicopter for the surgery so that they can be near their families while they wait.

That wasn't possible for Linda, who had to quit her job at Josten's Yearbook Co. in State College, Pa., after she became too ill to work. So instead of being hospitalized in nearby Altoona, she spent her summer in Cleveland, staring out her hospital window and waiting for the death of a stranger.

The turning point

The temperature in the operating room was a cool 60 degrees when Stewart walked in wearing white pants and a white short-sleeved shirt. The call had arrived: The heart was good.

While teams of procurement specialists, who had arrived to claim other organs, hovered over the donor in Youngstown, the Clinic's surgical team readied an unconscious Linda for her five-hour surgery.

The heart is always the first organ to be procured, and doctors have a maximum of six hours after "cross-clamp" — the cutting off of the blood supply to the donor heart — to transplant the heart into the recipient.

By 10:22 p.m., it was clear that the procurement team was running later than expected. Linda's chest was open and Stewart was ready to remove her heart. She had been on the heart-lung bypass machine for 12 minutes.

"They didn't forget where we were, did they?" Stewart joked dryly.

Three minutes later, McCarthy and the procurement team swept into the room, carrying Linda's new heart in an Igloo Playmate cooler.

It took Stewart about three minutes to remove Linda's heart. Simultaneously, two nurses carefully removed the donor's heart — which was suspended in a saline solution — weighed it and prepared it for transplant.

Then the delicate work of stitching the new heart into Linda's chest began.

Stewart said little. Because the Clinic averages more than one heart transplant a week, team members have spent a lot of time working together.

The turning point in the surgery came when Stewart was ready to allow partial blood flow into Linda's new heart. It would either begin beating on its own or he would have to shock it back to life.

Or Linda would die.

The doctor removed the clamp. Immediately, the heart began beating, confirming Stewart's intuition: A perfect match.

"That restores my equilibrium," he said.

He asked a nurse to call George and Rita in the waiting room and tell them the surgery was going well. Rita began to cry. George, for the first time, saw an end to Linda's long ordeal.

"I can't help but think about where the heart came from, and why things have worked out this way," he said, his eyes focused on the floor. "I guess only one Man knows for sure. Still, I think about it, about the family on the other end of this.

"Do you think they would get us in touch with them? If they had hard feelings, I wouldn't want to intrude on them," he said as his eyes welled with tears.

For a moment he could not speak.

"I'd like to let them know what we're like, to thank them very much for the second chance they gave my wife."

The Robinsons know only that Linda's new heart came from a 31-year-old woman who died from a gunshot wound. They now know that at least two other families benefited from the donor family's generosity, with the liver and kidneys also being procured for waiting patients.

Although organ recipients are given no other information about the donor, they are allowed to send a letter, usually relayed through the hospital or organ bank, to the donor's family. The family then chooses whether to respond.

Many don't, preferring their gift to remain a silent, selfless act.

'Bye bye, y'all'

At 1:04 a.m., the surgery ended. Stewart walked into the waiting room and extended his hand to George.

"It went very well," the doctor said. "It was a good match. Best I've seen in some time."

Stewart said he was optimistic about Linda's long-term outlook. Her chance of surviving the first year, he said, was about 95 percent.

"The real question now is what's going to happen to the donor heart, specifically coronary artery disease," he said. "And there's about one chance in three that, five years from now, that will have caused her major problems, either death or re-transplantation."

While those odds may not sound great, most heart transplant patients will take them any day over the immediate alternative — death. Many heart recipients are now living more than 10 years. And the longest-living recipient, a 40-year-old patient transplanted at Stanford University in 1974, has logged more than 20 years.

"Every year, things get a little bit better," Stewart added. "So the outlook's not bad for Linda at all."

Linda's recovery was swift. On Sept. 7, eight days after her transplant, she left G90-26.

She tried not to cry, but even the heavens wept. The rain came in torrents as Linda, Rita and George loaded boxes into George's truck. Linda's nurses, many of whom made it part of their daily rituals to take their breaks in her room, gathered to say goodbye and wish her well.

"It was hard to leave those people," Rita said. "You get really close after being with them all that time."

"I didn't even see my cousins as much as I saw those people," Linda added. "I saw them every day."

And then she left, carrying the heart of a woman she had never known, along with the hopes and fears of a life she almost lost.

All that was left of her 110-day stay at the Clinic was the note she had scrawled on the message board in her room:

"Thanks for all the special care, EVERYONE. Bye bye, y'all."

Back to Tyrone

Nestled in the hollows of central Pennsylvania, hard by the Little Juniata River, Tyrone is a world away from Cleveland.

This mill town of 1,800 residents is where Linda grew up, and where her children would have grown up had her fortunes been different. Lacking though it may be of the amenities she and Rita had grown used to in Cleveland, Tyrone is where her family and her heart is.

For the most part, Linda has been doing well since her transplant. She is also relieved to hear that Nancy Vigneau, her friend at the Cleveland Clinic who was kept alive by the HeartMate, got "her" new heart a week before Thanksgiving, and that Nancy is recovering, too.

Because she has been so fixated on living, Linda has given little thought to what Renee Fox, a professor of sociology at the University of Pennsylvania, calls "the tyranny of the gift" — the inability of organ recipients to ever repay such an extraordinary act of giving. She was allowed only to send a brief thank-you card to the donor's family — who chose not to respond — and that was the end of it.

Like many transplant recipients, Linda expected her life to pretty much return to normal after she came home. It hasn't.

Every day, she checks her blood pressure, temperature and weight, walks 30 laps (five miles) around the interior of the high school and swallows 23 pills, ranging from anti-rejection drugs to Geritol. She returns to the Clinic every three weeks for a biopsy.

"My body's fighting my heart because it knows it's not part of my body; it's someone else's," she said. "But I didn't think I would have to take all the medicine I take. I take a lot more medicine than I took before, and that bums me out a lot."

But in other ways Linda's life has returned to normal. Sweaters still needed to be cross-stitched for Christmas presents and the many chores associated with maintaining the Robinsons' small trailer home had to be done.

George hasn't been around to help much. After Linda came home, he took a job with a Conrail subcontractor, helping to clean up train-derailment sites. The money's good, Linda said — $10 an hour — but it keeps George away from home a lot.

But there's a more important reason Linda has not had time to convalesce. It is now her turn to take care of Rita, who has been suffering terribly from her cancer.

Since completing her chemotherapy regimen, Rita has been receiving radiation therapy at Altoona Hospital. Every day, a hospital van makes its rounds through the hollows near Tyrone and its surrounding communities, picking up cancer patients and delivering them to the hospital's cancer center.

The patients with early appointments simply sit and wait until everyone is done. Then they are delivered back to their homes, where they wait until the van arrives again the next morning.

Linda vowed that her mom would not be on that van. So, every day, she drives Rita to the hospital, doing her cross-stitching in the lobby while Rita gets her radiation. Then they go bargain-hunting.

"She stayed with me the three months in Cleveland," said Linda. "I think I can get out and take her to the hospital."

These are precious months for Linda and Rita, filled with laughter and Rita's infectious optimism. For the first time in years, it appears that daughter will outlive mother — as every parent knows it should be.

And still, Linda isn't sure she would be willing to endure it all again.

"They say you might have to have another transplant within a certain time, but I don't know if I'd do it again," she said. "I say that now, but when it came down to dying at the hospital, I didn't want to.

"I guess I can say I wouldn't do it again, now that I'm doing so good."

Photos and Captions Omitted

FOR YOUR INFORMATION

If you are facing a transplant

When deciding where to go for a transplant, patients should consider the annual number of transplants a center performs, its mortality rate and the surgeons' experience, medical experts say.

Centers that perform large numbers of transplants tend to have better survival rates and are less likely to turn away donated organs matched for patients on their waiting lists, according to Dr. Robert W. Stewart, head of the Cleveland Clinic's heart transplant program.

"Volume almost answers everything else," he said. "If you wanted to pick a transplant center just on the available information, pick the top 20 according to [volume] numbers, and then go down the top 20 and pick them according to survival rates."

Volume and mortality data for transplant centers are published by the United Network for Organ Sharing in its "1994 Report of Center Specific Graft and Patient Survival Rates." The full report costs $115 and can be obtained by calling 1-800-243-6667.

UNOS also provides mortality rates on up to 10 centers free of charge to transplant candidates who send a written request to: UNOS communications, P.O. Box 13770, Richmond, Va., 23225.

Information about a surgeon's experience must be requested from the transplant center.

Additionally, "Transplant News," an industry newsletter, offers in-depth coverage on the latest issues of interest to patients and transplant professionals. You can subscribe by calling 1-800-689-4262.

And computer users with access to the World Wide Web will find useful transplant information on homepages published by UNOS:

http://www.ew3.att.net/unos

and the U.S. Department of Health and Human Services' Division of Organ Transplantation:

http://www.hrsa.dhhs.gov/bhrd/dot/dotmain.htm

TRANSPLANT FACTS

Estimated first-year charges per organ transplant, 1996

Heart	$253,200
Liver	$314,500
Kidney	$116,100
Kidney/pancreas	$141,300
Pancreas	$125,800
Heart-lung	$271,400
Lung	$265,900

SOURCE: Milliman & Robertson Inc., Brookfield, Wis., consulting actuaries

TRANSPLANT FACTS

The length of time organs remain usable after procurement

Heart	4-6 hours
Lungs	4-6 hours
Pancreas	12-24 hours
Liver	16-32 hours
Kidney	48-72 hours

SOURCE: Center for Organ Recovery and Education

Cleveland Plain Dealer
Monday, February 3, 1997

Hospitals reject healthy hearts

Waiting patients not told

Second of five articles

By DAVE DAVIS,
JOAN MAZZOLINI
and TED WENDLING
PLAIN DEALER REPORTERS

ROYAL OAK, Mich. — The sum of Patti Szuber's donated parts was two eyes, two kidneys, a liver, 30 bone and tissue samples, and one beating heart.

In a wrenching, bittersweet story of love and death, the heart of the 22-year-old nursing student went to her father, and it made Michigan tree farmer Chester Szuber the most famous heart transplant recipient in America.

Patti Szuber's tragic death in a car accident in Tennessee in August 1994 and the transplantation of her heart into the chest of her ailing 58-year-old father also thrust the suburban Detroit hospital at which the surgery was performed into the national spotlight.

Chester Szuber had been waiting four years for a transplant, and William Beaumont Hospital in Royal Oak was inundated with calls from reporters and TV producers who wanted to tell the family's heartbreaking story.

But what Beaumont officials never told Szuber or any of the other 23 patients on their waiting list in 1994 was that the national shortage of donor organs wasn't the only reason they had been waiting so long for new hearts.

That year, Beaumont staff turned down for nonmedical reasons 101 offers of hearts suitable for transplant. The reasons for the turndowns, as reported to the United Network for Organ Sharing by the organ banks that offered the hearts to Beaumont, were either "surgeon unavailable/program too busy" or "administrative."

Another 76 heart offers were turned down by Beaumont administrators in 1994 for medical reasons. They accepted just one — Patti Szuber's.

Beaumont wasn't the only program that was turning down heart offers for nonmedical reasons that year. While transplant professionals were publicly lamenting the shortage of donor organs, 28 of the nation's 167 heart transplant centers refused for nonmedical reasons 20 percent or more of the total heart offers they received during the last seven months of 1994, according to UNOS records. About 97 percent of those hearts were later transplanted into patients at other hospitals, a UNOS official said.

"I'm surprised that the numbers are that high," said Thomas H. Murray, director of the Center of Biomedical Ethics at Case Western Reserve University and one of several ethicists and doctors who said they were unaware of the practice. "You'd like to know what the circumstances were ... but if they can't give good reasons, it's troubling.

"You can count me among those who were surprised to hear that it happens at all. I assumed it was extremely rare, and it ought to be extremely rare."

Transplant professionals say a hospital's rate of turning down organs for nonmedical reasons is just one factor that patients should consider when choosing a hospital. Other important factors are a hospital's mortality rate and the median length of time its patients must wait before being transplanted.

A center's high nonmedical turndown rate also doesn't necessarily translate into longer median waiting times for patients. In some cases, a high rate of turning down organs for nonmedical reasons simply reflects the size of a program and the resources the hospital has devoted to transplantation.

For example, of the 806 offers of hearts turned away for nonmedical reasons during the last seven months of 1994, many were refused by smaller programs, such as Beaumont's, which has just one transplant team. That means vacations, medical conferences and other cardiac surgeries that might call any member of the team away forced those centers to turn down hearts they otherwise might have accepted for waiting patients.

More recent turndown data could not be obtained because UNOS, the government contractor responsible for allocating donated organs, has refused to give 1995 and 1996 organ turndown figures for individual hospitals to the U.S. Department of Health and Human Services.

UNOS officials claim that transplant centers have not reviewed the figures and that the data may have been inaccurately or nonuniformly reported by the nation's 66 organ banks. They also fear that making the data public would discourage centers from voluntarily providing information, provoke lawsuits and change the way the data is reported in the future, rendering it scientifically useless.

Beaumont — which has done an average of just 2.6 heart transplants a year since its program opened in 1989 — had the third highest percentage of nonmedical turndowns in the country during

the last seven months of 1994. During that time. Beaumont turned down 52 offers of hearts for nonmedical reasons, an average of more than two per patient, UNOS records show.

In an interview in October, Beaumont administrators disputed the accuracy of the turndown figures. But last month, after referring the matter to the hospital's peer review committee, they confirmed that the figures were correct.

Hospital officials would not reveal the results of the committee's report, which was completed in December, but said they had addressed the problems and had not turned down any hearts in 1996 for nonmedical reasons.

"Nonmedical turndowns of hearts is something that we don't find acceptable around here, at least anymore," said hospital spokesman Mike Killian. "The issue is that it shouldn't have been done in the first place."

Beaumont administrators attributed part of the problem to the busy schedule of Dr. Jeffrey M. Altshuler, the hospital's only heart transplant surgeon. Altshuler performs about 230 heart surgeries a year, or about four a week. When a heart is offered, he often must be available to remove as well as transplant it.

"The big problem in having one transplant surgeon is when I go on vacation . . . what happens to the recipients?" Altshuler said. "We've made arrangements with other transplant programs now that if I'm gone for a week, we call them . . . and they will cover for us."

Beaumont officials would not say whether any of the patients for whom hearts had been refused died without receiving a transplant. Because patient information is confidential, The Plain Dealer was unable to identify Beaumont patients or their survivors to interview for this story.

Patients not told

In a practice officials at Beaumont and some other hospitals said was universal, Beaumont did not tell any of the patients on its waiting list about the nonmedical turndowns. That deprived them of the choice of transferring to another heart transplant program.

Patients at Beaumont and elsewhere generally also aren't aware that transplant centers turn down most of the hearts they are offered for important medical reasons, such as the recipient was too ill or the donor's size or weight were incompatible with the recipient.

"There are always exceptions, but as a general practice, patients are not told about [organ] turndowns," said Dr. Leslie Rocher, Beaumont's director of transplantation services. "It doesn't add to their well-being."

Some medical ethicists disagree. Jeffrey M. Prottas, a UNOS ethics committee member, even goes a step further — advocating that patients be given turndown data when they are deciding where to have a transplant, rather than after they are already hospitalized.

"Whenever I have my say on this issue, I say that UNOS ought to be publishing all of this," said Prottas, who teaches health politics at Brandeis University in Waltham, Mass. "It's really unfair. Everybody should know these sorts of things."

But they don't — particularly when organs are turned down for nonmedical reasons. Officials at Ohio State University Hospital, Vanderbilt University Medical Center and other transplant centers around the country all said they don't tell patients about nonmedical turndowns.

As a consequence, patients at Vanderbilt didn't know in 1994 that 41 percent of the heart offers were being turned down for nonmedical reasons while the head of the Nashville, Tenn., hospital's heart transplant program, Bill Frist, was campaigning for the U.S. Senate.

Vanderbilt refused 93 offers of hearts in the last seven months of 1994, 46 of them for nonmedical reasons, according to UNOS data.

Frist, who was elected to the Senate that year, declined to comment for this story. Since becoming a senator, he has remained involved in transplant issues and, along with Ohio Sen. Michael DeWine, founded the Congressional Task Force on Organ and Tissue Donation.

It is unclear how many of the nonmedical turndowns are attributable to Frist's absence, but hospital officials said that when he took a leave from Vanderbilt in late 1993, they were left short-staffed.

"When Frist left, it left two guys doing everything — all the adult heart surgery, all the adult thoracic surgery, and all the transplants," said Dr. Richard N. Pierson III, the current director of Vanderbilt's heart transplant program. "When I got here, I got that [turndown] list from our cardiologist, who was unhappy that we had had to turn down organs because we didn't have enough people."

Pierson conceded that Vanderbilt turned down organs for nonmedical reasons before he arrived in July 1994, but he disputed UNOS data stating that 39 of the 46 heart offers Vanderbilt turned down from July to the end of 1994 were because a surgeon was unavailable or the program was too busy. He said just one heart was turned down in 1994 because a surgeon was unavailable — in August of that year, while he was on vacation.

"Every program turns down organs," said Dr. John R. Wilson, director of Vanderbilt's heart failure program. "Whenever you have limited numbers of surgeons and you have patients on the waiting lists, you would not like to see any organ turned down. But that's just not a realistic expectation of any program. There is no program in this country that can guarantee that every organ that's acceptable is taken."

Aware of problems

Although heart transplant patients are not aware that many hospitals routinely turn down heart offers for nonmedical reasons, officials at UNOS and the Division of Organ Transplantation have known about the practice for almost two years.

In March 1995, prompted by questions about heart turndowns at the University of Kansas Medical Center, government officials asked UNOS to compile refusal data on each of the nation's 167 heart transplant programs.

The report, covering the last seven months of 1994, showed that the programs turned away for nonmedical reasons nearly 12 percent of all heart offers.

"Besides Kansas, there were a number of other heart transplant programs with high refusal rates," a Division of Organ Transplantation official wrote in an internal report. The report also said the turndown behavior at one hospital — Beaumont — appeared to fit the same "profile" as the University of Kansas.

The identification of that profile stemmed from a front-page story in the Kansas City Star in May 1995. The story reported that from April 1994 to March 1995, the center turned down all 50 hearts it was offered, most for nonmedical reasons.

Subsequent stories speculated that the turndowns may have contributed to the deaths of three patients, prompting an investigation by the state attorney general, numerous lawsuits and, ultimately, closure of the transplant program.

But information about Beaumont and the other hospitals with high heart-refusal rates was never made public, and federal regulators never pursued the matter, concluding that it was an unfortunate anomaly.

"There are about 850 transplant programs in the country ... and one, maybe two, have been brought to our attention as problems," said Judith B. Braslow, who heads HHS' Division of Organ Transplantation. "We do 19,000 to 20,000 transplants a year. We're talking about very small numbers. That's not to say patients should have been treated this way."

But according to Braslow and her deputy, Remy Aronoff, no one, including anyone from UNOS, ever even questioned Beaumont or any of the other programs with high refusal rates.

One reason Beaumont wasn't scrutinized, according to Aronoff, was because the hospital's 1995 heart turndown figures improved over 1994. Beaumont's nonmedical turndown rate dropped from 50 percent in 1994 to 33 percent in 1995.

"That put them in a category with a lot of other programs, so we didn't pursue it further," Aronoff said.

Although previous contracts did not require UNOS to report potential problems to the government, a new contract UNOS and HHS signed Dec. 30 requires UNOS to monitor, investigate and report any incident "that jeopardizes the health of waiting list patients or transplant recipients."

Because few people are aware that hospitals turn down donor organs, few have been advocating that patients be told. The exceptions are the patients and families who waited in vain for hearts at the University of Kansas Medical Center.

"I absolutely believe that patients or their families have a right to know what's going on so they can discuss it and make better decisions," said Loetta DeWalt, whose husband died before he could receive a heart transplant at the medical center. "We were not told anything."

Teddy DeWalt, 60, a retired Kansas City firefighter, endured months of poking and prodding with the hope of getting a new heart. But in February 1994, while he was being evaluated for a transplant, his enlarged heart failed.

"He was told that it was time to go on life support," his wife recalled. "At the last minute, he changed his mind, which was probably just as well since he would have been going to a place where they weren't even doing transplants.

"He died 10 minutes later."

Keeping secrets

With the exception of data involving Beaumont, UNOS officials have refused to release to the federal government or the public 1995 and 1996 figures showing how many hearts individual hospitals turned down for nonmedical reasons. They also have refused to release turndown data for other types of donor organs.

UNOS President Dr. James F. Burdick, a transplant surgeon at Johns Hopkins Hospital in Baltimore, said turndown figures were "not a very useful statistic" and should not be used to judge transplant center performance.

"If you want [to use the data] to say such-and-such center wasn't doing things right, I'm telling you, you're on thin ice there," Burdick said.

He added that giving patients information on organ refusals and median waiting times at transplant centers "don't help patients very much because, lo and behold, everybody's doing an excellent job.

"I think that in the big picture, the issue of releasing the data to patients is an idea that would be designed to fix something that isn't a big problem ... If you're trying to talk about ways to help patients understand the national system, we've got many ways that we can help patients more than by giving them this data."

One way UNOS helps patients, Burdick and others say, is by publishing survival rates for all transplant centers in the United States. But that information is based on transplants performed five or more years ago. An updated survival report is due out this summer.

The limited data UNOS and the government have been willing to release shows that the problem of nonmedical turndowns of hearts has worsened since 1994.

On average, in the last seven months of 1994, centers refused for nonmedical reasons nearly 12 percent of all heart offers.

By the next year, that rate had increased to 25 percent. And in the first quarter of 1996, it had dipped slightly, but was still at 19 percent.

Not all transplant centers turn down large numbers of hearts for nonmedical reasons, however. Seventy-one hospitals managed to

keep refusals for nonmedical reasons below 5 percent, according to the 1994 data. They included the Cleveland Clinic, where just 0.33 percent of the heart offers were refused for nonmedical reasons.

Dr. Robert W. Stewart, head of the Clinic's heart transplant program, attributed that number to the resources available at the Clinic, which performed 74 heart transplants in 1996, more than all but three other centers.

