SPECIAL ARTICLE

# Estimating the Number of Potential Organ Donors in the United States

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## ABSTRACT

### BACKGROUND

As the need for transplantable organs increases, waiting lists of patients become longer. We studied the size and composition of the national pool of brain-dead organ donors during a three-year period and, on the basis of these data, considered ways to increase the rate of donation.

### METHODS

We reviewed hospital medical records of deaths occurring in the intensive care unit from 1997 through 1999 in the service areas of 36 organ-procurement organizations to identify brain-dead potential organ donors. We examined data on characteristics of the potential donors, the processes of referral to organ-procurement organizations and of requesting donations, and the hospitals.

### RESULTS

We identified a total of 18,524 brain-dead potential organ donors during the study period. The predicted annual number of brain-dead potential organ donors is between 10,500 and 13,800. The overall consent rate (the number of families agreeing to donate divided by the number of families asked to donate) for 1997 through 1999 was 54 percent, and the overall conversion rate (the number of actual donors divided by the number of potential donors) was 42 percent. Hospitals with 150 or more beds were more likely than smaller hospitals to have potential donors and actual donors ($P<0.001$); 19 percent of hospitals accounted for 80 percent of all potential donors. Calculations of the number of donors per million persons in the general population did not correlate well with the performance of organ-procurement organizations as measured by the conversion rate.

### CONCLUSIONS

Lack of consent to a request for donation was the primary cause of the gap between the number of potential donors and the number of actual donors. Since potential and actual donors are highly concentrated in larger hospitals, resources invested to improve the process of obtaining consent in larger hospitals should maximize the rate of organ recovery. The performance of organ-procurement organizations can be assessed objectively through the comparison of the number of actual donors with the number of potential donors in the given service area.

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THE DEMAND FOR TRANSPLANTABLE organs continues to increase, while the organizations involved in the procurement of organs struggle with a stagnant or possibly diminishing pool of potential organ donors.[1] As of July 7, 2003, a total of 82,117 patients were waiting for a solid-organ transplant.[2]

The shortage of organs raises questions about the size of the national donor pool. Have organ-procurement organizations reached the limit of the number of organs that can be recovered? How many brain-dead potential donors are there each year? Do geographic regions vary in organ-donation potential? Is the rate of conversion of potential organ donors to actual donors uniform throughout the United States? Without quantification of the pool of potential donors, it is impossible to evaluate fairly either individual organ-procurement organizations or the overall procurement system.

Data-driven analysis of the pool of potential donors is essential for making appropriate changes to the system currently used by the Centers for Medicare and Medicaid Services to evaluate the performance of organ-procurement organizations. The number of donors per million population is currently used to determine whether organ-procurement organizations are recovering organs from an adequate number of donors. Proponents may defend the current measure as objective, timely, and inexpensive; most observers argue, however, that this measure is flawed because it is insensitive to regional variations in health status, mortality patterns, medical practice, and demographics.[1,3,4]

The Task Force on Organ Transplantation of the Department of Health and Human Services has estimated that the number of brain-dead potential organ donors in the United States ranges from 17,000 to 26,000 per year; this estimate was based in part on a three-state review of medical charts conducted by the Centers for Disease Control in 1975.[5] The Pennsylvania Statewide Donor Study reviewed hospital medical records from 1987 and estimated the size of the pool as 10,000 to 14,000 brain-dead potential donors per year.[6] Using similar methods for reviewing charts in the geographic areas encompassed by four organ-procurement organizations, the Partnership for Organ Donation corroborated the results of the Pennsylvania study with an estimate of 12,600 to 15,100 brain-dead potential donors per year.[7] Other studies relying on mortality data have suggested different estimates — both higher and lower — of the number of potential donors.[8,9] The methods of studies based on mortality data are considered inferior to the use of chart reviews, because the estimates are derived from data bases of death certificates, which provide insufficient information for determining a person's suitability for organ donation.

## METHODS

### POTENTIAL ORGAN DONORS

In 1996, the national Association of Organ Procurement Organizations invited all federally designated organ-procurement organizations to participate in a study of hospital death records in order to estimate the size and composition of the pool of brain-dead potential organ donors and to evaluate the validity of the number of donors per million population as a measure of their performance. A "potential organ donor" was defined as a patient who met the criteria for brain death with no absolute contraindication to organ donation as defined by a standardized list of codes from the *International Classification of Diseases, Ninth Revision* (ICD-9), such as those for metastatic cancer and seropositivity for human immunodeficiency virus. A patient was considered to meet the criteria for brain death if evidence of any or all of the following was found in the hospital chart: the absence of spontaneous respiration and two additional brain-stem reflexes; a physician's note declaring brain death; a flat electroencephalogram; or other brain studies indicating irreversible destruction of the brain.

### DEFINITION OF RATES

The conversion rate was defined as the number of actual donors divided by the number of potential donors. The referral rate was defined as the number of medically suitable patients referred by the hospital staff to the organ-procurement organization divided by the number of potential donors. The request rate was defined as the number of families who were asked to donate a family member's organs divided by the number of potential donors. The consent rate was defined as the number of families of medically suitable patients agreeing to donate the patient's organs, divided by the number of families who were asked to donate.

### STUDY DATA

Trained staff members of organ-procurement organizations reviewed the hospital charts for all deaths that occurred in the intensive care unit among

patients 70 years of age or younger who had no absolute contraindication to organ donation. A form was completed for each patient who met the criteria for brain death (whether or not brain death had been declared). Data were collected on the demographic characteristics of the patient, the processes of referral to organ-procurement organizations and requesting consent for donation, and the donation outcome. Data were also collected on characteristics of the hospital that were hypothesized to be related to its organ-donor potential, including the number of beds for acute care and for critical care, the presence or absence of particular services such as trauma and neurosurgery, and the type and location of the hospital. The study was deemed to be exempt from review by the human subjects committee, since patient identifiers were removed from the information entered into the data base before it was submitted, according to the standards of the Division of Transplantation of the Department of Health and Human Services, as well as those of the United Network for Organ Sharing.

Quality-assurance procedures were followed to ensure that the data submitted matched the information on donor activity reported to the Centers for Medicare and Medicaid Services. A study liaison at each organ-procurement organization was contacted in order to resolve discrepancies.

### STATISTICAL ANALYSIS

The statistical analyses were performed with the use of SAS software (SAS Institute). Descriptive statistics were used to examine the averages and ranges of the rates of conversion, request, and consent according to the particular organ-procurement organization. For the evaluation of measures of the performance of organ-procurement organizations, the analysis was limited to the 16 organ-procurement organizations that had submitted complete data for 1997, 1998, and 1999.

## RESULTS

### ESTIMATING THE SIZE OF THE NATIONAL DONOR POOL

A total of 36 organ-procurement organizations submitted data for 1997 through 1999: 33 for 1997, 28 for 1998, and 25 for 1999. The decrease in the number of participating organizations was to be expected, given the resources required to conduct chart reviews in all hospitals. The profile of organizations that dropped out of the study suggested no bias or pattern in the sample of participants in terms of geographic location, size of the organization, or other characteristics.

Table 1 contains information on donors and potential donors in the study, as well as the total number of actual donors in the United States in 1997, 1998, and 1999. The number of donors included in the study represents 50 percent of the total number of actual donors in the United States in 1997, 45 percent of the total in 1998, and 41 percent of the total in 1999. The participating organ-procurement organizations serve a population of more than 140 million people and represent a broad