"We almost never would have to turn down a heart because we don't have the manpower," Stewart said. "You cannot, in a smaller institution, have the privilege of having three separate teams. If you're just completing a transplant and they call you with another donor, you're probably not going to be able to use the people who are already doing that particular procedure. You're going to have to have an entirely new team standing in the wings."

Defining 'inactive'

Last summer, UNOS adopted a policy that calls for letters of inquiry to be sent to any program that turns down 10 consecutive organs. After some debate, it also decided that programs found to be "inactive" should inform their patients.

Left unaddressed were the issues of how long a center could go without performing transplants before being considered inactive, and what to do about programs that weren't technically inactive but were turning down large numbers of organs and not telling their patients.

UNOS Executive Director Walter K. Graham would not say whether UNOS had sent letters of inquiry to any of its members.

Braslow, director of the Division of Organ Transplantation, supported the policy, but said she was not entirely satisfied.

"To me, it is unconscionable that a program should be inactive and the patients not be notified," she said. "There isn't one of us who would sit still for that if it were our spouse or our kid."

Many donated organs are never transplanted

By TED WENDLING
STAFF WRITER

In phone conversations often held at night, organ bank donation specialists and hospital organ procurement coordinators carefully go over a standardized checklist.

Did the next-of-kin give written consent for donation? How did the donor die? Does the donor have a history of cigarette, alcohol or IV drug use? What medications were administered before the donor died?

Those and many other questions are asked of doctors, nurses and donors' families before an organ bank decides whether to offer an organ for transplantation. The information is then entered into the computer system of the United Network for Organ Sharing, which matches it against thousands of potential recipients on the national transplant waiting list. The matching process numerically ranks potential recipients based on their distance from the donor organ, the number of days they have waited, their medical status and other factors.

For a variety of reasons, many donated organs are never transplanted. For those that are, once the hospital verifies that a transplant was performed, the UNOS computer generates a form listing all potential recipients and sends it to the organ bank that procured the organ. The organ bank is required to show that the organ was offered to every patient ranked above the recipient, and to report the reason each hospital turned it down.

Collecting such data ensures that patients ranked higher on the waiting list were not skipped over because someone lower received unwarranted consideration.

Organs are rarely accepted on behalf of the first patient on the list. In 1995, for example, donor hearts were turned down by hospitals an average of six times before being transplanted. Three out of four times, they were turned down for medical reasons — ranging from issues related to the quality of the organ or the donor's social history to the recipient's immediate need for a multiple organ transplant.

The nation's 66 organ banks reported that another 3,448 heart offers — representing one-quarter of the 13,801 that were refused in 1995 — were turned down for nonmedical reasons, either because a surgeon was unavailable, the program was too busy or for other administrative reasons.

Some transplant physicians disagree with the way UNOS tallies turndown data. If, for instance, a hospital has three ranked patients on its waiting list that are matches for a heart and the hospital turns the heart down, UNOS counts it as three turndowns.

That's wrong, said Dr. Wayne E. Richenbacher, director of the heart transplant program at the University of Iowa Hospital.

"If you're offered a heart and turn it down, that's the end of it," he said. "That's one offer and one refusal."

Dean F. Kappel, president of Mid-America Transplant Services in St. Louis, said he would like to see medical and nonmedical turndown figures made public after being reviewed by the transplant centers. Kappel serves on the UNOS board of directors.

"I think it's really unacceptable if programs are consistently turning organs down," he said.

Contractor keeps government in dark on transplant data

By DAVE DAVIS
and TED WENDLING
PLAIN DEALER REPORTER

RICHMOND, Va. — For nearly two hours, Judith B. Braslow waited impatiently outside the closed meeting room as board members of the United Network for Organ Sharing met in executive session recently in Boston.

"I'm furious," she told anyone who would listen. "I can't believe they're doing this."

As director of the U.S. Department of Health and Human Services' Division of Organ Transplantation, Braslow heads an agency that regulates UNOS and supplied the nonprofit organization with about 18 percent of its $13.1 million in revenue in 1995, according to UNOS' most recent income tax return.

In the curious world of transplantation, that hasn't given her the access she believes she is due.

"There's a lot of tension right now between the government and UNOS," Braslow said. "And that tension centers on where does our authority stop, and what do we have the right to get and what don't we have the right to get."

In recent months, the Richmond contractor has repeatedly told the government what it doesn't have the right to get: data on transplant centers' turndowns of organ offers, access to records and meetings of UNOS' Council on Organ Availability and, on occasion, even minutes of UNOS' public board and committee meetings.

Dr. James F. Burdick, a transplant surgeon and UNOS' president, acknowledged that tension exists between UNOS and Braslow's office. "I think there are people in the government who would like UNOS to be a lot less private," he said.

UNOS, which was formed in 1986 as part of a public/private partnership intended to manage the acquisition and distribution of the nation's scarce supply of donated organs, has made itself indispensable to the government. But after years of allowing UNOS to operate a system in which compliance is voluntary and failing to enforce a key provision in one of its contracts with UNOS, Braslow's office increasingly finds itself helpless when UNOS says no.

Some people think the government has abdicated its responsibility.

"You can't delegate public policy to a private contractor," said Dr. John P. Roberts, a liver transplant surgeon at the University of California at San Francisco. "You can't have the people who are in control — essentially competitors — make policy."

UNOS Executive Director Walter K. Graham disagrees.

"I personally believe that the essence of democracy is self-regulation," he said. "That's what we do in this country ... and that's what UNOS does, so I think it's a very good reflection of the whole principle of democracy in this country."

UNOS owes its clout to a pair of three-year contracts it renewed last month for a total of $6.07 million. Administered by HHS, one contract allows UNOS to operate the Organ Procurement and Transplantation Network, a 24-hour organ-placement system that matches donor organs with waiting patients. The other gives UNOS authority to run the Scientific Registry of Transplant Recipients, a database of medical information on people who receive transplants.

Those contracts have allowed UNOS to become the transplant community's most powerful player: a tax-exempt organization whose members include 281 hospital transplant programs, 55 laboratories, 66 organ banks and 29 medical/scientific organizations.

UNOS, which enjoys the overwhelming support of those involved in organ transplantation in the United States, is governed by a physician-dominated, 39-member board of directors that includes 11 members of the pub-

lic. Board members also include representatives from each of UNOS' 11 geographic regions.

Most decisions are reached by consensus through meetings of the 21 committees UNOS operates. Board members, who are not compensated but are reimbursed for expenses, also hire the executive staff, who run the day-to-day operations of the 164-employee organization.

Ninety percent of UNOS' budget comes from the two government contracts and the $340-per-person computer registration fee that patients or their insurers pay to be placed on the national waiting list. The remaining 10 percent comes from member fees and other activities.

The national waiting list contains more than 50,000 registrations and receives about 7,000 new registrations a year.

Graham and other UNOS officials criticize the government for failing to pass regulations that would give UNOS legal authority to prohibit poor-performing transplant programs from receiving organs and take enforcement action against members who violate UNOS' guidelines.

But although Graham says the lack of regulations has left UNOS executives with "our hands tied behind our backs" because virtually all policies governing transplantation are voluntary, he and other UNOS officials adamantly opposed a recent move by HHS Secretary Donna Shalala to impose federal regulations on UNOS members.

Graham said UNOS was not objecting to government regulation per se, but said HHS' proposed rules "will basically do away with our standards ... so there is a huge philosophical difference."

While some HHS officials have become frustrated at their inability to force UNOS to provide data, some of those conflicts are due to the government's own inaction. A case in point is the OPTN contract, which, until it was rewritten last month, required UNOS "to establish an on-line data capability ... so that [HHS] shall have immediate access to OPTN data."

But government officials have never had that access. The reason? Braslow, citing a small staff and lack of technological expertise within her department, says she has never "exercised" that clause in the contract.

"It doesn't do me any good to have that on-line capability if I'm not going to use it," she said. "We can get whatever information we need. If I want to know how many people were transplanted in 1995 that have blue shirts, a mustache and a beard in the western half of this country, I can get that information [from UNOS], and I can probably get it within 24 hours."

Braslow made those comments last summer. Since then, UNOS has repeatedly denied requests by her office for data listing the reasons transplant programs turn down organ offers. The Plain Dealer requested the information under the Freedom of Information Act for centers that transplant hearts, lungs, kidneys, pancreases and livers.

Last July, Braslow, Deputy Director Remy Aronoff and attorney David Benor agreed to request the data from UNOS and provide it to The Plain Dealer.

They backed down when UNOS objected to the newspaper's request. After the paper appealed the denial, Braslow made a written demand to UNOS for the data. On Jan. 15, Graham said no.

UNOS officials have repeatedly contended that the data are "misleading" and "meaningless" indicators of transplant centers' quality.

After several discussions with UNOS officials, however, Aronoff stated in different terms what he believed was UNOS' objection to release of the data.

"I had asked for the data you requested ... [but] they don't want to give us the data for the purpose that we're asking for it," Aronoff said. "They think if it's given out and publicized, it will jeopardize their ability to get that same data from their sources."

"Because it's potentially embarrassing?" Aronoff was asked.

"Well, yeah, right."

Photos and Captions Omitted

FFERS OF HEARTS REFUSED FOR NONMEDICAL REASONS

Between June 1, 1994, and Dec. 31, 1994, the nation's transplant centers turned away about 83 percent of the offers of hearts matched to their patients. Nearly nine out of 10 times they did so based on a medical judgment, such as the recipient was too ill or the donor was the wrong size or weight. Most programs also refused heart offers for nonmedical reasons - because the surgeon was unavailable, the hospital was too busy or for some other administrative reason. This chart includes only hospitals that received 12 or more heart offers during the last seven months of 1994, the latest period for which such information is available.

TOP 20

	Hospital, City, State	Heart offers	Transplanted	Refused	Refused nonmedical	Percent refused nonmedical	Patients waiting
1	University of Kansas, Kansas City, KS	47	0	47	32	68.09	17
2	University of Maryland, Baltimore, MD	13	2	11	7	53.85	18
3	William Beaumont, Royal Oak, MI	106	1	105	52	49.06	23
4	Vanderbilt University, Nashville, TN	112	19	93	46	41.07	30
5	University, Lexington, KY	29	8	21	10	34.48	10
6	University of Iowa, Iowa City, IA	72	6	66	24	33.33	18
7	Henry Ford, Detroit, MI	37	10	27	12	32.43	17
8	Latter-Day Saints, Salt Lake City, UT	20	6	14	6	30	13
9	Methodist, Dallas, TX	18	2	16	5	27.78	6
10	University of Wisconsin, Madison, WI	59	32	27	16	27.12	39
11	St. Thomas, Nashville, TN	56	11	45	15	26.79	48
12	Johns Hopkins, Baltimore, MD	27	7	20	7	25.93	21
13	University of Alabama, Birmingham, AL	88	24	64	22	25	23
13	Hartford, Hartford, CT	20	7	13	5	25	19
13	University of Utah, Salt Lake City, UT	20	10	10	5	25	18
16	St. Francis, Tulsa, OK	25	9	16	6	24	20
17	Jackson Memorial, Miami, FL	71	9	62	17	23.94	13
18	Jewish, Louisville, KY	140	12	128	33	23.57	40
19	Newark Beth Israel, Newark, NJ	68	12	56	14	20.59	12
20	University, Denver, CO	35	17	18	7	20	13

BOTTOM 20

	Hospital, City, State	Heart offers	Transplanted	Refused	Refused nonmedical	Percent refused nonmedical	Patients waiting
0	Sacred Heart, Spokane, WA	98	10	88	2	2.04	4
1	St. Joseph's, Atlanta, GA	58	9	49	1	1.72	35
2	Methodist, Indianapolis, IN	66	12	54	1	1.52	37
3	University of Virginia, Charlottesville, VA	73	20	53	1	1.37	34
4	Stanford University, Palo Alto, CA	435	22	413	3	0.69	33
5	Cleveland Clinic, Cleveland	303	36	267	1	0.33	42
6	Children's of Los Angeles, Los Angeles, CA	32	2	30	0	0	1
6	Loma Linda University, Loma Linda, CA	27	20	7	0	0	9
6	USC-University, Los Angeles, CA	18	3	15	0	0	10
6	Tampa General, Tampa, FL	47	12	35	0	0	14
6	Rush-Presbyterian-St. Luke's, Chicago, IL	24	14	10	0	0	18
6	New England, Boston, MA	15	3	12	0	0	14
6	Brigham & Women's, Boston, MA	45	14	31	0	0	14
6	Barnes, St. Louis, MO	32	14	18	0	0	46
6	Children's, St. Louis, MO	29	13	16	0	0	12
6	University of Mississippi, Jackson, MS	12	9	3	0	0	5
6	Medical College of Ohio, Toledo	25	3	22	0	0	16
6	Medical University, Charleston, SC	20	9	11	0	0	10
6	Methodist, Houston, TX	68	14	54	0	0	19
6	University, Seattle, WA	32	5	27	0	0	15

OTHERS IN OHIO

3	Children's, Cincinnati	17	2	15	3	17.65	1
5	Ohio State University, Columbus	127	8	119	5	3.94	31
5	University of Cincinnati, Cincinnati	81	18	63	2	2.47	17

RCE: United Network for Organ Sharing

PLAIN DEALER

Cleveland Plain Dealer
Tuesday, February 4, 1997

Hospital halts transplants, doesn't tell dying patients

Third of five articles

By TED WENDLING, DAVE DAVIS and JOAN MAZZOLINI
PLAIN DEALER REPORTERS

KANSAS CITY, Kan. — Two months after Adrianne Hart entered the hospital to be evaluated for a heart transplant, her mother leaned over her hospital bed and gave the 16-year-old honor student permission to die.

"I said, 'Honey, if you see a bright light and it feels good to you, you can go. I won't be mad at you.'" Janice Hart recalled. "She couldn't talk, but I knew what she was thinking: 'You mean I'm dying?'

"I just couldn't come out and tell her that she was."

Hart's grief over Adrianne's Aug. 6, 1994, death didn't end with the funeral. A month later, her nephew, Raymond Price, 20, stricken by the same heart ailment that afflicted his cousin, was hospitalized for evaluation for a heart transplant in the same University of Kansas Medical Center intensive-care room in which Adrianne had died.

Told he had been added to the center's transplant waiting list, Raymond chose the option in November 1994 of waiting for a heart at home in King City, Mo., instead of the hospital, said his mother, Sherri Curtis. The following March, he was found dead on a waterbed in the home of a friend in nearby St. Joseph, Mo.

Hart and Curtis didn't know it, but the university's heart transplant program was dead, too. Even before Adrianne's death, it had fallen victim to an internal political struggle that saw program administrators turn down every one of the heart offers matched to patients on the center's waiting list, most of them for nonmedical reasons.

Officials at the two agencies that oversee the nation's transplant system insist that the University of Kansas Medical Center scandal was an isolated case. But their own records show that at the same time the Kansas story was unfolding in the local press, 27 other heart transplant programs around the country were turning down as many as one-fifth of their heart offers for nonmedical reasons.

Until recently, none of that information was ever made public by the United Network for Organ Sharing or the U.S. Department of Health and Human Services, and neither agency made as much as a single phone call to the programs to inquire about the high nonmedical turndown rates, officials at both agencies say. UNOS has been designated by HHS to manage organ transplantation.

In Kansas, as investigators would later conclude, patients were deceived, university officials failed to act and UNOS, lacking regulatory authority over its member institution, never notified state or federal authorities that there was a problem.

By the time Kansas' attorney general announced last August that the University of Kansas Medical Center and two foundations affiliated with the university had agreed to pay $265,000 in restitution and penalties for "egregious behavior," Hart and Curtis had heard it all.

The sisters had heard the assurances of medical center personnel that Adrianne would be added to the waiting list as soon as her health stabilized. Curtis also remembered the contradictory statements of nurses, some of whom had falsely told her that Raymond had been added to the waiting list.

"I'm angry," said Curtis, who will use part of the settlement her lawyer recently negotiated to buy a tombstone for Raymond's grave. "I'm mad because if he had gone to St. Luke's [in Kansas City, Mo.], maybe he would have lived. To let our children die just because of a businesslike, money mentality — that's what gets to us."

Internal conflict

In investigations spurred by stories in the Kansas City Star, state authorities found that between Jan. 1, 1994, and March 31, 1995, the medical center placed on its waiting list, or evaluated for placement, 38 patients who had little chance of actually receiving a heart transplant. Thirteen of those patients have died.

Patients, but no transplants

Investigators found that problems at the medical center began in the spring of 1994, when several nurses, unhappy about a departmental merger, quit and others started refusing to work overtime. As a consequence, the two heart transplant surgeons, Drs. Jon F. Moran and Clay Beggerly, began to turn down heart offers for their patients, convinced that the number of remaining staff was inadequate and that they lacked proper training in post-operative care.

Although Moran detailed his concerns in memos he sent to his superiors, the staffing issue was never adequately addressed, and Moran continued to refuse hearts, the auditors said.

"As we talked with medical center officials throughout this audit . . . clearly, no one thought it was their responsibility to inform patients about the problems that continued to plague the program," a report by the Kansas Legislative Post Audit Committee said.

Investigators found that Dr. Steven B. Gollub, the medical center's director of cardiovascular medicine, deceived patients by leading them to believe the center was doing transplants and by falsely telling some patients that they were on the waiting list.

That's what happened to Cara Lee Gardner of Emporia, Kan., in July 1994. After three months of waiting, Gardner's husband, Bill, asked Gollub to refer his wife to another hospital. According to an affidavit Cara Lee Gardner provided to the attorney general's office, Gollub turned to the heart transplant coordinator and said, "Let's get her a heart real soon."

Gardner didn't know it then, but, according to a lawsuit she filed last July, her name wasn't even on the center's waiting list at the time Gollub is alleged to have made the comment. Although she was added the next month, the suit says, she later underwent triple-bypass surgery and was taken off the list.

Gollub and other university and medical center officials declined to answer questions about the heart-transplant program, which has been closed.

"With the filing of litigation, we found ourselves in a delicate situation," university spokesman Randy Attwood said in a prepared statement. "Because of the legal element, we have declined further interviews."

Both Beggerly and Moran have left the University of Kansas. Beggerly declined to comment, but Moran, who filed a defamation lawsuit against the university and several of its officials last July, said he had been unfairly made a scapegoat.

"When I wanted to close the program at KU . . . I tried by every avenue my attorneys said was appropriate," he said. "I called UNOS, I went to the [medical center] chief of staff, I said, 'Please, let me close the program,' and I was refused permission to close the program.

"I could have resigned and I guess lots of ethicists would stand up and say . . . I was like the guard at Buchenwald. But I was trying to keep a program that had been very good either good or going, and there were other programs I was responsible for that were saving the lives of children in Kansas."

Did Budig know?

Problems at the medical center went far beyond Moran and Gollub. They extended to the office of former university Chancellor Gene A. Budig, whose name auditors placed at the top of a report listing 12 people "who were aware of problems in the heart transplant program but did nothing to address them."

Budig is now president of baseball's American League.

In an August 1995 interview with Kansas auditors, Budig said he was "not aware of any specific problems" with the heart transplant program and claimed he "wasn't aware that hearts were being turned down for other than medical reasons" until May 1995.

But state records show that between April and July 1994, Budig received four letters describing serious problems in the program. The correspondence included a June 1994 letter from Moran's lawyer, who claimed that the medical center had "refused to confirm that its heart transplant program is on inactive status, thereby misleading the patients" and violating its agreement with UNOS.

Phyllis Merhige, Budig's spokeswoman, said he would not comment.

Ads tout program

University and medical center officials refused to close the heart transplant program because colleagues in the liver and kidney transplant programs "felt firmly that any period of inactivity . . . would be harmful to our [other] transplant programs," the medical staff chief said in a June 1994 memo to Moran.

So concerned were medical center officials with the heart transplant program's image that in November 1994, six months after the center began refusing every heart offer, the university started running radio ads touting its program.

"Our transplant programs for the heart, liver, kidney and bone marrow continue to transform lives," the ad's narrator said as a heart beat in the background. "Place your trust in the area's largest medical university . . . KU Medical Center. Our doctors teach the other doctors."

By that time, Adrianne Hart was dead. So were patients Richard Miller, 61, of Topeka, Kan., and Robert J. Weingart, 44, of Kansas City.

And Lloyd Croft, 55, a carpenter who had been waiting for a new heart since 1991, was still inching his way up the waiting list. Or so he thought.

After being listed for three years, Croft said he was told by a doctor in 1994 that he wouldn't need a heart transplant immediately and would be placed on "standby," meaning he could be reactivated on the list if his condition worsened. He remained in that status until the scandal broke. He is now a patient at another hospital.

"You're under these professional people's hands, and you're trusting these people," Croft said. "They've got your life literally in their hands, and they back-stab you for a couple of dollars."

Auditors found that Croft and 13 other people who were on the waiting list between May 1994 and April 1995 were billed by the medical center for more than $418,000 in fees not covered by insurance.

UNOS didn't blow whistle

Records show that UNOS, the nonprofit contractor that develops voluntary policies for the University of Kansas Medical Center and other member transplant institutions, was aware early on that the medical center was not doing heart transplants.

Moran, the transplant surgeon who was turning down hearts, told auditors that he called UNOS in May 1994 — when the center stopped doing transplants — to try to get the program inactivated, but was told only hospital administrators had that authority. UNOS officials disputed that, telling auditors they weren't aware of any problems at the center until November 1994.

UNOS was dissuaded from pressuring the university to close the program after several conversations with Dr. George E. Pierce, a University of Kansas kidney transplant surgeon who served as the medical center's UNOS representative.

Pierce told auditors he came away from the discussions with the understanding that the medical center would be given an "'unofficial grace period' to get things straightened out."

He also maintained that "adhering to UNOS guidelines was less important than keeping the heart transplant program active."

UNOS officials also were aware that the medical center had hired Dr. Hamner Hannah, who had not assisted in enough heart transplants to be certified by UNOS, as Moran's replacement. But Pierce told auditors that after initially raising concerns about Hannah's lack of experience, UNOS officials said they "wouldn't object to Dr. Hannah and would, as Dr. Pierce said UNOS implied, 'look the other way.'"

UNOS officials have denied that claim. UNOS legal counsel Cindy H. Sommers declined to answer auditors' questions about whether UNOS allowed Hannah to operate, saying she "didn't want to get into a 'he said, she said.'"

UNOS certification standards, which are voluntary but widely accepted within transplantation, call for heart transplant surgeons to have performed or assisted in at least 20 transplants within three years. Hannah had done just eight, according to the auditors' report.

Hannah, who would not comment for this story, performed his first transplant at the university on March 25, 1995. The patient was Robert W. Trent of Wichita, Kan. Trent, 32, died the same day.

So solicitous was UNOS toward its member institution that after the Star broke the story, former UNOS Executive Director Gene A. Pierce called the medical center's George Pierce (no relation) to assure him that "UNOS didn't blow the whistle" on the medical center, George Pierce told auditors.

The Kansas surgeon went on to quote Gene Pierce of UNOS as telling him that "UNOS had to give in to the reporter's requests under the Freedom of Information Act, and that UNOS stalled on releasing the information for as long as it could," according to the auditors' report.

George Pierce of the medical center declined to comment. Gene Pierce, now retired and living in a Richmond, Va., suburb, said he didn't recall making such comments to the Kansas surgeon.

"I don't recall it exactly like George said, but I trust George so it could have been a misinterpretation or something like that, I'm really not sure," Gene Pierce said. "But we have never tried to stonewall anybody, not while I was there, and if it appeared that way it was for another reason. It certainly was not just stonewalling to stonewall."

Walter K. Graham, who was Gene Pierce's top assistant and succeeded him in 1995 as UNOS' executive director, said UNOS was not aware of the full scope of the problems at the university until after the story broke. But even had UNOS known that patients were being deceived, Graham said UNOS had no legal authority to intercede.

That has changed under a contract UNOS and the government signed Dec. 30. The contract includes a new clause that requires UNOS to monitor, investigate and report to the government any incident that "jeopardizes the health of waiting-list patients or transplant recipients."

Graham said UNOS was not in a position to do anything about the Kansas City scandal under the previous contract. He said that responsibility belonged to the hospital.

"Those are issues of fraud, they're issues of malpractice, they're issues that UNOS can not ever get involved in," he added. "We're not ever going to get involved in something like that. That's very much a local legal issue."

'Fear of public opinion'

The University of Kansas scandal also caught the attention of HHS' Division of Organ Transplantation, the agency that regulates UNOS. Director Judith B. Braslow asked UNOS to do a computer run of all times hearts were turned down at the nation's 167 heart transplant centers for the last seven months of 1994. The report showed that 28 centers had turned down for nonmedical reasons 20 percent or more of the heart offers made to them.

And that is where the government's inquiry stopped. Not one of the centers with the high turndown rates was audited, not one was even contacted, Braslow acknowledged.

"What I was interested in primarily was putting in place a system so that the same thing wouldn't happen a second time," she said. "What's done is done. The Kansas situation had come to light and I thought our role should be to ensure that this didn't happen again. And so we asked that it be referred to the [UNOS] membership and professional standards committee, which it was."

The issue was not addressed by the UNOS committee until last June, when members voted to begin sending letters of inquiry to any program that turned down 10 consecutive organ offers. As for the sticky issue of what to tell patients, the committee decided that "inactive" programs should inform their patients.

But the committee never decided how long a center could go without performing transplants before being considered inactive, nor did it decide what to do about programs that were turning down large numbers of organs for non-medical reasons and not telling their patients.

UNOS President Dr. James F. Burdick said those issues were "under careful study to determine what might be done to correct them."

"To say that UNOS was at fault there is incorrect," said Burdick, a transplant surgeon at Johns Hopkins Medical Center in Baltimore. "UNOS has done quite a bit in a general way.... UNOS doesn't take legal action against transplant centers. In fact, UNOS really doesn't have the power to cause any actual concrete negative impact.

"UNOS' punishment is really fear of public opinion of what might happen if they're not compliant."

From Moran's perspective, there has been no real punishment of the people who were responsible for what went wrong at the University of Kansas Medical Center. As a result, he doesn't foresee being a heart transplant surgeon again.

"Let me tell you: This is a dirty business," said Moran, now a cardiothoracic surgeon at Pitt County Memorial Hospital in Greenville, N.C. "I don't do transplants and I have no interest in ever being involved in transplantation again. It would have to change."

Photos and Captions Omitted

A CHRONOLOGY OF THE UNIVERSITY OF KANSAS MEDICAL CENTER'S HEART TRANSPLANT PROGRAM

THE PROGRAM

SURGEON SUSPENDED
April 13, 1994 – Dr. Jon F. Moran, one of two heart transplant surgeons at the University of Kansas Medical Center, is suspended as chairman of the Department of Cardiothoracic Surgery after he refuses to do transplants due to inadequate nursing staff.

PATIENTS MISLED
June 24, 1994 – Moran's lawyer sends a letter to university Chancellor Gene A. Budig and others, informing them that the hospital has been "misleading" heart transplant patients by refusing to tell them the program is inactive.

BUDIG RESIGNS
Aug. 1, 1994 – Budig resigns as chancellor to become president of baseball's American League.

SURGEON QUITS
Nov. 1, 1994 – Dr. Clay Beggerly resigns, leaving Moran as the hospital's only UNOS-certified heart transplant surgeon. Moran informs the United Network for Organ Sharing, the national organ donor databank, that neither he nor Beggerly will be performing heart transplants.

NO SHUTDOWN
Dec. 1, 1994 – Dr. George E. Pierce, the hospital's UNOS representative, informs UNOS that the university does not want to close the heart transplant program and that it has hired Dr. Hamner Hannah to replace Moran.

NOT ENOUGH EXPERIENCE
Jan. 24, 1995 – UNOS informs the hospital that Hannah does not meet minimum experience requirements because he has only done eight transplants.

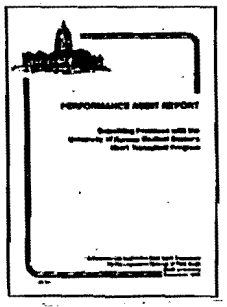
NOT UP TO STANDARDS
Feb. 21, 1995 – A UNOS committee again informs the hospital that Hannah does not meet certification criteria.

INTERVIEW REQUESTED
March 3, 1995 – Hospital officials request an interview with UNOS to discuss Hannah's qualifications.

PROGRAM SHUTS DOWN
April 7, 1995 – The hospital agrees to "voluntarily" close its heart transplant program.

MORE TURNDOWNS
May 31, 1995 – A UNOS report finds that numerous other heart transplant centers have high non-medical turndown rates. None of the centers are audited or questioned about the findings.

REVEALING REPORT
May 7, 1995 – The Kansas City Star reports that between May 1994 and March 1995, the hospital performed no heart transplants, turning down all 50 heart offers to its patients.



A CHARGE OF DECEPTION
Sept. 26, 1995 – A state audit of the hospital's heart transplant program finds that doctors and nurses deceived patients by failing to inform them that the program was inactive.

1994 | 1995 | 1996

Apr. | May | June | July | Aug. | Sept. | Oct. | Nov. | Dec. | Jan. | Feb. | Mar. | Apr. | May | June | July | Aug. | Sept. | August

SETTLEMENT FOR 15 PATIENTS
Aug. 29, 1996 – The hospital and two medical foundations agree to pay $265,000 in restitution, penalties and fees. The settlement calls for payments of $11,000 to 15 patients or their survivors.

THE PATIENTS

DIES June 30, 1994 – Emery D. Day, a machinist and welder from Topeka, Kan., dies after receiving a heart transplant on May 1, 1994. He is the last person to be transplanted at the hospital until March 25, 1995.

DIES Aug. 6, 1994 – Adrianne Hart, 16, of St. Joseph, Mo., dies while being evaluated for a heart transplant.

DIES Aug. 17, 1994 – Richard Miller, 61, of Topeka, dies while waiting for a heart.

DIES July 7, 1994 – Robert J. Weingart, 44, of Kansas City, Kan., dies while being evaluated for a heart transplant.

Hart

DIES Dec. 15, 1994 – Winifred E. Hesse, 49, of Topeka, dies while waiting for a donor heart.

DIES Feb. 4, 1995 – Gary K. Bergmann, 61, of Pleasant Hill, Mo., dies. His widow's affidavit says his cardiologist told the Bergmanns in April 1994 that Bergmann would be added to the waiting list. Bergmann dies never realizing he was not on the list.

DIES Feb. 15, 1995 – Robert M. Arslaga, 47, of Kansas City, Mo., dies while waiting for a heart.

DIES March 23, 1995 – Raymond Price, 20, of King City, Mo., dies after being sent home to wait for a new heart. He was never on the waiting list.

DIES March 25, 1995 – Robert W. Trent, 32, of Wichita, Kan., dies a few hours after Hannah, whose UNOS certification is still unresolved, performs a heart transplant on him.

Price

Cleveland Plain Dealer
Monday, February 3, 1997

Hospitals reject healthy hearts

Waiting patients not told

Second of five articles

By DAVE DAVIS, JOAN MAZZOLINI and TED WENDLING
PLAIN DEALER REPORTERS

ROYAL OAK, Mich. — The sum of Patti Szuber's donated parts was two eyes, two kidneys, a liver, 30 bone and tissue samples, and one beating heart.

In a wrenching, bittersweet story of love and death, the heart of the 22-year-old nursing student went to her father, and it made Michigan tree farmer Chester Szuber the most famous heart transplant recipient in America.

Patti Szuber's tragic death in a car accident in Tennessee in August 1994 and the transplantation of her heart into the chest of her ailing 58-year-old father also thrust the suburban Detroit hospital at which the surgery was performed into the national spotlight.

Chester Szuber had been waiting four years for a transplant, and William Beaumont Hospital in Royal Oak was inundated with calls from reporters and TV producers who wanted to tell the family's heartbreaking story.

But what Beaumont officials never told Szuber or any of the other 23 patients on their waiting list in 1994 was that the national shortage of donor organs wasn't the only reason they had been waiting so long for new hearts.

That year, Beaumont staff turned down for nonmedical reasons 101 offers of hearts suitable for transplant. The reasons for the turndowns, as reported to the United Network for Organ Sharing by the organ banks that offered the hearts to Beaumont, were either "surgeon unavailable/program too busy" or "administrative."

Another 76 heart offers were turned down by Beaumont administrators in 1994 for medical reasons. They accepted just one — Patti Szuber's.

Beaumont wasn't the only program that was turning down heart offers for nonmedical reasons that year. While transplant professionals were publicly lamenting the shortage of donor organs, 28 of the nation's 167 heart transplant centers refused for nonmedical reasons 20 percent or more of the total heart offers they received during the last seven months of 1994, according to UNOS records. About 97 percent of those hearts were later transplanted into patients at other hospitals, a UNOS official said.

"I'm surprised that the numbers are that high," said Thomas H. Murray, director of the Center of Biomedical Ethics at Case Western Reserve University and one of several ethicists and doctors who said they were unaware of the practice. "You'd like to know what the circumstances were ... but if they can't give good reasons, it's troubling.

"You can count me among those who were surprised to hear that it happens at all. I assumed it was extremely rare, and it ought to be extremely rare."

Transplant professionals say a hospital's rate of turning down organs for nonmedical reasons is just one factor that patients should consider when choosing a hospital. Other important factors are a hospital's mortality rate and the median length of time its patients must wait before being transplanted.

A center's high nonmedical turndown rate also doesn't necessarily translate into longer median waiting times for patients. In some cases, a high rate of turning down organs for nonmedical reasons simply reflects the size of a program and the resources the hospital has devoted to transplantation.

For example, of the 806 offers of hearts turned away for nonmedical reasons during the last seven months of 1994, many were refused by smaller programs, such as Beaumont's, which has just one transplant team. That means vacations, medical conferences and other cardiac surgeries that might call any member of the team away forced those centers to turn down hearts they otherwise might have accepted for waiting patients.

More recent turndown data could not be obtained because UNOS, the government contractor responsible for allocating donated organs, has refused to give 1995 and 1996 organ turndown figures for individual hospitals to the U.S. Department of Health and Human Services.

UNOS officials claim that transplant centers have not reviewed the figures and that the data may have been inaccurately or nonuniformly reported by the nation's 66 organ banks. They also fear that making the data public would discourage centers from voluntarily providing information, provoke lawsuits and change the way the data is reported in the future, rendering it scientifically useless.

Beaumont — which has done an average of just 2.6 heart transplants a year since its program opened in 1989 — had the third highest percentage of nonmedical turndowns in the country during

the last seven months of 1994. During that time, Beaumont turned down 52 offers of hearts for nonmedical reasons, an average of more than two per patient, UNOS records show.

In an interview in October, Beaumont administrators disputed the accuracy of the turndown figures. But last month, after referring the matter to the hospital's peer review committee, they confirmed that the figures were correct.

Hospital officials would not reveal the results of the committee's report, which was completed in December, but said they had addressed the problems and had not turned down any hearts in 1996 for nonmedical reasons.

"Nonmedical turndowns of hearts is something that we don't find acceptable around here, at least anymore," said hospital spokesman Mike Killian. "The issue is that it shouldn't have been done in the first place."

Beaumont administrators attributed part of the problem to the busy schedule of Dr. Jeffrey M. Altshuler, the hospital's only heart transplant surgeon. Altshuler performs about 230 heart surgeries a year, or about four a week. When a heart is offered, he often must be available to remove as well as transplant it.

"The big problem in having one transplant surgeon is when I go on vacation ... what happens to the recipients?" Altshuler said. "We've made arrangements with other transplant programs now that if I'm gone for a week, we call them ... and they will cover for us."

Beaumont officials would not say whether any of the patients for whom hearts had been refused died without receiving a transplant. Because patient information is confidential, The Plain Dealer was unable to identify Beaumont patients or their survivors to interview for this story.

Patients not told

In a practice officials at Beaumont and some other hospitals said was universal, Beaumont did not tell any of the patients on its waiting list about the nonmedical turndowns. That deprived them of the choice of transferring to another heart transplant program.

Patients at Beaumont and elsewhere generally also aren't aware that transplant centers turn down most of the hearts they are offered for important medical reasons, such as the recipient was too ill or the donor's size or weight were incompatible with the recipient.

"There are always exceptions, but as a general practice, patients are not told about [organ] turndowns," said Dr. Leslie Rocher, Beaumont's director of transplantation services. "It doesn't add to their well-being."

Some medical ethicists disagree. Jeffrey M. Prottas, a UNOS ethics committee member, even goes a step further — advocating that patients be given turndown data when they are deciding where to have a transplant, rather than after they are already hospitalized.

"Whenever I have my say on this issue, I say that UNOS ought to be publishing all of this," said Prottas, who teaches health politics at Brandeis University in Waltham, Mass. "It's really unfair. Everybody should know these sorts of things."

But they don't — particularly when organs are turned down for nonmedical reasons. Officials at Ohio State University Hospital, Vanderbilt University Medical Center and other transplant centers around the country all said they don't tell patients about nonmedical turndowns.

As a consequence, patients at Vanderbilt didn't know in 1994 that 41 percent of the heart offers were being turned down for nonmedical reasons while the head of the Nashville, Tenn., hospital's heart transplant program, Bill Frist, was campaigning for the U.S. Senate.

Vanderbilt refused 93 offers of hearts in the last seven months of 1994, 46 of them for nonmedical reasons, according to UNOS data.

Frist, who was elected to the Senate that year, declined to comment for this story. Since becoming a senator, he has remained involved in transplant issues and, along with Ohio Sen. Michael DeWine, founded the Congressional Task Force on Organ and Tissue Donation.

It is unclear how many of the nonmedical turndowns are attributable to Frist's absence, but hospital officials said that when he took a leave from Vanderbilt in late 1993, they were left short-staffed.

"When Frist left, it left two guys doing everything — all the adult heart surgery, all the adult thoracic surgery, and all the transplants," said Dr. Richard N. Pierson III, the current director of Vanderbilt's heart transplant program. "When I got here, I got that [turndown] list from our cardiologist, who was unhappy that we had had to turn down organs because we didn't have enough people."

Pierson conceded that Vanderbilt turned down organs for nonmedical reasons before he arrived in July 1994, but he disputed UNOS data stating that 39 of the 46 heart offers Vanderbilt turned down from July to the end of 1994 were because a surgeon was unavailable or the program was too busy. He said just one heart was turned down in 1994 because a surgeon was unavailable — in August of that year, while he was on vacation.

"Every program turns down organs," said Dr. John R. Wilson, director of Vanderbilt's heart failure program. "Whenever you have limited numbers of surgeons and you have patients on the waiting lists, you would not like to see any organ turned down. But that's just not a realistic expectation of any program. There is no program in this country that can guarantee that every organ that's acceptable is taken."

Aware of problems

Although heart transplant patients are not aware that many hospitals routinely turn down heart offers for nonmedical reasons, officials at UNOS and the Division of Organ Transplantation have known about the practice for almost two years.

In March 1995, prompted by questions about heart turndowns at the University of Kansas Medical Center, government officials asked UNOS to compile refusal data on each of the nation's 167 heart transplant programs.

The report, covering the last seven months of 1994, showed that the programs turned away for nonmedical reasons nearly 12 percent of all heart offers.

"Besides Kansas, there were a number of other heart transplant programs with high refusal rates," a Division of Organ Transplantation official wrote in an internal report. The report also said the turndown behavior at one hospital — Beaumont — appeared to fit the same "profile" as the University of Kansas.

The identification of that profile stemmed from a front-page story in the Kansas City Star in May 1995. The story reported that from April 1994 to March 1995, the center turned down all 50 hearts it was offered, most for nonmedical reasons.

Subsequent stories speculated that the turndowns may have contributed to the deaths of three patients, prompting an investigation by the state attorney general, numerous lawsuits and, ultimately, closure of the transplant program.

But information about Beaumont and the other hospitals with high heart-refusal rates was never made public, and federal regulators never pursued the matter, concluding that it was an unfortunate anomaly.

"There are about 850 transplant programs in the country . . . and one, maybe two, have been brought to our attention as problems," said Judith B. Braslow, who heads HHS' Division of Organ Transplantation. "We do 19,000 to 20,000 transplants a year. We're talking about very small numbers. That's not to say patients should have been treated this way."

But according to Braslow and her deputy, Remy Aronoff, no one, including anyone from UNOS, ever even questioned Beaumont or any of the other programs with high refusal rates.

One reason Beaumont wasn't scrutinized, according to Aronoff, was because the hospital's 1995 heart turndown figures improved over 1994. Beaumont's nonmedical turndown rate dropped from 50 percent in 1994 to 33 percent in 1995.

"That put them in a category with a lot of other programs, so we didn't pursue it further," Aronoff said.

Although previous contracts did not require UNOS to report potential problems to the government, a new contract UNOS and HHS signed Dec. 30 requires UNOS to monitor, investigate and report any incident "that jeopardizes the health of waiting list patients or transplant recipients."

Because few people are aware that hospitals turn down donor organs, few have been advocating that patients be told. The exceptions are the patients and families who waited in vain for hearts at the University of Kansas Medical Center.

"I absolutely believe that patients or their families have a right to know what's going on so they can discuss it and make better decisions," said Loetta DeWalt, whose husband died before he could receive a heart transplant at the medical center. "We were not told anything."

Teddy DeWalt, 60, a retired Kansas City firefighter, endured months of poking and prodding with the hope of getting a new heart. But in February 1994, while he was being evaluated for a transplant, his enlarged heart failed.

"He was told that it was time to go on life support," his wife recalled. "At the last minute, he changed his mind, which was probably just as well since he would have been going to a place where they weren't even doing transplants.

"He died 10 minutes later."

Keeping secrets

With the exception of data involving Beaumont, UNOS officials have refused to release to the federal government or the public 1995 and 1996 figures showing how many hearts individual hospitals turned down for nonmedical reasons. They also have refused to release turndown data for other types of donor organs.

UNOS President Dr. James F. Burdick, a transplant surgeon at Johns Hopkins Hospital in Baltimore, said turndown figures were "not a very useful statistic" and should not be used to judge transplant center performance.

"If you want [to use the data] to say such-and-such center wasn't doing things right, I'm telling you, you're on thin ice there," Burdick said.

He added that giving patients information on organ refusals and median waiting times at transplant centers "don't help patients very much because, lo and behold, everybody's doing an excellent job.

"I think that in the big picture, the issue of releasing the data to patients is an idea that would be designed to fix something that isn't a big problem . . . If you're trying to talk about ways to help patients understand the national system, we've got many ways that we can help patients more than by giving them this data."

One way UNOS helps patients, Burdick and others say, is by publishing survival rates for all transplant centers in the United States. But that information is based on transplants performed five or more years ago. An updated survival report is due out this summer.

The limited data UNOS and the government have been willing to release shows that the problem of nonmedical turndowns of hearts has worsened since 1994.

On average, in the last seven months of 1994, centers refused for nonmedical reasons nearly 12 percent of all heart offers.

By the next year, that rate had increased to 25 percent. And in the first quarter of 1996, it had dipped slightly, but was still at 19 percent.

Not all transplant centers turn down large numbers of hearts for nonmedical reasons, however. Seventy-one hospitals managed to

keep refusals for nonmedical reasons below 5 percent, according to the 1994 data. They included the Cleveland Clinic, where just 0.33 percent of the heart offers were refused for nonmedical reasons.

Dr. Robert W. Stewart, head of the Clinic's heart transplant program, attributed that number to the resources available at the Clinic, which performed 74 heart transplants in 1996, more than all but three other centers.

"We almost never would have to turn down a heart because we don't have the manpower," Stewart said. "You cannot, in a smaller institution, have the privilege of having three separate teams. If you're just completing a transplant and they call you with another donor, you're probably not going to be able to use the people who are already doing that particular procedure. You're going to have to have an entirely new team standing in the wings."

Defining 'inactive'

Last summer, UNOS adopted a policy that calls for letters of inquiry to be sent to any program that turns down 10 consecutive organs. After some debate, it also decided that programs found to be "inactive" should inform their patients.

Left unaddressed were the issues of how long a center could go without performing transplants before being considered inactive, and what to do about programs that weren't technically inactive but were turning down large numbers of organs and not telling their patients.

UNOS Executive Director Walter K. Graham would not say whether UNOS had sent letters of inquiry to any of its members.

Braslow, director of the Division of Organ Transplantation, supported the policy, but said she was not entirely satisfied.

"To me, it is unconscionable that a program should be inactive and the patients not be notified," she said. "There isn't one of us who would sit still for that if it were our spouse or our kid."

Many donated organs are never transplanted

By TED WENDLING
STAFF WRITER

In phone conversations often held at night, organ bank donation specialists and hospital organ procurement coordinators carefully go over a standardized checklist.

Did the next-of-kin give written consent for donation? How did the donor die? Does the donor have a history of cigarette, alcohol or IV drug use? What medications were administered before the donor died?

Those and many other questions are asked of doctors, nurses and donors' families before an organ bank decides whether to offer an organ for transplantation. The information is then entered into the computer system of the United Network for Organ Sharing, which matches it against thousands of potential recipients on the national transplant waiting list. The matching process numerically ranks potential recipients based on their distance from the donor organ, the number of days they have waited, their medical status and other factors.

For a variety of reasons, many donated organs are never transplanted. For those that are, once the hospital verifies that a transplant was performed, the UNOS computer generates a form listing all potential recipients and sends it to the organ bank that procured the organ. The organ bank is required to show that the organ was offered to every patient ranked above the recipient, and to report the reason each hospital turned it down.

Collecting such data ensures that patients ranked higher on the waiting list were not skipped over because someone lower received unwarranted consideration.

Organs are rarely accepted on behalf of the first patient on the list. In 1995, for example, donor hearts were turned down by hospitals an average of six times before being transplanted. Three out of four times, they were turned down for medical reasons — ranging from issues related to the quality of the organ or the donor's social history to the recipient's immediate need for a multiple organ transplant.

The nation's 66 organ banks reported that another 3,448 heart offers — representing one-quarter of the 13,801 that were refused in 1995 — were turned down for nonmedical reasons, either because a surgeon was unavailable, the program was too busy or for other administrative reasons.

Some transplant physicians disagree with the way UNOS tallies turndown data. If, for instance, a hospital has three ranked patients on its waiting list that are matches for a heart and the hospital turns the heart down, UNOS counts it as three turndowns.

That's wrong, said Dr. Wayne E. Richenbacher, director of the heart transplant program at the University of Iowa Hospital.

"If you're offered a heart and turn it down, that's the end of it," he said. "That's one offer and one refusal."

Dean F. Kappel, president of Mid-America Transplant Services in St. Louis, said he would like to see medical and nonmedical turndown figures made public after being reviewed by the transplant centers. Kappel serves on the UNOS board of directors.

"I think it's really unacceptable if programs are consistently turning organs down," he said.

Contractor keeps government in dark on transplant data

By DAVE DAVIS
and TED WENDLING
PLAIN DEALER REPORTER

RICHMOND, Va. — For nearly two hours, Judith B. Braslow waited impatiently outside the closed meeting room as board members of the United Network for Organ Sharing met in executive session recently in Boston.

"I'm furious," she told anyone who would listen. "I can't believe they're doing this."

As director of the U.S. Department of Health and Human Services' Division of Organ Transplantation, Braslow heads an agency that regulates UNOS and supplied the nonprofit organization with about 18 percent of its $13.1 million in revenue in 1995, according to UNOS' most recent income tax return.

In the curious world of transplantation, that hasn't given her the access she believes she is due.

"There's a lot of tension right now between the government and UNOS," Braslow said. "And that tension centers on where does our authority stop, and what do we have the right to get and what don't we have the right to get."

In recent months, the Richmond contractor has repeatedly told the government what it doesn't have the right to get: data on transplant centers' turndowns of organ offers, access to records and meetings of UNOS' Council on Organ Availability and, on occasion, even minutes of UNOS' public board and committee meetings.

Dr. James F. Burdick, a transplant surgeon and UNOS' president, acknowledged that tension exists between UNOS and Braslow's office. "I think there are people in the government who would like UNOS to be a lot less private," he said.

UNOS, which was formed in 1986 as part of a public/private partnership intended to manage the acquisition and distribution of the nation's scarce supply of donated organs, has made itself indispensable to the government. But after years of allowing UNOS to operate a system in which compliance is voluntary and failing to enforce a key provision in one of its contracts with UNOS, Braslow's office increasingly finds itself helpless when UNOS says no.

Some people think the government has abdicated its responsibility.

"You can't delegate public policy to a private contractor," said Dr. John P. Roberts, a liver transplant surgeon at the University of California at San Francisco. "You can't have the people who are in control — essentially competitors — make policy."

UNOS Executive Director Walter K. Graham disagrees.

"I personally believe that the essence of democracy is self-regulation," he said. "That's what we do in this country ... and that's what UNOS does, so I think it's a very good reflection of the whole principle of democracy in this country."

UNOS owes its clout to a pair of three-year contracts it renewed last month for a total of $6.07 million. Administered by HHS, one contract allows UNOS to operate the Organ Procurement and Transplantation Network, a 24-hour organ-placement system that matches donor organs with waiting patients. The other gives UNOS authority to run the Scientific Registry of Transplant Recipients, a database of medical information on people who receive transplants.

Those contracts have allowed UNOS to become the transplant community's most powerful player: a tax-exempt organization whose members include 281 hospital transplant programs, 55 laboratories, 66 organ banks and 29 medical/scientific organizations.

UNOS, which enjoys the overwhelming support of those involved in organ transplantation in the United States, is governed by a physician-dominated, 39-member board of directors that includes 11 members of the pub-

lic. Board members also include representatives from each of UNOS' 11 geographic regions.

Most decisions are reached by consensus through meetings of the 21 committees UNOS operates. Board members, who are not compensated but are reimbursed for expenses, also hire the executive staff, who run the day-to-day operations of the 164-employee organization.

Ninety percent of UNOS' budget comes from the two government contracts and the $340-per-person computer registration fee that patients or their insurers pay to be placed on the national waiting list. The remaining 10 percent comes from member fees and other activities.

The national waiting list contains more than 50,000 registrations and receives about 7,000 new registrations a year.

Graham and other UNOS officials criticize the government for failing to pass regulations that would give UNOS legal authority to prohibit poor-performing transplant programs from receiving organs and take enforcement action against members who violate UNOS' guidelines.

But although Graham says the lack of regulations has left UNOS executives with "our hands tied behind our backs" because virtually all policies governing transplantation are voluntary, he and other UNOS officials adamantly opposed a recent move by HHS Secretary Donna Shalala to impose federal regulations on UNOS members.

Graham said UNOS was not objecting to government regulation per se, but said HHS' proposed rules "will basically do away with our standards ... so there is a huge philosophical difference."

While some HHS officials have become frustrated at their inability to force UNOS to provide data, some of those conflicts are due to the government's own inaction. A case in point is the OPTN contract, which, until it was rewritten last month, required UNOS "to establish an on-line data capability ... so that [HHS] shall have immediate access to OPTN data."

But government officials have never had that access. The reason? Braslow, citing a small staff and lack of technological expertise within her department, says she has never "exercised" that clause in the contract.

"It doesn't do me any good to have that on-line capability if I'm not going to use it," she said. "We can get whatever information we need. If I want to know how many people were transplanted in 1995 that have blue shirts, a mustache and a beard in the western half of this country, I can get that information [from UNOS], and I can probably get it within 24 hours."

Braslow made those comments last summer. Since then, UNOS has repeatedly denied requests by her office for data listing the reasons transplant programs turn down organ offers. The Plain Dealer requested the information under the Freedom of Information Act for centers that transplant hearts, lungs, kidneys, pancreases and livers.

Last July, Braslow, Deputy Director Remy Aronoff and attorney David Benor agreed to request the data from UNOS and provide it to The Plain Dealer.

They backed down when UNOS objected to the newspaper's request. After the paper appealed the denial, Braslow made a written demand to UNOS for the data. On Jan. 15, Graham said no.

UNOS officials have repeatedly contended that the data are "misleading" and "meaningless" indicators of transplant centers' quality.

After several discussions with UNOS officials, however, Aronoff stated in different terms what he believed was UNOS' objection to release of the data.

"I had asked for the data you requested ... [but] they don't want to give us the data for the purpose that we're asking for it," Aronoff said. "They think if it's given out and publicized, it will jeopardize their ability to get that same data from their sources."

"Because it's potentially embarrassing?" Aronoff was asked.

"Well, yeah, right."

Photos and Captions Omitted

FFERS OF HEARTS REFUSED FOR NONMEDICAL REASONS

Between June 1, 1994, and Dec. 31, 1994, the nation's transplant centers turned away about 83 percent of the offers of hearts matched to their patients. Nearly nine out of 10 times they did so based on a medical judgment, such as the recipient was too ill or the donor was the wrong size or weight. Most programs also refused heart offers for nonmedical reasons - because the surgeon was unavailable, the hospital was too busy or for some other administrative reason. This chart includes only hospitals that received 12 or more heart offers during the last seven months of 1994, the latest period for which such information is available.

OP 20

	Hospital, City, State	Heart offers	Transplanted	Refused	Refused nonmedical	Percent refused nonmedical	Patients waiting
1	University of Kansas, Kansas City, KS	47	0	47	32	68.09	17
2	University of Maryland, Baltimore, MD	13	2	11	7	53.85	18
3	William Beaumont, Royal Oak, MI	106	1	105	52	49.06	23
	Vanderbilt University, Nashville, TN	112	19	93	46	41.07	30
	University, Lexington, KY	29	8	21	10	34.48	10
	University of Iowa, Iowa City, IA	72	6	66	24	33.33	18
	Henry Ford, Detroit, MI	37	10	27	12	32.43	17
	Latter-Day Saints, Salt Lake City, UT	20	6	14	6	30	13
	Methodist, Dallas , TX	18	2	16	5	27.78	6
	University of Wisconsin, Madison, WI	59	32	27	16	27.12	39
	St. Thomas, Nashville, TN	56	11	45	15	26.79	48
	Johns Hopkins, Baltimore, MD	27	7	20	7	25.93	21
	University of Alabama, Birmingham, AL	88	24	64	22	25	23
3	Hartford, Hartford, CT	20	7	13	5	25	19
3	University of Utah, Salt Lake City , UT	20	10	10	5	25	18
6	St. Francis, Tulsa, OK	25	9	16	6	24	20
7	Jackson Memorial, Miami, FL	71	9	62	17	23.94	13
8	Jewish, Louisville, KY	140	12	128	33	23.57	40
9	Newark Beth Israel, Newark, NJ	68	12	56	14	20.59	12
0	University, Denver, CO	35	17	18	7	20	13

OTTOM 20

	Hospital, City, State	Heart offers	Transplanted	Refused	Refused nonmedical	Percent refused nonmedical	Patients waiting
)	Sacred Heart, Spokane, WA	98	10	88	2	2.04	4
1	St. Joseph's, Atlanta, GA	58	9	49	1	1.72	35
2	Methodist, Indianapolis, IN	66	12	54	1	1.52	37
3	University of Virginia, Charlottesville, VA	73	20	53	1	1.37	34
4	Stanford University, Palo Alto, CA	435	22	413	3	0.69	33
5	Cleveland Clinic, Cleveland	303	36	267	1	0.33	42
6	Children's of Los Angeles, Los Angeles, CA	32	2	30	0	0	1
6	Loma Linda University, Loma Linda, CA	27	20	7	0	0	9
6	USC-University, Los Angeles, CA	18	3	15	0	0	10
6	Tampa General, Tampa, FL	47	12	35	0	0	14
6	Rush-Presbyterian-St. Luke's, Chicago, IL	24	14	10	0	0	18
6	New England, Boston, MA	15	3	12	0	0	14
6	Brigham & Women's, Boston, MA	45	14	31	0	0	14
6	Barnes, St. Louis, MO	32	14	18	0	0	46
6	Children's , St. Louis, MO	29	13	16	0	0	12
6	University of Mississippi, Jackson, MS	12	9	3	0	0	5
6	Medical College of Ohio, Toledo	25	3	22	0	0	16
6	Medical University, Charleston, SC	20	9	11	0	0	10
6	Methodist, Houston, TX	68	14	54	0	0	19
6	University, Seattle, WA	32	5	27	0	0	15

THERS IN OHIO

Children's, Cincinnati	17	2	15	3	17.65	1
Ohio State University, Columbus	127	8	119	5	3.94	31
University of Cincinnati, Cincinnati	81	18	63	2	2.47	17

RCE: United Network for Organ Sharing

PLAIN DEALER

Cleveland Plain Dealer
Tuesday, February 4, 1997

Hospital halts transplants, doesn't tell dying patients

Third of five articles

By TED WENDLING, DAVE DAVIS and JOAN MAZZOLINI
PLAIN DEALER REPORTERS

KANSAS CITY, Kan. — Two months after Adrianne Hart entered the hospital to be evaluated for a heart transplant, her mother leaned over her hospital bed and gave the 16-year-old honor student permission to die.

"I said, 'Honey, if you see a bright light and it feels good to you, you can go. I won't be mad at you.'" Janice Hart recalled. "She couldn't talk, but I knew what she was thinking: 'You mean I'm dying?'

"I just couldn't come out and tell her that she was."

Hart's grief over Adrianne's Aug. 6, 1994, death didn't end with the funeral. A month later, her nephew, Raymond Price, 20, stricken by the same heart ailment that afflicted his cousin, was hospitalized for evaluation for a heart transplant in the same University of Kansas Medical Center intensive-care room in which Adrianne had died.

Told he had been added to the center's transplant waiting list, Raymond chose the option in November 1994 of waiting for a heart at home in King City, Mo., instead of the hospital, said his mother, Sherri Curtis. The following March, he was found dead on a waterbed in the home of a friend in nearby St. Joseph, Mo.

Hart and Curtis didn't know it, but the university's heart transplant program was dead, too. Even before Adrianne's death, it had fallen victim to an internal political struggle that saw program administrators turn down every one of the heart offers matched to patients on the center's waiting list, most of them for nonmedical reasons.

Officials at the two agencies that oversee the nation's transplant system insist that the University of Kansas Medical Center scandal was an isolated case. But their own records show that at the same time the Kansas story was unfolding in the local press, 27 other heart transplant programs around the country were turning down as many as one-fifth of their heart offers for nonmedical reasons.

Until recently, none of that information was ever made public by the United Network for Organ Sharing or the U.S. Department of Health and Human Services, and neither agency made as much as a single phone call to the programs to inquire about the high nonmedical turndown rates, officials at both agencies say. UNOS has been designated by HHS to manage organ transplantation.

In Kansas, as investigators would later conclude, patients were deceived, university officials failed to act and UNOS, lacking regulatory authority over its member institution, never notified state or federal authorities that there was a problem.

By the time Kansas' attorney general announced last August that the University of Kansas Medical Center and two foundations affiliated with the university had agreed to pay $265,000 in restitution and penalties for "egregious behavior," Hart and Curtis had heard it all.

The sisters had heard the assurances of medical center personnel that Adrianne would be added to the waiting list as soon as her health stabilized. Curtis also remembered the contradictory statements of nurses, some of whom had falsely told her that Raymond had been added to the waiting list.

"I'm angry," said Curtis, who will use part of the settlement her lawyer recently negotiated to buy a tombstone for Raymond's grave. "I'm mad because if he had gone to St. Luke's [in Kansas City, Mo.], maybe he would have lived. To let our children die just because of a businesslike, money mentality — that's what gets to us."

Internal conflict

In investigations spurred by stories in the Kansas City Star, state authorities found that between Jan. 1, 1994, and March 31, 1995, the medical center placed on its waiting list, or evaluated for placement, 38 patients who had little chance of actually receiving a heart transplant. Thirteen of those patients have died.

Patients, but no transplants

Investigators found that problems at the medical center began in the spring of 1994, when several nurses, unhappy about a departmental merger, quit and others started refusing to work overtime. As a consequence, the two heart transplant surgeons, Drs. Jon F. Moran and Clay Beggerly, began to turn down heart offers for their patients, convinced that the number of remaining staff was inadequate and that they lacked proper training in post-operative care.

Although Moran detailed his concerns in memos he sent to his superiors, the staffing issue was never adequately addressed, and Moran continued to refuse hearts, the auditors said.

"As we talked with medical center officials throughout this audit . . . clearly, no one thought it was their responsibility to inform patients about the problems that continued to plague the program." a report by the Kansas Legislative Post Audit Committee said.

Investigators found that Dr. Steven B. Gollub, the medical center's director of cardiovascular medicine, deceived patients by leading them to believe the center was doing transplants and by falsely telling some patients that they were on the waiting list.

That's what happened to Cara Lee Gardner of Emporia, Kan., in July 1994. After three months of waiting, Gardner's husband, Bill, asked Gollub to refer his wife to another hospital. According to an affidavit Cara Lee Gardner provided to the attorney general's office, Gollub turned to the heart transplant coordinator and said, "Let's get her a heart real soon."

Gardner didn't know it then, but, according to a lawsuit she filed last July, her name wasn't even on the center's waiting list at the time Gollub is alleged to have made the comment. Although she was added the next month, the suit says, she later underwent triple-bypass surgery and was taken off the list.

Gollub and other university and medical center officials declined to answer questions about the heart-transplant program, which has been closed.

"With the filing of litigation, we found ourselves in a delicate situation," university spokesman Randy Attwood said in a prepared statement. "Because of the legal element, we have declined further interviews."

Both Beggerly and Moran have left the University of Kansas. Beggerly declined to comment, but Moran, who filed a defamation lawsuit against the university and several of its officials last July, said he had been unfairly made a scapegoat.

"When I wanted to close the program at KU . . . I tried by every avenue my attorneys said was appropriate," he said. "I called UNOS, I went to the [medical center] chief of staff, I said, 'Please, let me close the program,' and I was refused permission to close the program.

"I could have resigned and I guess lots of ethicists would stand up and say . . . I was like the guard at Buchenwald. But I was trying to keep a program that had been very good either good or going, and there were other programs I was responsible for that were saving the lives of children in Kansas."

Did Budig know?

Problems at the medical center went far beyond Moran and Gollub. They extended to the office of former university Chancellor Gene A. Budig, whose name auditors placed at the top of a report listing 12 people "who were aware of problems in the heart transplant program but did nothing to address them."

Budig is now president of baseball's American League.

In an August 1995 interview with Kansas auditors, Budig said he was "not aware of any specific problems" with the heart transplant program and claimed he "wasn't aware that hearts were being turned down for other than medical reasons" until May 1995.

But state records show that between April and July 1994, Budig received four letters describing serious problems in the program. The correspondence included a June 1994 letter from Moran's lawyer, who claimed that the medical center had "refused to confirm that its heart transplant program is on inactive status, thereby misleading the patients" and violating its agreement with UNOS.

Phyllis Merhige, Budig's spokeswoman, said he would not comment.

Ads tout program

University and medical center officials refused to close the heart transplant program because colleagues in the liver and kidney transplant programs "felt firmly that any period of inactivity . . . would be harmful to our [other] transplant programs," the medical staff chief said in a June 1994 memo to Moran.

So concerned were medical center officials with the heart transplant program's image that in November 1994, six months after the center began refusing every heart offer, the university started running radio ads touting its program.

"Our transplant programs for the heart, liver, kidney and bone marrow continue to transform lives," the ad's narrator said as a heart beat in the background. "Place your trust in the area's largest medical university . . . KU Medical Center. Our doctors teach the other doctors."

By that time, Adrianne Hart was dead. So were patients Richard Miller, 61, of Topeka, Kan., and Robert J. Weingart, 44, of Kansas City.

And Lloyd Croft, 55, a carpenter who had been waiting for a new heart since 1991, was still inching his way up the waiting list. Or so he thought.

After being listed for three years, Croft said he was told by a doctor in 1994 that he wouldn't need a heart transplant immediately and would be placed on "standby," meaning he could be reactivated on the list if his condition worsened. He remained in that status until the scandal broke. He is now a patient at another hospital.

"You're under these professional people's hands, and you're trusting these people," Croft said. "They've got your life literally in their hands, and they back-stab you for a couple of dollars."

Auditors found that Croft and 13 other people who were on the waiting list between May 1994 and April 1995 were billed by the medical center for more than $418,000 in fees not covered by insurance.

UNOS didn't blow whistle

Records show that UNOS, the nonprofit contractor that develops voluntary policies for the University of Kansas Medical Center and other member transplant institutions, was aware early on that the medical center was not doing heart transplants.

Moran, the transplant surgeon who was turning down hearts, told auditors that he called UNOS in May 1994 — when the center stopped doing transplants — to try to get the program inactivated, but was told only hospital administrators had that authority. UNOS officials disputed that, telling auditors they weren't aware of any problems at the center until November 1994.

UNOS was dissuaded from pressuring the university to close the program after several conversations with Dr. George E. Pierce, a University of Kansas kidney transplant surgeon who served as the medical center's UNOS representative.

Pierce told auditors he came away from the discussions with the understanding that the medical center would be given an " 'unofficial grace period' to get things straightened out."

He also maintained that "adhering to UNOS guidelines was less important than keeping the heart transplant program active."

UNOS officials also were aware that the medical center had hired Dr. Hamner Hannah, who had not assisted in enough heart transplants to be certified by UNOS, as Moran's replacement. But Pierce told auditors that after initially raising concerns about Hannah's lack of experience, UNOS officials said they "wouldn't object to Dr. Hannah and would, as Dr. Pierce said UNOS implied, 'look the other way.' "

UNOS officials have denied that claim. UNOS legal counsel Cindy H. Sommers declined to answer auditors' questions about whether UNOS allowed Hannah to operate, saying she "didn't want to get into a 'he said, she said.' "

UNOS certification standards, which are voluntary but widely accepted within transplantation, call for heart transplant surgeons to have performed or assisted in at least 20 transplants within three years. Hannah had done just eight, according to the auditors' report.

Hannah, who would not comment for this story, performed his first transplant at the university on March 25, 1995. The patient was Robert W. Trent of Wichita, Kan. Trent, 32, died the same day.

So solicitous was UNOS toward its member institution that after the Star broke the story, former UNOS Executive Director Gene A. Pierce called the medical center's George Pierce (no relation) to assure him that "UNOS didn't blow the whistle" on the medical center, George Pierce told auditors.

The Kansas surgeon went on to quote Gene Pierce of UNOS as telling him that "UNOS had to give in to the reporter's requests under the Freedom of Information Act, and that UNOS stalled on releasing the information for as long as it could," according to the auditors' report.

George Pierce of the medical center declined to comment. Gene Pierce, now retired and living in a Richmond, Va., suburb, said he didn't recall making such comments to the Kansas surgeon.

"I don't recall it exactly like George said, but I trust George so it could have been a misinterpretation or something like that, I'm really not sure," Gene Pierce said. "But we have never tried to stonewall anybody, not while I was there, and if it appeared that way it was for another reason. It certainly was not just stonewalling to stonewall."

Walter K. Graham, who was Gene Pierce's top assistant and succeeded him in 1995 as UNOS' executive director, said UNOS was not aware of the full scope of the problems at the university until after the story broke. But even had UNOS known that patients were being deceived, Graham said UNOS had no legal authority to intercede.

That has changed under a contract UNOS and the government signed Dec. 30. The contract includes a new clause that requires UNOS to monitor, investigate and report to the government any incident that "jeopardizes the health of waiting-list patients or transplant recipients."

Graham said UNOS was not in a position to do anything about the Kansas City scandal under the previous contract. He said that responsibility belonged to the hospital.

"Those are issues of fraud, they're issues of malpractice, they're issues that UNOS can not ever get involved in," he added. "We're not ever going to get involved in something like that. That's very much a local legal issue."

'Fear of public opinion'

The University of Kansas scandal also caught the attention of HHS' Division of Organ Transplantation, the agency that regulates UNOS. Director Judith B. Braslow asked UNOS to do a computer run of all times hearts were turned down at the nation's 167 heart transplant centers for the last seven months of 1994. The report showed that 28 centers had turned down for nonmedical reasons 20 percent or more of the heart offers made to them.

And that is where the government's inquiry stopped. Not one of the centers with the high turndown rates was audited, not one was even contacted, Braslow acknowledged.

"What I was interested in primarily was putting in place a system so that the same thing wouldn't happen a second time," she said. "What's done is done. The Kansas situation had come to light and I thought our role should be to ensure that this didn't happen again. And so we asked that it be referred to the [UNOS] membership and professional standards committee, which it was."

The issue was not addressed by the UNOS committee until last June, when members voted to begin sending letters of inquiry to any program that turned down 10 consecutive organ offers. As for the sticky issue of what to tell patients, the committee decided that "inactive" programs should inform their patients.

But the committee never decided how long a center could go without performing transplants before being considered inactive, nor did it decide what to do about programs that were turning down large numbers of organs for non-medical reasons and not telling their patients.

UNOS President Dr. James F. Burdick said those issues were "under careful study to determine what might be done to correct them."

"To say that UNOS was at fault there is incorrect," said Burdick, a transplant surgeon at Johns Hopkins Medical Center in Baltimore. "UNOS has done quite a bit in a general way.... UNOS doesn't take legal action against transplant centers. In fact, UNOS really doesn't have the power to cause any actual concrete negative impact.

"UNOS' punishment is really fear of public opinion of what might happen if they're not compliant."

From Moran's perspective, there has been no real punishment of the people who were responsible for what went wrong at the University of Kansas Medical Center. As a result, he doesn't foresee being a heart transplant surgeon again.

"Let me tell you: This is a dirty business," said Moran, now a cardiothoracic surgeon at Pitt County Memorial Hospital in Greenville, N.C. "I don't do transplants and I have no interest in ever being involved in transplantation again. It would have to change."

Photos and Captions Omitted

A CHRONOLOGY OF THE UNIVERSITY OF KANSAS MEDICAL CENTER'S HEART TRANSPLANT PROGRAM

THE PROGRAM

SURGEON SUSPENDED
April 13, 1994 – Dr. Jon F. Moran, one of two heart transplant surgeons at the University of Kansas Medical Center, is suspended as chairman of the Department of Cardiothoracic Surgery after he refuses to do transplants due to inadequate nursing staff.

PATIENTS MISLED
June 24, 1994 – Moran's lawyer sends a letter to university Chancellor Gene A. Budig and others, informing them that the hospital has been "misleading" heart transplant patients by refusing to tell them the program is inactive.

BUDIG RESIGNS
Aug. 1, 1994 – Budig resigns as chancellor to become president of baseball's American League.

SURGEON QUITS
Nov. 1, 1994 – Dr. Clay Beggerly resigns, leaving Moran as the hospital's only UNOS-certified heart transplant surgeon. Moran informs the United Network for Organ Sharing, the national organ donor databank, that neither he nor Beggerly will be performing heart transplants.

NO SHUTDOWN
Dec. 1, 1994 – Dr. George E. Pierce, the hospital's UNOS representative, informs UNOS that the university does not want to close the heart transplant program and that it has hired Dr. Hamner Hannah to replace Moran.

NOT ENOUGH EXPERIENCE
Jan. 24, 1995 – UNOS informs the hospital that Hannah does not meet minimum experience requirements because he has only done eight transplants.

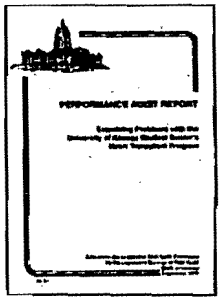
NOT UP TO STANDARDS
Feb. 21, 1995 – A UNOS committee again informs the hospital that Hannah does not meet certification criteria.

INTERVIEW REQUESTED
March 3, 1995 – Hospital officials request an interview with UNOS to discuss Hannah's qualifications.

PROGRAM SHUTS DOWN
April 7, 1995 – The hospital agrees to "voluntarily" close its heart transplant program.

MORE TURNDOWNS
May 31, 1995 – A UNOS report finds that numerous other heart transplant centers have high non-medical turndown rates. None of the centers are audited or questioned about the findings.

REVEALING REPORT
May 7, 1995 – The Kansas City Star reports that between May 1994 and March 1995, the hospital performed no heart transplants, turning down all 50 heart offers to its patients.



A CHARGE OF DECEPTION
Sept. 26, 1995 – A state audit of the hospital's heart transplant program finds that doctors and nurses deceived patients by failing to inform them that the program was inactive.

SETTLEMENT FOR 15 PATIENTS
Aug. 29, 1996 – The hospital and two medical foundations agree to pay $265,000 in restitution, penalties and fees. The settlement calls for payments of $11,000 to 15 patients or their survivors.

1994 | 1995 | 1996

Apr. | May | June | July | Aug. | Sept. | Oct. | Nov. | Dec. | Jan. | Feb. | Mar. | Apr. | May | June | July | Aug. | Sept. | August

THE PATIENTS

DIES June 30, 1994 – Emery D. Day, a machinist and welder from Topeka, Kan., dies after receiving a heart transplant on May 1, 1994. He is the last person to be transplanted at the hospital until March 25, 1995.

DIES July 7, 1994 – Robert J. Weingart, 44, of Kansas City, Kan., dies while being evaluated for a heart transplant.

DIES Aug. 6, 1994 – Adrianne Hart, 16, of St. Joseph, Mo., dies while being evaluated for a heart transplant.

DIES Aug. 17, 1994 – Richard Miller, 61, of Topeka, dies while waiting for a heart.

Hart

DIES Dec. 15, 1994 – Winifred E. Hesse, 49, of Topeka, dies while waiting for a donor heart.

DIES Feb. 4, 1995 – Gary K. Bergmann, 61, of Pleasant Hill, Mo., dies. His widow's affidavit says his cardiologist told the Bergmanns in April 1994 that Bergmann would be added to the waiting list. Bergmann dies never realizing he was not on the list.

DIES Feb. 15, 1995 – Robert M. Arslaga, 47, of Kansas City, Mo., dies while waiting for a heart.

DIES March 23, 1995 – Raymond Price, 20, of King City, Mo., dies after being sent home to wait for a new heart. He was never on the waiting list.

DIES March 25, 1995 – Robert W. Trent, 32, of Wichita, Kan., dies a few hours after Hannah, whose UNOS certification is still unresolved, performs a heart transplant on him.

Price

Cleveland Plain Dealer
Wednesday, February 5, 1997

Doctor to patient: Get out of here or you'll die waiting

Fourth of five articles

By JOAN MAZZOLINI,
TED WENDLING
and DAVE DAVIS
PLAIN DEALER REPORTERS

SAN FRANCISCO — Liver surgeon John Roberts is doing the unthinkable — telling some of his most seriously ill patients that if they don't go elsewhere, they will die waiting on his hospital's transplant list.

And if Ralph Vairo, a 60-year-old former painting contractor who lives near Santa Cruz, makes it to 61, he may owe his life to Roberts' decision.

Vairo has a cancerous tumor in his liver that will spread throughout his body and kill him if he doesn't receive a new liver soon.

His insurance company, Kaiser Permanente, contracts with the University of California at San Francisco to do liver transplants. So Vairo's doctor dutifully referred him there to see if he was a candidate for transplantation.

But when Roberts saw him in October, Vairo recalled the surgeon saying, "You need a liver. It's too long of a wait here. I'm going to recommend to your doctor and insurance company that you go someplace else."

Transplant patients are keenly aware that they may die while waiting their turn for an organ. What many don't know is that, due to wide disparities in donation rates and attempts by organ banks and transplant centers to keep locally donated organs, the waiting time for an organ varies dramatically depending on where they are treated.

Hospital administrators are not happy about Roberts telling patients to go elsewhere, he said. "The issue has to do with the fact that you're telling patients to go to other centers, not that we will do fewer transplants. We won't."

But his overriding concern is that the median waiting time for a liver in San Francisco in 1995 was 473 days — the longest in the state and third longest in the country. In contrast, the median wait at one center in Los Angeles was just 87 days.

And the difference of 386 days, for seriously ill patients such as Vairo, may be the difference between life and death.

Vairo and his wife, Donna, said they were shocked by the differences in waiting times. Even the doctor who referred him to San Francisco had no idea about the long wait.

Most transplant doctors don't provide patients with information about waiting times. Roberts and others say the discrepancy in waiting times is irrefutable evidence that the nation's organ allocation system remains unfair and that not everyone has an equal chance of getting a donated organ.

And the disparity in waiting times doesn't pertain just to livers, but to all organs. For example, patients in Cincinnati had a median wait of about six months for a heart in 1995, while patients in nearby Fort Wayne, Ind., waited about 1½ years.

Numbers like these pose a dilemma for the United Network for Organ Sharing, the nonprofit organization that tracks waiting times and holds a government contract to match donated organs with waiting patients. A major function of UNOS' Organ Procurement and Transplantation Network is to establish an equitable and medically sound organ distribution system.

"In some parts of the Southeast, there are waiting times that are two to three weeks long, and then you go to the Northeast in Boston, where the waiting times are over a year," said Dr. John J. Fung, director of the liver transplant program at the University of Pittsburgh.

Waiting times differ around nation

"If anything is going to tell the public that, hey, something doesn't smell right, it's that kind of disparity," Fung said. "It jumps out at you."

Dr. James F. Burdick, UNOS president, believes that attempts by transplant centers and organ banks to control locally harvested organs have hurt the national, voluntary allocation policy.

Burdick, a transplant surgeon at Johns Hopkins Hospital in Baltimore, said that sense of ownership "impedes the development of an equitable and national system for distributing organs."

Many doctors and transplant professionals say, however, that the quest for true equity may be unobtainable because any actions UNOS takes will still involve the rationing of scarce organs, and thousands of people will continue to die on waiting lists.

They also note that UNOS is an agency that rules by consensus, and that UNOS' 39-member board and more than 400 member institutions make consensus difficult.

Dirty laundry

In an anonymous survey done by UNOS last fall, most UNOS members involved in liver transplantation said they believed data on waiting times and deaths on the waiting list should be available to transplant patients and their referring doctors.

Although government pressure forced UNOS to begin publishing center-specific mortality data, UNOS officials and a small group of doctors have kept center-specific waiting time data from being made public, claiming that the data are "meaningless" because centers are listing patients at different stages of their illnesses.

One liver transplant official who responded to the survey opposed releasing the waiting time data because to do so "would condemn the current UNOS allocation system and make its gross inequities public knowledge. I do not feel that we need to air our dirty laundry. Let's just fix it."

In November, the UNOS board of directors voted to release a report in 1997 on waiting times. But instead of publishing waiting times by center, which would help patients decide where to go, the board decided to release a report on waiting times by organ bank, which serve regions of the country.

"I'm afraid that if patients take a look at the report on the [organ banks], it still won't help them make a decision about what transplant center to go to," said Phyllis G. Weber, executive director of the California Transplant Donor Network in San Francisco and a member of the UNOS board.

Weber isn't alone in her concern that organ bank waiting time will be of little help. Weber and some other board members also were unaware that UNOS has center-specific waiting time reports, which The Plain Dealer obtained under the Freedom of Information Act.

If transplant center officials were to explain to patients that waiting times vary greatly in different parts of the country, they also would have to explain that there is no true national waiting list for patients needing a lifesaving organ transplant, something that many patients do not understand.

Many patients believe there is one long waiting list for each organ. They believe they have a place on that list, and that they move up as they get sicker or with each transplant that is performed.

They are wrong. Instead, what's in place is more like a network of smaller statewide or communitywide lists. And how long patients wait for organs depends greatly on where they live and how well their local organ banks do at persuading people to donate.

While UNOS has established a "policy" on how to allocate organs, it's not followed throughout the country. The voluntary policy has been revised by sharing agreements and variances granted by UNOS that cover about 16 states, including Ohio.

Ohio, like some other states and regions, has a sharing agreement that attempts to keep organs in-state, regardless of whether more seriously ill patients need them elsewhere.

Few transplant officials advocate a national system that would establish a single national waiting list that would ship organs cross-country to the next waiting patient.

Instead, many doctors believe that waiting times could be equalized and equity could be achieved by sharing organs within several "super regions" that would account for differences in population, donor patterns and rates of disease.

The liver wars

The disparity in waiting times has been especially hotly debated within the liver transplant community, where since 1991 UNOS has used an allocation system that is different than for any other organ. It is a system, its critics say, that allocates organs to transplant centers, not patients.

The decision by UNOS to allocate livers locally instead of giving them to the sickest patients has been a major incentive for hospitals to set up liver transplant programs, now a more than $300 million-a-year industry. The new allocation system provides organs to newly established programs that otherwise wouldn't get them because they generally have small waiting lists and few seriously ill patients.

It also provides a source of local organs for patients whose problems have not yet become life-threatening and who are expected to have a better chance of surviving a transplant.

In 1989, two years before the policy was implemented, there were 79 liver transplant centers, according to UNOS. Two years after the change, in 1993, there were 112 centers, a 29 percent increase.

The allocation change had serious side effects for large centers. Those centers could not now draw many organs from outside their local areas, despite drawing patients nationwide. With the number of patients who could benefit from transplantation increasing, the effect was to cut off organs for many critically ill patients, creating hopelessly long waiting lists.

At the same time, the waiting-time disparity grew, which in 1994 and 1995 ranged from 18 days at Tulane Medical Center Hospital in New Orleans to an average of 648 days at the four liver transplant centers in Boston.

"The control of donor organs by transplant centers and their professionals is driven by financial considerations, not by what is fair and equitable for their patients," Dr. Jeffrey S. Crippin, a liver transplant surgeon at Baylor University Medical Center in Dallas, testified at a UNOS hearing in September.

"In a situation of unmet need, with patients dying daily for the want of a donor liver, what is fair to all patients is to have approximately the same opportunity of receiving a donor liver," Crippin said.

At the hearing, a move by UNOS to equalize waiting times by creating wider geographic regions to match organs for the sickest patients was tabled after small- and medium-sized centers, concerned about controlling local organs, opposed it.

Nearly 80 percent of UNOS' 118 liver transplant center members fall into the small- and medium-sized group — those that do fewer than 50 transplants a year. They dominate UNOS' committees, which make policy recommendations to the board.

One of the more outspoken critics of the UNOS proposal was Dr. John C. McDonald, chairman of the department of surgery at the Louisiana State University School of Medicine in Shreveport.

"This policy will divert livers from needy ... patients in Louisiana to wealthy patients in other states," said McDonald, who added that state residents are guaranteed access to transplantation under state law, regardless of their ability to pay. "It will divert livers to centers which have taken on more patients than they can serve."

The inability of UNOS to resolve the controversy internally prompted U.S. Department of Health and Human Services Secretary Donna Shalala, whose agency has allowed transplant centers to largely regulate themselves, to intervene.

Shalala called three days of public hearings on the issue in December and said she would determine, within three months, how best to allocate scarce donor organs. In a letter outlining her reasons for the hearing, Shalala said a federal decision on liver allocation would eliminate the public perception that UNOS isn't able to change the current policy because the self-interest of its members stands in the way.

"Any decision, whether it be a new policy or a reaffirmation of the current one, is certain to draw intense public and congressional interest," Shalala wrote. She added, "I am disappointed that the allocation policies to date have provoked considerable unresolved controversy within the transplant community."

No standardized listing

Even though livers are allocated according to a different system, the variance in median waiting times for other major organs is about as great, according to UNOS data.

For hearts, it stretched from a low of 28 days at Medical City Dallas Hospital (for adults) to a high of 815 days at the University of Minnesota Hospital in Minneapolis. For kidneys, it ranged from 54 days at Harris Methodist Hospital in Fort Worth, Texas, to 858 days at Milton S. Hershey Medical Center in Hershey, Pa.

Transplant doctors point out that patients' waiting times are based on many factors, including blood type, height, weight, and the stage of illness at which the patient is put on the waiting list. Those and other factors make one person's wait longer or shorter than another's.

"You've got to look at it in the light of the listing criteria — that's a large part of the problem," said Dr. J. Michael Henderson, director of the Cleveland Clinic's liver transplant program. "The nation does not have a standardized listing criteria. You can get on a list in one part of the country a lot earlier than other parts of the country."

In November, the UNOS board voted to establish standardized

listing this year, modeled in part after Ohio's system.

But for the last 12 years in Ohio, patients have been listed at the same stages of their disease, and the waiting times for heart, liver and pancreas transplants at the centers here still vary greatly.

Henderson said that was because "you still have local priority" and because some programs are more aggressive than others about transplanting so-called "marginal" organs into their sickest patients.

"Waiting time is not the gold standard of equity," said Dr. Ronald M. Ferguson, a liver transplant surgeon at Ohio State University Hospital. "If you have too few organs and too many patients, somebody is going to get the sticky end of the Popsicle stick."

Aside from the ethical arguments for telling patients about the differences in waiting times, Roberts, the San Francisco surgeon, said that doctors who are worried about being sued should have a selfish motive for disclosing the differences.

"If you don't open up the issue, the next thing that happens is the family says, 'Why didn't you tell me my mother could go and get transplanted someplace else?' We'll start being asked, and rightly so, 'Is the issue money, doctor?'"

Roberts and others say the same is true for insurance companies, which could be asked whether they are directing patients to specific centers — some with long waiting times — because the centers are giving them big price breaks.

For Vairo, the retired painting contractor, the insurance issue is being worked out. In addition to the University of California at San Francisco, Kaiser contracts with four other hospitals for adult liver transplantation, including the University of Alabama at Birmingham Hospital.

In 1995, the median waiting time at UAB was 88 days, more than a year shorter than his expected wait in San Francisco.

Vairo heard recently, after visiting the Alabama center with his wife, that he had been accepted and placed on the list in Birmingham.

Kaiser agreed to pay for the trip, as well as his expenses to move there for several months to wait for a liver.

"I'm lucky because it's very small," Vairo said of his cancer. "But it could spread, and then they wouldn't do anything.

"My doctor said, 'They'd open you up and if they see that it's spread, they close you up and you just wait.'

"I'm not ready to check out. I've got too much to live for."

TRANSPLANT FACTS

As of December 1996, 999 patients were waiting for organs at northeast Ohio hospitals.

For a kidney	675
For a heart	112
For a liver	112
For a pancreas	8
For a lung	37
For a heart/lung	3
For a kidney/pancreas	52

SOURCE: LifeBanc

TRANSPLANT FACTS

Annual number of heart transplants in the U.S.

1989	1,705
1990	2,108
1991	2,125
1992	2,171
1993	2,297
1994	2,340
1995	2,434
1996 (est.)	2,507

SOURCE: Milliman & Robertson Inc., Brookfield, Wis., consulting actuaries

FOR YOUR INFORMATION

Internet newsgroup on transplants

Information about transplants is available on the Internet.

If you have access to electronic mail, the transplant newsgroup provides a forum for organ transplant recipients and donors, their families and members of the transplant community.

Recent topics include waiting times, transplant costs, the negative side effects of anti-rejection drugs and media coverage of transplantation.

To participate, send an e-mail message that states "SUB TRNSPLNT (Your full name) to *listserv@wuvmd.wustl.edu.*

State's policy: Ohio organs for Ohioans first

By JOAN MAZZOLINI
PLAIN DEALER REPORTER

If you die in Ohio, Ohio wants your organs.

Preferably, for another Ohioan.

In what may be the ultimate act of provincialism, the architects of the national organ-distribution network have created a system in which local ownership rules.

Say, for instance, that a donor heart becomes available in Toledo, but isn't a match for a patient at the Medical College of Ohio, the only heart transplant center in northwest Ohio. Under rules adopted by the Ohio Solid Organ Transplant Consortium, the next step would be to look for the best match for the sickest patient waiting at one of Ohio's three other heart transplant centers — in Cleveland or Columbus, which are, respectively, 97 and 121 miles from Toledo, or in Cincinnati, 184 miles away.

That's true even if the nearest matching patient for the Toledo heart is sicker than the Ohio patients and is dying just 53 miles away in Detroit.

"I think that's very reasonable," said Dr. Thomas E. Walsh, a consortium board member and director of the heart transplant program at the Medical College of Ohio. "You have to draw boundaries somehow, and that turns out to be the way the boundaries are drawn. . . . I think it's been very fair."

Ohio is one of about 16 states, regions and metropolitan areas around the country that have variances or sharing agreements. They allow states, transplant centers and organ banks to circumvent the national organ allocation policy.

That policy was established by the United Network for Organ Sharing under the auspices of Congress. Congress passed the National Organ Transplant Act in 1984 and the Transplant Amendments Act in 1990, which required the development of an "equitable" organ distribution plan that would be carried out "in accord with a national system."

Despite that edict, investigations by the U.S. Department of Health and Human Services' office of the inspector general in 1991 and the General Accounting Office in 1993 both found that in addition to the huge differences in the length of time patients waited for organs at different centers, there was no true national allocation system.

The investigations found that as the number of waiting patients, transplant centers and the competition for scarce donor organs grew, so had the transplant facilities' desire to control organs from local or state residents.

"It's extremely alarming when in fact we don't have a national system at all, but instead these arbitrary geographic boundaries, which preclude a national system," said Charles E. Fiske, co-director of the National Transplant Action Committee, a patient-advocacy group of transplant recipients and their families. "These variances protect the best interest of the transplant center rather than the best interest of the patient."

UNOS, which since 1986 has held the government contract for matching waiting patients with donor organs, has approved these variances and sharing agreements.

Ohio's system was set up about 12 years ago. It is considered a model in the country because, in addition to sharing organs for critically ill patients across the state, groups of doctors from the Ohio centers, under the auspices of the Ohio Solid Organ Transplant Consortium, approve patients who are put on transplant waiting lists at the Ohio hospitals.

But, like sharing agreements in New York, Tennessee, Georgia and some other states, Ohio's strives to keep most organs within state lines, even though patients commonly cross those boundaries when seeking medical care, often at the insistence of their insurers.

"It's another exception after another exception," Fiske said. "This flies in the face of treating the sickest patient first."

Staying close to home

Challenging the odds, a liver transplant patient shuns a shorter wait to be at home

By JOAN MAZZOLINI
PLAIN DEALER REPORTER

OAKLAND, Calif. — Like many patients awaiting an organ transplant, Karl Lindinger didn't know about the big differences in waiting times among transplant centers.

But after 18 months on Stanford University Hospital's liver transplant list, Lindinger now knows that where you are treated can have as much to do with when you get a transplant as how sick you are.

Lindinger, 42, already has waited twice as long as patients at the University of California at Los Angeles. And his two separate insurance policies would allow him to go to out-of-state centers with even shorter waits.

But Lindinger said he feels comfortable being closer to home and with a staff he has gotten to know at Stanford.

"My doctors here are extremely good, and I feel very confident about them," Lindinger said when asked why he doesn't look into going to a center with a shorter waiting time. "I don't want to change it.

"My gastroenterologist is a doll. He's so concerned about patient care before the money issue comes in, which is really nice to have."

Lindinger is a native of Austria. He lives in a low-rent apartment he moved into after he became too sick to continue his hotel manager's job.

He has no family nearby, but many friends. Melba Ohl, a 74-year-old friend from Illinois who had planned to help him after the transplant, came to Oakland early because Lindinger's health had deteriorated.

Lindinger's liver was damaged by cirrhosis. He said his doctors recently told him that the cirrhosis was caused by a non-viral type of hepatitis.

His liver is three times its normal size. He takes megadoses of medication that leave him barely conscious, and internal bleeding and brain swelling have put him in comas and in and out of the hospital.

But if a liver becomes available in Sacramento, someone who is well enough to be home and working there could get the organ before Lindinger, who lives about 1½ hours away.

When Lindinger went on the waiting list in August 1995 at Stanford University Hospital in Palo Alto, Calif., his doctors told him he would live less than two years without a transplant. And they told him it would be about a year before he got a new liver.

After the year came and went, Lindinger said the doctors told him the wait would be another six months. Now Lindinger is worried that his time is running out.

"My doctor said there's nothing more they can do for me, that I might go into another coma and that'll be that," Lindinger said. "Unless I get the transplant."

Stanford officials have told him they are doing everything they can to find him a liver. And that has won Lindinger's trust and kept him from going elsewhere.

Lindinger is like many — if not most — patients, say officials in the transplant field. Overwhelmed by anxiety and the need to be close to friends and family at home, many patients put their faith in their local hospitals and doctors. They don't ask many questions, afraid of the answers.

"I don't want to change," he said. "It's a gamble."

Photos and Captions Omitted

WAITING TIMES

The lists below rank the nation's transplant centers according to the median number of days patients waited for a transplant. The "Patients added" column is the number of people who joined the waiting list during the year and the "Median waiting time" is the mid-point in days those patients waited for a transplant. The data below covers the most recent year for which a median waiting time could be calculated, either 1994 or 1995. NA means the waiting time could not be calculated, because fewer than 10 people joined the waiting list and/or the center did not perform enough transplants for the waiting time to be statistically significant.

HEART

	Hospital, City, State	Patients added	Median waiting time
Ten shortest			
1	Henrietta Egleston, Atlanta, GA	23	27
2	Medical City Dallas, Dallas, TX	25	28
3	St. Louis Children's, St. Louis, MO	28	38
4	Mercy, Des Moines, IA	12	48
5	Jackson Memorial, Miami, FL	44	51
6	Loma Linda University, Loma Linda, CA	52	52
7	Methodist, Houston, TX	20	53
8	UCSD, San Diego, CA	17	57
9	Cedars-Sinai, Los Angeles, CA	33	58
10	St. Christopher, Philadelphia, PA	16	59
Ten longest			
99	Donald N. Sharp Memorial, San Diego, CA	27	408
100	Baptist, Oklahoma City, OK	38	426
101	Loyola University, Maywood, IL	33	430
102	Presbyterian-University, Pittsburgh, PA	62	436
103	Lutheran, Fort Wayne, IN	22	544
104	St. Mary's, Rochester, MN	41	594
105	Emory University, Atlanta, GA	72	665
106	Allegheny General, Pittsburgh, PA	20	740
107	Willis Knighton, Shreveport, LA	62	768
108	University of Minnesota, Minneapolis, MN	31	815
Others in Ohio			
32	University of Cincinnati, Cincinnati	33	122
41	Cleveland Clinic, Cleveland	128	149
	Children's, Cincinnati	1	NA
	Medical College of Ohio, Toledo	22	NA
	Ohio State University, Columbus	20	NA
	Children's, Columbus	0	NA

KIDNEY

	Hospital, City, State	Patients added	Median waiting time
Ten shortest			
1	Harris Methodist, Fort Worth, TX	58	54
2	Presbyterian-University, Pittsburgh, PA	12	79
3	Southwest Florida, Fort Myers, FL	37	114
4	Henrietta Egleston, Atlanta, GA	10	144
5	Oregon Health Sciences, Portland, OR	137	147
6	University, Lubbock, TX	13	154
7	Methodist, Lubbock, TX	14	162.5
8	Jackson Memorial, Miami, FL	140	166
9	St. John, Tulsa, OK	11	170
10	University of Cincinnati, Cincinnati, OH	42	174
Ten longest			
109	Virginia Mason, Seattle, WA	116	750
110	Francis Scott Key, Baltimore, MD	44	761
111	Parkland Memorial, Dallas, TX	74	763
112	University of North Carolina, Chapel Hill, NC	59	810
113	Mount Sinai, New York, NY	101	812
114	University of Pennsylvania, Philadelphia, PA	163	822
115	Northwestern Memorial, Chicago, IL	186	828
116	Lehigh Valley, Allentown, PA	38	838
117	William Beaumont, Royal Oak, MI	106	850
118	Milton Hershey, Hershey, PA	111	858
Others in Ohio			
14	Miami Valley, Dayton	28	204
19	Medical College, Toledo	46	216
25	Christ, Cincinnati	36	260
62	Ohio State University, Columbus	276	431
	Akron City, Akron	28	NA
	Children's, Cincinnati	9	NA
	Children's, Columbus	1	NA
	Children's, Akron	1	NA
	Cleveland Clinic, Cleveland	142	NA
	University Hospitals, Cleveland	126	NA
	St. Elizabeth, Youngstown	44	NA

LIVER

	Hospital, City, State	Patients added	Median waiting time
Ten shortest			
1	Tulane, New Orleans, LA	16	18
2	University of Kansas, Kansas City, KS	30	21
3	Jewish, Louisville, KY	47	38
4	University, Newark, NJ	50	40
5	Children's, Dallas, TX	21	42
6	University of Wisconsin, Madison, WI	101	54
7	Jackson Memorial, Miami, FL	265	64
8	Vanderbilt University, Nashville, TN	41	71
9	Henrietta Egleston, Atlanta, GA	12	77
10	Froedtert Memorial Lutheran, Milwaukee, WI	31	80
Ten longest			
75	Methodist, Indianapolis, IN	34	385
76	Cleveland Clinic, Cleveland, OH	97	394
77	University of Michigan, Ann Arbor, MI	162	401
78	University, Denver, CO	113	405
79	Rush-Presbyterian/St. Luke's, Chicago, IL	186	423
80	University, Cleveland, OH	51	445
81	California Pacific, San Francisco, CA	217	473
82	University of Maryland, Baltimore, MD	27	518
83	Johns Hopkins, Baltimore, MD	165	563
84	New England Organ Bank Centers*	307	648
Others in Ohio			
20	Ohio State University, Columbus	46	104
26	Children's, Cincinnati	15	132
58	University of Cincinnati, Cincinnati	43	258
	Children's, Columbus	0	NA

*Includes combined figures for Children's, Boston; New England Deaconess, Boston; Massachusetts General, Boston; and New England Medical Center, Boston.

LUNG

	Hospital, City, State	Patients added	Median waiting time
Ten shortest			
1	Ochsner, New Orleans, LA	12	43
2	Children's, Philadelphia, PA	18	62
3	University of Alabama, Birmingham, AL	32	77
4	Vanderbilt University, Nashville, TN	17	80
5	Medical University, Charleston, SC	12	99
6	University, Lexington, KY	38	114
7	Shands, Gainesville, FL	30	124
8	Methodist, Houston, TX	22	126
9	University of CA Davis, Sacramento, CA	12	129.5
10	Temple University, Philadelphia, PA	16	148
Ten longest			
28	St. Louis Children's, St. Louis, MO	41	408
29	UCLA, Los Angeles, CA	37	417
30	Duke University, Durham, NC	60	449
31	University of Pennsylvania, Philadelphia, PA	73	466
32	University of Virginia, Charlottesville, VA	26	528
33	Methodist, Indianapolis, IN	25	598
34	Barnes, St. Louis, MO	125	690
35	University of North Carolina, Chapel Hill, NC	50	762
36	University of Michigan, Ann Arbor, MI	44	793
37	Presbyterian, New York, NY	73	801
Others in Ohio			
22	Cleveland Clinic, Cleveland	40	332

SOURCE: United Network for Organ Sharing

PLAIN DEALER

Cleveland Plain Dealer
Thursday, February 6, 1997

Low-volume centers lead in rate of death

Last of five articles

By JOAN MAZZOLINI,
DAVE DAVIS
and TED WENDLING
PLAIN DEALER REPORTERS

Patients who receive organ transplants at so-called "low-volume" centers are more likely to die within the first year than those who go to high-volume centers, a Plain Dealer analysis of transplant records shows.

Few patients understand that the number of transplants performed plays a crucial role in keeping surgical teams sharp, or that they can significantly increase their chances of survival by going to transplant centers that do the risky surgery more often.

"Yeah, it would save some lives if those [low-volume] centers basically stopped doing transplants," said Dr. Jeffrey D. Hosenpud, a heart transplant cardiologist at the Medical College of Wisconsin Hospital in Milwaukee. "And, obviously, that's critically important if you happen to be one of those lives."

Hosenpud co-authored a study that concluded that the risks of mortality at one month and at one year were "substantially higher" at low-volume heart transplant centers, those that perform fewer than nine transplants a year. Such centers accounted for about half of those doing heart transplants in the United States, but they performed only 15 percent of all heart transplants.

The study, which examined the outcomes of 7,893 heart transplants between October 1987 and 1991, was published in the Journal of the American Medical Association in 1994.

Hosenpud also said the number of lives that could be saved by eliminating low-volume heart centers is probably not as great as the number that could be saved by eliminating low-volume liver centers. Liver transplants require greater technical ability on the part of the surgical team.

A study sponsored by the University of Pittsburgh found that if low-volume liver centers or those with higher-than-expected mortality rates were closed, the lives of about 350 transplant patients a year would be saved.

"There are some small centers that have done well, but not a majority," said Dr. John J. Fung, director of Pittsburgh's liver transplant program. "In fact, 75 percent of the small programs are not good programs.

"We try not to focus on this because we end up polarizing the transplant community. But we believe poorly performing programs should be looked at."

The Plain Dealer analysis of transplant centers was based on 55,990 organ transplants performed from Oct. 1, 1987, to Dec. 31, 1991, the most recent period for which records were available. For each type of organ transplant, roughly half the centers in the country fell into the low-volume category. Low-volume centers accounted for 9,049 organ transplants, or about 16 percent of the total transplants in the analysis.

The analysis showed that the patient death rate during the first year was higher on average for low-volume centers than for high-volume centers. For example:

- At low-volume heart transplant centers, those averaging fewer than nine transplants a year, 24 percent of the patients died within a year — an increase of 33 percent over the death rate of 18 percent at high-volume centers.
- At low-volume liver transplant centers, those averaging 13 or fewer transplants a year, 32 percent of the patients died within a year — an increase of 28 percent over the death rate of 25 percent at high-volume centers.
- And at low-volume pancreas centers, those averaging fewer than six transplants a year, 15 percent of the patients died within a year — an increase of 50 percent over the death rate of 10 percent at high-volume centers.

The mortality rates for the low- and high-volume centers are averages for each group. A particular low-volume center may have a one-year mortality rate that is significantly higher or lower than the low-volume group average, just as any high volume center might differ from the overall high-volume group average.

Experts say patients and their families should know the most recent mortality rates for the centers they are visiting, as well as the median waiting time for the needed organ.

The importance of volume

Transplants are risky even under the best circumstances, and volume is only one predictor of patient mortality. Other factors, such as a patient's overall medical condition or whether it is a first or second transplant, are considered better indicators of whether someone will live a year or longer.

But understanding the effect of volume on outcome can help patients pick the right transplant center and increase their likelihood of surviving.

Even when the data were adjusted to account for differences in the severity of patients' illnesses and the quality of the donor organs hospitals received — to avoid penalizing hospitals that transplanted higher-risk patients — the odds of dying within one year remained significantly greater at low-volume hospitals, the Plain Dealer's analysis showed.

The analysis showed that patients would have a better chance of survival at high-volume centers for all six major types of organ transplants — hearts, heart-lungs, livers, kidneys, lungs and pancreases.

"Everyone ought to be aware that volume is an important issue," said Dr. Lawrence G. Hunsicker, co-author with Hosenpud of the 1994 JAMA study and a heart transplant cardiologist at the University of Iowa Hospital in Iowa City. Hunsicker is vice president of the United Network for Organ Sharing, the private, nonprofit organization that holds the government contract to match donated organs with patients waiting for transplants.

"Clearly, what I take away from this is that the [heart] centers that regularly do fewer than 10 transplants a year should examine whether they should be in the business at all," Hunsicker said. "And what's hard to justify is places where there's two or three centers in a city, all of whom are doing seven transplants.

"That doesn't make any sense. They ought to get their acts together and get a single center that's got the volume to get the level of expertise that's needed."

In fact, four-fifths of the nation's low-volume heart transplant centers are in metropolitan areas that have another heart transplant center. Since 1988, the number of heart transplant programs has increased from 129 to 166.

"In principal, we would do better with fewer centers," Hunsicker added. "But you can't use volume as the only consideration."

Among the other considerations are ensuring that patients in rural, sparsely populated states have access to a transplant center.

The Health Care Financing Administration, an arm of the U.S. Department of Health and Human Services, has set minimum volume guidelines for hospitals to receive Medicare reimbursement for transplants. Heart and liver centers must perform at least 12 transplants a year, kidney centers must perform at least 15, while lung and heart-lung centers must do at least 10.

But many low-volume centers have chosen to continue their programs even though they don't do enough transplants to get federal reimbursement. And neither HHS' Division of Organ Transplantation nor UNOS has set volume or minimum-survival standards that cover non-Medicare patients.

"We don't have any way to actually remove a center from receiving organs, technically speaking," said Dr. James F. Burdick, president of UNOS and a transplant surgeon at Johns Hopkins Hospital. "That [volume] is not a question we've addressed directly because our job is to make things fair and work on centers that don't do well."

An exception

Although the Plain Dealer analysis showed that low-volume centers as a group had a higher one-year death rate, there are exceptions. One of them is the Via Christie Regional Medical Center in Wichita, Kan.

The hospital performed an average of about eight heart transplants a year during the four years analyzed. Its one-year survival rate during that period was 100 percent, making it one of the three best-performing centers in the nation.

As of December, over the nine-year lifetime of its program, Via Christie had performed 102 heart transplants and 93 percent of those patients had survived one year. The national average is 82 percent.

"I think center volume does matter to an extent, but I think there are a lot of other things that add to the equation," said Dr. Thomas H. Estep, director of the heart transplant program.

Via Christie has the only heart transplant program in Kansas. The nearest center to it is a three-hour drive, in Kansas City, Mo.

Estep said attempts to limit the number of centers performing transplants should be based first on death rates, then on volume.

"If any center has poor outcomes, then I think that donor organs should go to other centers, where the chance of a patient living is greater," he said.

Because donor organs are scarce — for most types of transplants, there are about two people waiting for every one person who receives a transplant — transplant surgeons have hotly debated the best use of donor organs and whether to close low-volume centers. But that debate has remained within the fraternity. Few patients are aware that volume is a predictor of mortality, many doctors acknowledge.

"For the 5 percent who know all the statistics and know where I went to school, there's a whole host of people who are going wherever they're told to go," said Dr. Robert W. Stewart, head of the Cleveland Clinic's heart transplant program, one of the busiest in the country.

That wasn't the case with Anita Lupo, an administrator at Illinois State University who lives in Normal, Ill. Lupo, who is still working, has been on the waiting list for a heart transplant at Barnes Hospital in St. Louis since May 1995. Barnes is a high-volume center, averaging about 24 transplants a year.

Because she has twice undergone open-heart surgery, Lupo is considered to be at a higher risk for death or complications resulting from a transplant. That was a major factor in her evaluation of transplant centers, and she bypassed three programs closer to home — one in Peoria, Ill., and two in Chicago — because she thought they had not done enough transplants or because their surgical teams were too new.

She now has a much longer drive, about three hours, to go for her quarterly tests, but that doesn't bother her.

Lupo said she learned about the importance of volume when she sought a second opinion from a transplant cardiologist who was not involved in her care.

"He said don't go anywhere where they do less than 20 — that your quality is a lot better if you do at least 20 a year," Lupo said. "I am a believer that small-town hospitals and small-town doctors are not the place to go. So when I heard the number 20, that just reinforced what I already knew — that there had to be some minimum number, and that it just wouldn't be a good idea to go somewhere where they did less than that."

At that time, only 47 of the nation's 145 heart transplant centers, 32 percent, met that qualification.

Programs on probation

In many areas of medicine, the average number of procedures performed by doctors, nurses and technicians has long been considered a significant indicator of quality.

"As a physician, I strongly believe that the outcome does depend upon how many times you have performed a given procedure," said Dr. Peter Somani, Ohio's top health official. "Therefore, volume is important."

In addition to being the state director of health, Somani is on the board of the Ohio Solid Organ Transplant Consortium, the association that, with his department, oversees transplantation in Ohio. Somani's staff included volume requirements for all types of major organ transplants in the state's recently passed quality-assurance rules, which are designed to provide minimum standards for a wide variety of health care activities. The rules don't take effect until next fall.

"What we're saying is if your volume is less than the minimum, we'll automatically look at your results in more detail," Somani said.

The Ohio consortium has had volume requirements for several years, but it has no authority to close programs that don't meet them. And when hospitals are placed on probation for failing to perform enough transplants or for any other reason, that information is not made public because the consortium, a private organization, chooses not to disclose it.

In the past, minutes of the consortium's non-public board meetings have shown which transplant centers were placed on probation and why. But Audrey Bohnengel, the consortium's executive director, said the group would discontinue that practice after The Plain Dealer obtained consortium minutes through Somani's office showing that heart transplant programs at the Medical College of Ohio in Toledo and Ohio State University were placed on probation in 1996 for failing to perform enough transplants.

The consortium requires heart transplant programs to perform a minimum of 12 transplants a year — the same number required by the federal government to obtain Medicare reimbursement.

According to consortium board minutes, Dr. Thomas E. Walsh, a board member and director of the heart transplant program at the Medical College of Ohio, argued against a volume requirement, saying, "There is no substantiation in literature that links volume to quality."

Walsh also said there were "better quality indicators than volume to demonstrate a successful program, such as length of stay, hospital charges and readmissions."

Last April, the consortium extended the Medical College's one-year probation for a second year for failure to meet volume standards. The hospital performed 15 heart transplants in 1996, and Walsh said in an interview that he expected the program to be taken off probation in April.

"My contention was that, despite the numbers, we've always had more than acceptable outcomes — that's mortality, readmissions, rejection, length of stay and cost," Walsh said. "It seems to me that because we have a very small program where everything is done by a small, intimate group, that we profit by our experience much more greatly than if it was diffused over a large number of people."

OSU's heart transplant program has struggled even more to meet the volume standard. The center performed 11 transplants in 1995 and just seven in 1996.

Dr. P. David Myerowitz, director of OSU's heart transplant program, partly attributed the slowdown to the loss of two transplant cardiologists in 1996. That resulted in fewer patients — particularly fewer critically ill patients — being placed on OSU's waiting list.

Myerowitz also said that OSU, because it has a conservative approach about which hearts to accept for transplantation, occasionally turns away donor hearts that other programs use.

"It's the same way as how you invest your money," he said. "Some guys are on the fringe and some guys invest in CDs. That's an attitude of life. I admit I'm a conservative individual, and our program's probably conservative."

Statistical analysis used most recent transplant data available

By DAVE DAVIS
PLAIN DEALER REPORTER

Records of 55,990 organ transplants performed over four years were analyzed for this story to determine whether low-volume transplant centers had a higher one-year mortality rate than high-volume centers.

The analysis included all heart, heart-lung, liver, lung, kidney and pancreas transplants in the United States between Oct. 1, 1987, and Dec. 31, 1991 — the most recent period for which records were available. Transplant patients were followed through 1993.

Based on the average number of transplants performed in a year, centers were labeled either high- or low-volume.

For each type of organ, roughly half of the centers in the country fell into each category. Low-volume centers, however, performed just 16 percent of the total organ transplants included in the analysis.

The analysis showed that, on average, patients who underwent a transplant at a low-volume center had a significantly greater chance of dying in the first year following the transplant. This was true for all six types of organ transplants.

The records also were analyzed to examine whether the increased rate of death was explained by differences in patients and donors, or whether a significant portion of the increased rate could be attributed to transplant center volume.

Even when a sophisticated statistical method was used to adjust for differences in patient risk factors and donor characteristics — to avoid penalizing hospitals that undertook more difficult cases — the odds of dying remained greater at low-volume centers. Using that method, known as logistic regression, The Plain Dealer found that center volume was a significant predictor of mortality at one year.

The newspaper included the overall experience of a center, as expressed by the number of years it had operated, in risk-adjusting the data.

The Plain Dealer obtained transplant records on patients and donors — one record for each transplant — from the United Network for Organ Sharing, which holds a federal contract to match donor organs with waiting patients. The information did not reveal the names of donors or recipients and is publicly available by calling UNOS at 1-800-243-6667.

The analysis was completed in SPSS for Windows version 6.1. The methodology for the analysis was developed with guidance from John Bare and Philip Meyer.

Bare holds a doctorate in mass communication research from the University of North Carolina and is a research consultant in Chapel Hill, N.C. He helped developed the statistical methods used in numerous stories published by U.S. News & World Report and other news organizations.

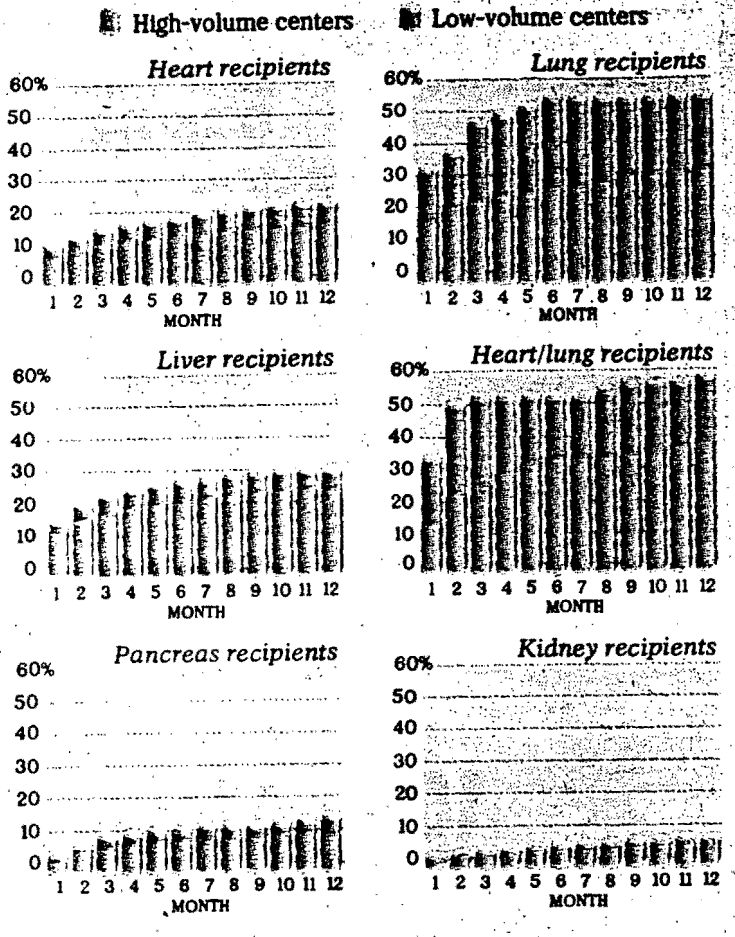
Meyer is the Knight Professor of Journalism at the University of North Carolina and the author of five books, including "The New Precision Journalism." He is a pioneer in the use of computers and social science research methods in journalism.

Photos and Captions Omitted

SURVIVING A TRANSPLANT

DEATH RATES BY TYPE OF ORGAN

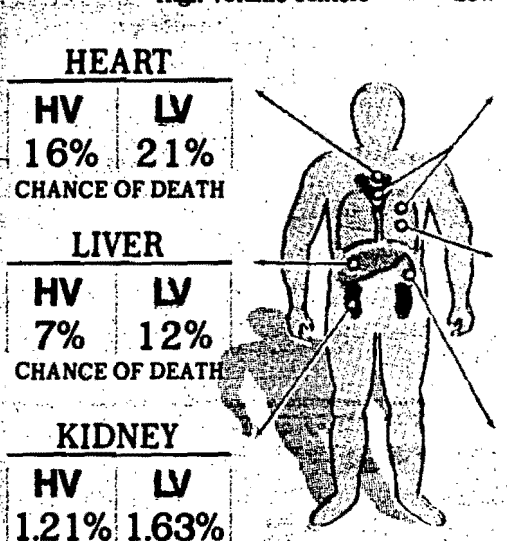
For each type of organ transplant, the death rate during the first year was always higher for low-volume centers.



INCREASED CHANCE OF DEATH WITHIN YEAR OF TRANSPLANT

All other factors being equal, patients face an increased risk of death within one year if they have an organ transplant at a low-volume center. For example, based on an analysis of the 55,990 organ transplants performed from Oct. 1, 1987, through 1991, the risk of death for a 40-year-old white male would increase at a low-volume center for each type of transplant. Patients with different characteristics would have different outcomes, but statistically would be expected to fare better at a high-volume center.

HV High-volume centers **LV** Low-volume centers



	HV	LV
HEART	16%	21%
HEART/LUNG	56%	78%
LIVER	7%	12%
LUNG	31%	54%
KIDNEY	1.21%	1.63%
PANCREAS	14%	21%

CHANCE OF DEATH

DEFINING HIGH- AND LOW-VOLUME CENTERS

High- and low-volume centers were defined in this analysis by the average number of transplants they performed in a year. For each organ type, roughly half the enters in the country fell into each group.

	HEART	HEART/LUNG	KIDNEY	LIVER	LUNG	PANCREAS
High-volume centers	9 or more	2 or more	27 or more	14 or more	3 or more	6 or more
Low-volume centers	8 or fewer	1 or fewer	26 or fewer	13 or fewer	2 or fewer	5 or fewer

SOURCE: Plain Dealer analysis of United Network for Organ Sharing data

PLAIN DEALER

ORGAN TRANSPLANT CENTERS IN THE UNITED STATES

WAITING TIMES & MORTALITY RATES

This chart lists median waiting times, one-year mortality rates and volume for the nation's transplant centers, based on information compiled by the United Network for Organ Sharing. The median waiting time figure is in days and is based on data from either 1994 or 1995. The mortality rate is for all transplants performed at a center over a four-year period beginning in October 1987. Volume shows the average annual number of transplants at that center during those same four years. Although the figures listed below are the most recent available, patients may be able to obtain current information from individual centers.

WAIT- Median waiting time (days) **M**- One-year mortality rate **V**- Volume (average annual transplants)

HEART

STATE	HOSPITAL	CITY	WAIT	M	V
AL	U. of Alabama	Birmingham	190	17.9	27
AR	Baptist	Little Rock	264	23.1	4
AR	Arkansas	Little Rock	287	40.0	3
AR	University	Little Rock	84	NA	NA
AZ	University	Tucson	176	6.5	35
CA	Children's	Los Angeles	245	NA	NA
CA	Cedars-Sinai	Los Angeles	58	14.9	17
CA	U. Of Calif.-Irvine	Orange	NA	12.5	4
CA	Loma Linda U.	Loma Linda	52	15.7	45
CA	California Pacific	San Francisco	348	9.8	28
CA	Hoag Memrl.	Newport Beach	NA	24.0	6
CA	UCSD	San Diego	57	5.0	10
CA	U. Of California	San Francisco	201	15.4	13
CA	Sutter Memrl.	Sacramento	368	4.8	7
CA	Donald N. Sharp Memrl.	San Diego	408	8.2	18
CA	U. of Calif. Davis	Sacramento	NA	0.0	1
CA	Stanford U.	Palo Alto	98	19.1	47
CA	St. Vincent	Los Angeles	86	4.5	6
CA	UCLA	Los Angeles	157	15.0	56
CA	USC	Los Angeles	184	NA	NA
CO	Children's	Denver	69	12.5	4
CO	Presby./St. Luke's	Denver	NA	33.9	8
CO	University	Denver	87	10.7	9
CT	Hartford	Hartford	188	13.0	14
CT	Yale New Haven	New Haven	NA	28.3	12
DC	Children's NMC	Washington	NA	57.1	2
DC	Georgetown U.	Washington	NA	6.3	4
DC	George Washington U.	Washington	NA	10.0	3
DC	Washington	Washington	212	8.3	12
FL	Jackson Memrl.	Miami	51	17.5	10
FL	Tampa General	Tampa	177	18.1	28
FL	Tallahassee Memrl.	Tallahassee	79	23.5	9
FL	Shands Teaching	Gainesville	67	12.8	22
GA	Henrietta Egleston	Atlanta	27	17.6	4
GA	Emory U.	Atlanta	665	7.2	21
GA	St. Joseph's	Atlanta	290	15.8	30
HI	St. Francis	Honolulu	NA	20.0	3
IA	U. Of Iowa	Iowa City	399	29.3	10
IA	Mercy Hospital	Des Moines	48	21.4	7
IL	Children's Memrl.	Chicago	163	27.3	8
IL	Evanston	Evanston	NA	13.6	6
IL	Loyola U.	Maywood	430	21.8	30
IL	Rush-Presby.-St. Luke's	Chicago	249	36.4	3
IL	St. Francis	Peoria	407	18.2	11
IL	U. Of Chicago	Chicago	332	33.3	2
IL	U. Of Illinois	Chicago	NA	20.0	4
IL	Hines VA	Hines	NA	38.5	7
IN	Methodist	Indianapolis	189	20.8	18
IN	Indiana U.	Indianapolis	181	12.2	19
IN	Luthrn.	Fort Wayne	544	22.2	18
IN	St. Vincent	Indianapolis	376	29.0	8
KS	St. Francis	Wichita	NA	0.0	9
KS	U. Of Kansas	Kansas City	NA	5.7	9
KY	Audubon Regional	Louisville	NA	50.0	2
KY	Jewish	Louisville	294	21.7	15
KY	Kosair Children's	Louisville	NA	66.7	4
KY	University	Lexington	273	29.4	17
LA	Ochsner	New Orleans	107	12.1	27
LA	Tulane	New Orleans	60	NA	NA
LA	Willis Knighton	Shreveport	768	10.7	14
MA	Children's	Boston	93	6.3	4
MA	Massachusetts General	Boston	93	16.2	9
MA	New England	Boston	93	21.1	5
MA	Brigham & Women's	Boston	93	17.4	33
MD	Johns Hopkins	Baltimore	223	23.9	17
MD	U. Of Maryland	Baltimore	136	42.9	2
MI	William Beaumont	Royal Oak	297	40.0	2
MI	Henry Ford	Detroit	206	6.7	15
MI	Harper Grace	Detroit	NA	44.4	3
MI	U. of Michigan	Ann Arbor	326	18.7	34
MN	Abbott-Northwestern	Minneapolis	NA	14.7	24
MN	St. Mary's	Rochester	594	7.4	7
MN	U. Of Minnesota	Minneapolis	815	12.6	24
MO	Barnes	St. Louis	139	9.7	26
MO	Cardinal Glennon Memrl.	St. Louis	NA	44.4	2
MO	St. Louis Children's	St. Louis	38	16.7	6
MO	St. Luke's	Kansas City	248	15.8	14
MO	Menorah	Kansas City	NA	83.3	2
MO	St. Louis U.	St. Louis	371	10.9	22
MO	University	Columbia	188	13.3	5
MS	U. Of Mississippi	Jackson	101	11.1	5
NC	North Carolina Baptist	Winst.-Salem	296	75.0	2
NC	Carolinas	Charlotte	202	19.0	20
NC	Duke U.	Durham	124	14.0	13
NC	Pitt County Memrl.	Greenville	NA	60.0	1
NC	U. Of North Carolina	Chapel Hill	359	21.2	8
NE	Bryan Memrl.	Lincoln	NA	9.7	8
NE	AMI St. Joseph	Omaha	NA	50.0	2
NE	U. Of Nebraska	Omaha	100	NA	NA
NJ	Newark Beth Israel	Newark	83	25.0	14
NM	Presby.	Albuquerque	139	18.6	15
NY	Children's	Buffalo	NA	0.0	1
NY	Buffalo General	Buffalo	NA	35.3	9
NY	Presby.	New York	149	23.5	85
NY	Mount Sinai	New York	NA	15.6	11
NY	VA	Buffalo	NA	37.5	2
OH	Cleveland Clinic	Cleveland	149	14.3	28
OH	Children's	Cincinnati	NA	14.3	4
OH	Medical College Of Ohio	Toledo	NA	16.7	6
OH	Ohio State	Columbus	NA	20.0	15
OH	U. Of Cincinnati	Cincinnati	122	13.0	17
OK	Baptist	Okla. City	426	9.6	28
OK	Children's	Okla. City	NA	66.7	3
OK	University	Okla. City	211	30.8	3
OK	St. Anthony	Okla. City	NA	100.0	NA
OK	St. Francis	Tulsa	374	NA	NA

OR	Oregon Health Sciences	Portland	116	13.8	31
PA	Allegheny General	Pittsburgh	740	14.0	13
PA	Children's	Pittsburgh	153	27.5	10
PA	Children's	Philadelphia	71	37.5	8
PA	Penn St/Hershey	Hershey	250	18.9	13
PA	Hahnemann U.	Philadelphia	94	0.0	4
PA	Presby.-U.	Pittsburgh	436	12.2	44
PA	St. Christopher For Chdrn.	Philadelphia	59	57.1	4
PA	Temple U.	Philadelphia	78	21.4	35
PA	U. Of Penna.	Philadelphia	147	23.4	16
SC	Medical U.	Charleston	374	10.9	12
TN	Baptist Memrl.	Memphis	215	15.6	8
TN	Lebonheur Children's	Memphis	NA	16.7	2
TN	Methodist	Memphis	NA	13.9	9
TN	St. Thomas	Nashville	333	18.2	11
TN	Vanderbilt	Nashville	153	11.5	26
TX	UTHSC at San Antonio	San Antonio	NA	18.4	13
TX	Children's	Dallas	NA	16.7	3
TX	Seton	Austin	80	20.4	14
TX	Medical City Dallas	Dallas	28	40.0	5
TX	St. Luke's Episcopal	Houston	175	20.7	56
TX	San Antonio Regional	San Antonio	147	19.6	13
TX	U. Of Texas	Galveston	222	NA	NA
TX	Methodist	Lubbock	62	0.0	4
TX	Methodist	Dallas	271	13.5	9
TX	Methodist	Houston	53	29.9	36
TX	St. Paul	Dallas	173	8.4	21
TX	Baylor	Dallas	351	28.4	24
UT	Latter-Day Saints	Salt Lake City	253	7.7	23
UT	U. Of Utah	Salt Lake City	135	19.3	29
UT	Primary Children's	Salt Lake City	151	0.0	1
UT	VA	Salt Lake City	143	22.2	20
VA	Children's Kings Daughter	Norfolk	NA	30.0	5
VA	Fairfax	Falls Church	285	7.0	11
VA	Henrico Doctors	Richmond	348	23.8	7
VA	Medical College Of Va.	Richmond	292	18.8	29
VA	McGuire VA	Richmond	NA	14.5	16
VA	Sentara Norfolk General	Norfolk	307	17.0	16
VA	U. of Va.	Charlottesville	355	20.0	15
WA	Sacred Heart	Spokane	289	6.7	15
WA	University	Seattle	104	11.4	20
WI	Children's Of Wisconsin	Milwaukee	NA	100.0	1
WI	John L. Doyne	Milwaukee	NA	31.4	9
WI	St. Luke's	Milwaukee	241	17.6	26
WI	U. Of Wisconsin	Madison	117	19.6	14

LIVER

STATE	HOSPITAL	CITY	WAIT	M	V
AL	U. of Alabama	Birmingham	88	12.5	14
AZ	Good Samaritan	Phoenix	130	41.5	10
AZ	University	Tucson	242	NA	NA
CA	Cedars-Sinai	Los Angeles	120	15.9	29
CA	The Green	La Jolla	333	29.5	11
CA	U. Of Calif-Irvine	Orange	86	NA	NA
CA	Loma Linda U.	Loma Linda	154	NA	NA
CA	California Pacific	San Francisco	473	12.5	65
CA	UCSD	San Diego	236	100.0	0
CA	U. Of California	San Francisco	NA	13.6	74
CA	U. of Calif. Davis	Sacramento	299	NA	NA
CA	Stanford U.	Palo Alto	NA	0.0	2
CA	St. Vincent	Los Angeles	327	NA	NA
CA	UCLA	Los Angeles	NA	23.2	140
CO	Children's	Denver	276	20.0	5
CO	University	Denver	405	12.1	24
CT	Hartford	Hartford	147	33.3	7
CT	Yale New Haven	New Haven	NA	60.9	6
DC	Howard U.	Washington	138	100.0	1
FL	Jackson Memrl.	Miami	64	45.0	15
FL	Tampa General	Tampa	NA	75.0	1
FL	Shands Teaching	Gainesville	97	23.1	13
GA	Henrietta Egleston	Atlanta	77	22.2	5
GA	Emory U.	Atlanta	159	22.7	24
IA	U. Of Iowa	Iowa City	140	18.5	7
IL	Rush-Presby.-St. Luke's	Chicago	423	39.0	34
IL	U. Of Chicago	Chicago	306	35.5	70
IL	U. Of Illinois	Chicago	NA	57.9	5
IN	Methodist	Indianapolis	385	26.7	11
IN	Indiana U.	Indianapolis	382	28.8	26
KS	U. Of Kansas	Kansas City	21	22.6	16
KY	Jewish	Louisville	38	35.3	9
KY	University	Lexington	226	NA	NA
LA	University	New Orleans	262	NA	NA
LA	Ochsner	New Orleans	209	29.5	29
LA	Louisiana State U.	Shreveport	NA	33.3	1
LA	Tulane	New Orleans	18	NA	NA
LA	Willis Knighton	Shreveport	189	22.2	9
MA	Children's	Boston	648	23.4	8
MA	New England Deaconess	Boston	648	28.3	41
MA	Massachusetts General	Boston	648	26.8	21
MA	New England	Boston	648	24.0	25
MA	Brigham & Women's	Boston	648	NA	NA
MD	Johns Hopkins	Baltimore	563	30.5	30
MD	U. Of Maryland	Baltimore	518	NA	NA
MI	Henry Ford	Detroit	161	26.7	5
MI	U. of Michigan	Ann Arbor	401	23.7	69
MN	Rochester Methodist	Rochester	182	13.3	50
MN	St. Mary's	Rochester	124	NA	NA
MN	U. Of Minnesota	Minneapolis	258	NA	NA
MO	Barnes	St. Louis	240	29.0	30
MO	Cardinal Glennon Memrl.	St. Louis	NA	20.0	2
MO	St. Louis Children's	St. Louis	222	29.4	6
MO	St. Louis U.	St. Louis	215	33.8	9
MS	U. Of Mississippi	Jackson	NA	33.3	1
NC	Carolinas	Charlotte	190	NA	NA
NC	Duke U.	Durham	210	39.0	22
NC	U. Of North Carolina	Chapel Hill	206	25.0	4
NE	U. Of Nebraska	Omaha	267	20.4	119
NJ	University	Newark	40	30.8	13
NM	U. Of New Mexico	Albuquerque	151	NA	NA
NY	Strong Memrl.	Rochester	174	NA	NA
NY	Mount Sinai	New York	215	19.2	67
NY	NYU	New York	NA	10.5	10
OH	Cleveland Clinic	Cleveland	394	24.1	22
OH	Children's	Columbus	NA	16.7	2
OH	Children's	Cincinnati	132	19.6	14
OH	Ohio State	Columbus	104	20.8	18
OH	U. Of Cincinnati	Cincinnati	258	18.5	7
OH	University	Cleveland	445	13.5	9
OK	Baptist	Okla. City	83	NA	NA
OK	University	Okla. City	NA	100.0	1
OR	Oregon Health Sciences	Portland	123	19.4	9
OR	VA	Portland	170	25.0	7
PA	Albert Einstein	Philadelphia	224	0.0	1
PA	Children's	Pittsburgh	323	20.8	72
PA	Children's	Philadelphia	124	37.5	11
PA	Presby.-U.	Pittsburgh	272	21.5	357
PA	St. Christopher For Childrn.	Philadelphia	368	12.5	12
PA	Thomas Jefferson U.	Philadelphia	348	31.9	18
PA	U. Of Penna.	Philadelphia	274	36.6	24
PA	VA	Pittsburgh	152	15.6	16
SC	Medical U.	Charleston	99	13.3	8
TN	Lebonheur Children's	Memphis	NA	11.1	2
TN	U. Of Tennessee	Memphis	96	29.0	13
TN	Vanderbilt	Nashville	71	20.0	10
TX	UTHSC at San Antonio	San Antonio	229	NA	NA
TX	Children's	Dallas	42	27.6	23
TX	Hermann	Houston	223	42.3	7
TX	St. Luke's Episcopal	Houston	175	NA	NA
TX	Methodist	Houston	NA	51.4	9
TX	Texas Children's	Houston	149	26.9	3
TX	Baylor U.	Dallas	233	18.7	109
TX	Wilford Hall	Lackland AFB	184	50.0	7
UT	Latter-Day Saints	Salt Lake City	82	30.0	15
VA	Fairfax	Falls Church	320	NA	NA
VA	Medical College Of Va.	Richmond	253	32.5	20
VA	U. of Va.	Charlottesville	100	21.5	27
WA	Children's	Seattle	NA	0.0	3
WA	University	Seattle	271	16.9	36
WI	Children's Of Wisconsin	Milwaukee	NA	0.0	4
WI	Froedtert Memrl. Luthrn.	Milwaukee	NA	26.8	14
WI	U. Of Wisconsin	Madison	54	15.4	57

KIDNEY

STATE	HOSPITAL	CITY	WAIT	M	V
AL	U. of Alabama	Birmingham	NA	5.9	255
AR	Baptist	Little Rock	581	6.3	16
AR	Arkansas	Little Rock	NA	9.4	8
AR	University	Little Rock	251	5.3	35
AZ	Good Samaritan	Phoenix	630	8.1	88
AZ	Healthwest Regional	Phoenix	NA	25.0	1
AZ	St. Joseph's	Phoenix	390	3.8	20
AZ	VA	Tucson	NA	11.0	21
AZ	University	Tucson	705	0.0	1
CA	St. Bernardine	San Bernardino	NA	5.7	27
CA	Alta Bates	Berkeley	NA	5.0	41
CA	Children's	Los Angeles	NA	2.7	19
CA	Cedars-Sinai	Los Angeles	733	4.8	42
CA	U. Of Calif-Irvine	Orange	NA	5.8	26
CA	LA County Harbor-UCLA	Torrance	NA	7.7	40
CA	St. Mary	Long Beach	NA	3.4	15
CA	Loma Linda U.	Loma Linda	NA	4.6	44
CA	Santa Rosa Memrl.	Santa Rosa	NA	6.7	22
CA	California Pacific	San Francisco	NA	8.1	171
CA	San Bernardino County	San Bernard	NA	9.9	18
CA	USC - L.A. County	Los Angeles	NA	10.8	30
CA	UCSD	San Diego	NA	5.2	89
CA	U. Of California	San Francisco	NA	7.0	232
CA	Sutter Memrl.	Sacramento	NA	12.5	26
CA	Donald N. Sharp Memrl.	San Diego	NA	2.0	15
CA	St. Joseph	Orange	NA	4.0	31
CA	U. of Calif. Davis	Sacramento	581	8.0	28
CA	Stanford U.	Palo Alto	NA	0.0	5
CA	St. Vincent	Los Angeles	NA	7.4	206
CA	UCLA	Los Angeles	NA	2.4	108
CA	USC	Los Angeles	NA	0.0	2
CA	Western	Santa Ana	NA	2.7	19
CO	Children's	Denver	NA	0.0	1
CO	Porter Memrl.	Denver	NA	8.9	23
CO	Presby/St. Luke's	Denver	672	9.0	70
CO	University	Denver	585	2.2	35
CT	Hartford	Hartford	481	8.7	64
CT	Yale New Haven	New Haven	NA	5.8	39
DC	Children's NMC	Washington	NA	11.8	9
DC	Georgetown U.	Washington	NA	5.6	37
DC	George Washington U.	Washington	NA	5.3	10
DC	Howard U.	Washington	381	23.1	15
DC	Washington	Washington	NA	5.0	123
DC	Walter Reed Army	Washington	NA	6.8	22
FL	All Children's	St. Petersburg	NA	9.1	4
FL	Florida	Orlando	289	7.1	78
FL	Southwest Florida	Fort Meyers	114	4.2	6
FL	Jackson Memrl.	Miami	166	4.7	94
FL	Methodist	Jacksonville	396	9.5	11
FL	Tampa General	Tampa	314	7.1	128
FL	Shands Teaching	Gainesville	451	6.2	133
GA	Henrietta Egleston	Atlanta	144	4.0	13
GA	Emory U.	Atlanta	412	3.5	117
GA	Medical College Of Georgia	Augusta	NA	4.1	67
GA	Piedmont	Atlanta	340	5.9	66
HI	St. Francis	Honolulu	NA	6.5	27
IA	Iowa Methodist	Des Moines	436	2.1	12
IA	U. Of Iowa	Iowa City	333	5.0	75
IA	Mercy Hospital	Des Moines	NA	16.2	10
IL	Children's Memrl.	Chicago	NA	2.0	13
IL	Loyola U.	Maywood	NA	4.2	42
IL	Memrl.	Springfield	332	8.2	12
IL	Northwestern Memrl.	Chicago	828	8.2	37
IL	Rush-Presby.-St. Luke's	Chicago	370	8.7	76
IL	St. Francis	Peoria	331	9.1	22
IL	U. Of Chicago	Chicago	NA	6.2	92
IL	U. Of Illinois	Chicago	NA	5.7	54
IL	Hines VA	Hines	NA	0.0	1
IN	Methodist	Indianapolis	419	2.4	52
IN	Indiana U.	Indianapolis	476	3.7	102
KS	St. Francis	Wichita	273	5.7	39
KS	U. Of Kansas	Kansas City	457	6.6	30
KY	Jewish	Louisville	NA	7.7	62
KY	Kosair Children's	Louisville	NA	6.3	4
KY	University	Lexington	215	8.0	57
LA	University	New Orleans	710	12.4	22
LA	Ochsner	New Orleans	388	3.9	40
LA	S. Baptist	New Orleans	NA	5.3	5
LA	Schumpert	Shreveport	391	3.2	18
LA	Louisiana State U.	Shreveport	NA	6.4	24
LA	Tulane	New Orleans	208	4.9	36
LA	Willis Knighton	Shreveport	584	7.5	21
MA	Beth Israel	Boston	NA	6.8	26
MA	Baystate	Springfield	490	6.5	27
MA	Boston U.	Boston	NA	9.2	27
MA	VA	Boston	NA	0.0	14
MA	Children's	Boston	NA	6.8	19
MA	New England Deaconess	Boston	NA	8.0	57
MA	Lahey	Burlington	NA	6.7	8
MA	Massachusetts General	Boston	NA	5.0	70
MA	New England	Boston	NA	4.5	28
MA	Brigham & Women's	Boston	NA	5.3	61
MA	U. of Massachusetts	Worcester	490	3.0	26
MD	Francis Scott Key	Baltimore	761	6.4	25
MD	Johns Hopkins	Baltimore	NA	8.5	54
MD	U. Of Maryland	Baltimore	NA	5.8	26
ME	Maine	Portland	NA	6.1	41
MI	William Beaumont	Royal Oak	850	3.5	36
MI	Children's	Detroit	313	5.9	NA
MI	Henry Ford	Detroit	NA	7.3	72
MI	Harper Grace	Detroit	NA	14.8	20
MI	Hurley	Flint	NA	6.0	15
MI	Borgess	Kalamazoo	NA	14.9	20
MI	St. John	Detroit	NA	8.7	12
MI	St. Mary's	Grand Rapids	NA	4.8	47
MI	U. of Michigan	Ann Arbor	NA	5.7	99
MN	Hennepin County	Minneapolis	NA	6.5	64
MN	Rochester Methodist	Rochester	626	3.6	70
MN	Metropolitan	Minneapolis	NA	5.9	9
MO	Barnes	St. Louis	387	4.4	79
MO	Cardinal Glennon Memrl.	St. Louis	NA	0.0	3
MO	St. Louis Children's	St. Louis	NA	4.1	12
MO	Children's Mercy	Kansas City	NA	0.0	1
MO	DePaul	Bridgeton	NA	0.0	7
MO	St. Luke's	Kansas City	245	8.6	41
MO	Research	Kansas City	733	4.9	26
MO	St. Louis U.	St. Louis	NA	7.4	42
MO	University	Columbia	271	8.3	34
MS	U. Of Mississippi	Jackson	NA	3.6	21
NC	North Carolina Baptist	Winst.-Salem	NA	6.2	37
NC	Carolinas	Charlotte	302	10.0	51
NC	Duke U.	Durham	NA	4.4	63
NC	VA	Durham	NA	8.1	8
NC	Pitt County Memrl.	Greenville	NA	10.9	26
NC	U. Of North Carolina	Chapel Hill	810	4.8	39
ND	Dakota	Fargo	NA	7.7	3
ND	Medcenter One	Bismarck	NA	0.0	7
ND	St. Luke's	Fargo	NA	13.3	4
NE	Bishop Clarkson Memrl.	Omaha	338	3.5	57
NE	AMI St. Joseph	Omaha	381	4.9	11
NE	U. Of Nebraska	Omaha	406	0.0	1
NJ	Newark Beth Israel	Newark	NA	8.2	42
NJ	Our Lady Of Lourdes	Camden	450	6.3	21
NJ	St. Barnabas	Livingston	NA	9.4	49
NM	U. Of New Mexico	Albuquerque	461	4.5	39
NM	Presby.	Albuquerque	468	12.1	23
NV	Sunrise	Las Vegas	475	9.4	8
NV	U.M.C. Of S. Nevada	Las Vegas	417	3.7	7
NY	Albany	Albany	536	4.2	60
NY	Children's	Buffalo	NA	5.6	5
NY	Buffalo General	Buffalo	NA	9.0	25
NY	Presby.	New York	NA	5.7	53
NY	Suny Downstate/U.	Brooklyn	NA	5.2	77
NY	Erie County	Buffalo	654	12.2	12
NY	Strong Memrl.	Rochester	249	6.6	45
NY	Montefiore	Bronx	NA	3.4	75
NY	Mount Sinai	New York	812	4.7	39
NY	New York	New York	NA	8.5	53
NY	University	Stony Brook	583	4.1	31
NY	St. Luke's-Roosevelt	New York	NA	5.8	17
NY	NYU	New York	NA	10.0	5
NY	Suny at Syracuse	Syracuse	414	10.3	32
NY	Westchester County	Valhalla	727	4.6	35
OH	Akron City	Akron	NA	4.6	27
OH	Children's	Akron	NA	0.0	3
OH	Cleveland Clinic	Cleveland	NA	5.7	80
OH	Children's	Cincinnati	NA	8.1	10
OH	Medical College Of Ohio	Toledo	216	6.5	42
OH	Miami Valley	Dayton	204	5.7	22
OH	Ohio State U.	Columbus	431	8.6	180
OH	St. Elizabeth	Youngstown	NA	5.1	15
OH	Christ	Cincinnati	260	4.5	39
OH	U. Of Cincinnati	Cincinnati	174	6.1	40
OH	University	Cleveland	NA	5.1	52

OK	Baptist	Okla. City	230	10.5	27
OK	Children's	Okla. City	NA	7.8	13
OK	Hillcrest	Tulsa	490	9.9	23
OK	University	Okla. City	559	6.3	21
OK	St. Anthony	Okla. City	436	16.2	27
OR	Oregon Health Sciences	Portland	147	3.4	118
PA	Albert Einstein	Philadelphia	NA	8.4	57
PA	Allegheny General	Pittsburgh	520	6.8	67
PA	Children's	Pittsburgh	205	3.8	7
PA	Geisinger	Danville	486	13.5	36
PA	Penn St/Hershey	Hershey	858	5.4	65
PA	Hahnemann U.	Philadelphia	607	5.3	34
PA	Lehigh Valley	Allentown	838	0.0	1
PA	Presby.-U.	Pittsburgh	79	7.0	195
PA	St. Christopher For Childrn.	Philadelphia	NA	2.7	19
PA	Thomas Jefferson U.	Philadelphia	NA	2.4	75
PA	Temple U.	Philadelphia	438	0.0	7
PA	U. Of Penna.	Philadelphia	822	3.7	119
PR	Auxilio Mutuo	Hato Rey	NA	8.3	36
SC	Medical U.	Charleston	NA	4.3	88
TN	Erlanger	Chattanooga	434	4.5	17
TN	Johnson City	Johnson City	309	4.2	6
TN	Lebonheur Children's	Memphis	NA	10.0	5
TN	VA	Nashville	NA	7.6	12
TN	Centennial /Parkview	Nashville	487	1.7	15
TN	St. Thomas	Nashville	NA	0.0	5
TN	U. Of Tennessee	Knoxville	NA	5.8	36
TN	U. Of Tennessee	Memphis	514	6.8	70
TN	Vanderbilt	Nashville	NA	2.9	86
TX	Brackenridge	Austin	437	3.3	31
TX	UTHSC at San Antonio	San Antonio	427	10.0	15
TX	Children's	Dallas	210	8.5	12
TX	Harris Methodist	Fort Worth	54	2.0	25
TX	Hermann	Houston	NA	7.5	103
TX	St. Luke's Episcopal	Houston	333	7.9	33
TX	San Antonio Regional	San Antonio	611	5.6	83
TX	U. Of Texas	Galveston	344	6.5	72
TX	University	Lubbock	154	5.1	10
TX	Methodist	Lubbock	163	0.0	7
TX	Methodist	Dallas	315	4.1	109
TX	Methodist	Houston	466	3.6	43
TX	Parkland Memrl.	Dallas	763	5.2	56
TX	Sierra	El Paso	368	0.0	3
TX	Texas Children's	Houston	188	4.5	6
TX	Baylor U.	Dallas	376	7.1	46
TX	East Texas	Tyler	227	2.6	19
TX	Wilford Hall	Lackland AFB	345	7.2	46
UT	Latter-Day Saints	Salt Lake City	360	11.8	76
UT	U. Of Utah	Salt Lake City	328	4.7	48
VA	Henrico Doctors	Richmond	NA	4.2	6
VA	Medical College Of Va.	Richmond	NA	4.2	48
VA	Sentara Norfolk General	Norfolk	657	8.6	60
VA	U. of Va.	Charlottesville	388	4.3	47
VT	Medical Center Of Vermont	Burlington	NA	13.9	21
WA	Children's	Seattle	NA	4.0	6
WA	Sacred Heart	Spokane	193	7.9	27
WA	Swedish	Seattle	NA	7.5	56
WA	University	Seattle	NA	4.6	38
WA	Va. Mason	Seattle	759	7.3	97
WI	Children's Of Wisconsin	Milwaukee	NA	4.8	6
WI	Froedtert Memrl. Luthrn.	Milwaukee	725	7.3	114
WI	U. Of Wisconsin	Madison	754	2.9	202
WV	Charleston Area	Charleston	NA	8.6	25
WV	West Va. U.	Morgantown	666	4.7	13

LUNG

STATE	HOSPITAL	CITY	WAIT	M	V
AL	U. of Alabama	Birmingham	77	33.3	3
AZ	University	Tucson	NA	37.5	4
CA	Cedars-Sinai	Los Angeles	273	43.3	8
CA	UCSD	San Diego	371	5.6	9
CA	U. Of California	San Francisco	269	0.0	1
CA	Donald N. Sharp Memrl.	San Diego	NA	33.3	2
CA	U. of Calif. Davis	Sacramento	130	NA	NA
CA	Stanford U.	Palo Alto	363	34.8	8
CA	UCLA	Los Angeles	417	33.3	2
CO	Presby./St. Luke's	Denver	NA	77.8	2
CO	University	Denver	333	NA	NA
FL	Shands Teaching	Gainesville	124	NA	NA
GA	Emory U.	Atlanta	239	NA	NA
IA	U. Of Iowa	Iowa City	NA	57.1	2
IL	Loyola U.	Maywood	274	40.0	4
IL	U. Of Illinois	Chicago	282	NA	NA
IN	Methodist	Indianapolis	598	0.0	7
IN	Indiana U.	Indianapolis	NA	25.0	4
IN	Lutheran	Fort Wayne	NA	60.0	2
KY	Jewish	Louisville	233	0.0	1
KY	University	Lexington	114	100.0	1
LA	Ochsner	New Orleans	43	50.0	2
MA	Children's	Boston	NA	50.0	1
MA	Mass. General	Boston	NA	28.6	7
MA	Brigham & Women's	Boston	NA	27.3	7
MI	U. of Michigan	Ann Arbor	793	30.0	10
MN	Abbott-Northwestern	Minneapolis	NA	22.2	2
MN	St. Mary's	Rochester	NA	33.3	3
MN	U. Of Minnesota	Minneapolis	366	19.4	8
MO	Barnes	St. Louis	690	23.6	27
MO	St. Louis Children's	St. Louis	408	53.8	7
MO	St. Louis U.	St. Louis	NA	28.6	2
MS	U. Of Mississippi	Jackson	NA	66.7	3
NC	Duke U.	Durham	449	NA	NA
NC	U. Of North Carolina	Chapel Hill	762	16.7	18
NJ	Newark Beth Israel	Newark	347	NA	NA
NY	Presbyterian	New York	801	36.1	12
OH	Cleveland Clinic	Cleveland	332	43.5	12
OK	Baptist	Okla. City	NA	33.3	3
PA	Children's	Pittsburgh	NA	16.7	2
PA	Children's	Philadelphia	62	NA	NA
PA	Temple U.	Philadelphia	148	NA	NA
SC	Medical U.	Charleston	99	NA	NA
TN	Baptist Memrl.	Memphis	NA	50.0	2
TN	Vanderbilt	Nashville	80	0.0	7
TX	UTHSC at San Antonio	San Antonio	317	35.8	13
TX	San Antonio Regional	San Antonio	NA	100.0	1
TX	Methodist	Houston	126	43.2	6
TX	St. Paul	Dallas	NA	100.0	1
TX	Baylor	Dallas	180	75.0	2
VA	Fairfax	Falls Church	NA	0.0	1
VA	Medical College Of Va.	Richmond	NA	0.0	3
VA	McGuire VA	Richmond	NA	100.0	1
VA	U. of Va.	Charlottesville	528	30.0	5
WA	Sacred Heart	Spokane	NA	25.0	8
WA	University	Seattle	246	NA	NA
WI	John L. Doyne	Milwaukee	155	0.0	2
WI	U. of Wisconsin	Madison	162	50.0	1

PANCREAS

STATE	HOSPITAL	CITY	WAIT	M	V
AL	U. of Alabama	Birmingham	NA	31.8	6
AR	University	Little Rock	NA	16.7	6
CA	California Pacific	San Francisco	NA	30.8	4
CA	U. Of California	San Francisco	NA	2.9	12
CA	U. of Calif. Davis	Sacramento	NA	12.5	3
CA	Stanford U.	Palo Alto	NA	0.0	1
CA	UCLA	Los Angeles	NA	0.0	1
CO	Presby./St. Luke's	Denver	NA	22.2	3
DC	Georgetown U.	Washington	NA	0.0	4
DC	Washington	Washington	NA	10.0	10
FL	Jackson Memrl.	Miami	NA	0.0	3
IA	U. Of Iowa	Iowa City	NA	12.9	16
IL	U. Of Chicago	Chicago	NA	7.9	16
IL	U. Of Illinois	Chicago	NA	33.3	6
IN	Indiana U.	Indianapolis	NA	14.3	5
KS	St. Francis	Wichita	NA	25.0	1
KY	Jewish	Louisville	NA	15.0	5
LA	Ochsner	New Orleans	NA	0.0	7
MD	U. Of Maryland	Baltimore	600	0.0	9
MA	Beth Israel	Boston	NA	20.0	3
MA	New England Deaconess	Boston	NA	3.6	7
MA	Massachusetts General	Boston	NA	8	8
MI	Henry Ford	Detroit	NA	11.1	2
MI	U. of Michigan	Ann Arbor	NA	50.0	1
MN	Rochester Methodist	Rochester	NA	8.3	9
MN	U. Of Minnesota	Minneapolis	181	11.2	49
MO	St. Louis U.	St. Louis	NA	5.9	9
NC	Duke U.	Durham	NA	5.9	12
NE	Bishop Clarkson Memrl.	Omaha	NA	4.2	24
NY	Montefiore	Bronx	NA	50.0	1
OH	Cleveland Clinic	Cleveland	NA	8.3	4
OH	Ohio State	Columbus	290	7.6	33
OH	U. Of Cincinnati	Cincinnati	NA	10.5	5
OH	University	Cleveland	NA	5.0	10
OR	Oregon Health Sciences	Portland	NA	6.7	5
PA	Albert Einstein	Philadelphia	NA	11.1	11
PA	Allegheny General	Pittsburgh	NA	40.0	3
PA	Penn St/Hershey	Hershey	NA	0.0	3
PA	U. Of Penna.	Philadelphia	NA	2.5	10
SC	Medical U.	Charleston	99	11.1	9
TN	Centennial /Parkview	Nashville	NA	0.0	3
TN	U. Of Tennessee	Memphis	NA	13.0	15
TN	Vanderbilt	Nashville	NA	17.6	6
TX	U. Of Texas	Galveston	NA	9.1	8
TX	Methodist	Dallas	NA	0.0	7
TX	Methodist	Houston	NA	15.4	7
TX	Parkland Memrl.	Dallas	NA	9.1	6
TX	Wilford Hall	Lackland AFB	NA	27.3	4
UT	Latter-Day Saints	Salt Lake City	NA	17.4	12
VA	U. of Va.	Charlottesville	NA	5.3	5
WA	University	Seattle	NA	3.6	14
WI	Froedtert Memrl. Luthrn.	Milwaukee	NA	7.9	10
WI	U. Of Wisconsin	Madison	NA	4.3	41

HEART-LUNG

STATE	HOSPITAL	CITY	WAIT	M	V
AL	U. of Alabama	Birmingham	NA	0.0	1
AZ	University	Tucson	NA	26.7	4
CA	UCSD	San Diego	NA	0.0	1
CA	Stanford U.	Palo Alto	535	33.3	14
CO	Presby./St. Luke's	Denver	NA	75.0	1
GA	Emory U.	Atlanta	NA	75.0	1
IA	U. Of Iowa	Iowa City	NA	100.0	1
IL	Loyola U.	Maywood	NA	60.0	2
IN	Methodist	Indianapolis	NA	50.0	1
LA	Ochsner	New Orleans	NA	0.0	1
MI	U. of Michigan	Ann Arbor	NA	100.0	1
MN	Abbott-Northwestern	Minneapolis	NA	16.7	2
MN	U. Of Minnesota	Minneapolis	NA	20.0	5
MO	St. Louis U.	St. Louis	NA	75.0	1
NC	U. Of North Carolina	Chapel Hill	NA	50.0	2
NY	Presby.	New York	NA	63.6	3
PA	Children's	Pittsburgh	NA	0.0	2
PA	Presby.-U.	Pittsburgh	NA	43.5	6
TN	Baptist Memrl.	Memphis	NA	0.0	1
TN	Vanderbilt	Nashville	NA	33.3	3
TX	San Antonio Regional	San Antonio	147	75.0	1
TX	Baylor	Dallas	NA	100.0	2
VA	Medical College Of Va.	Richmond	NA	25.0	1
VA	McGuire VA	Richmond	NA	100.0	1
VA	U. of Va.	Charlottesville	NA	100.0	2
WI	U. Of Wisconsin	Madison	NA	0.0	1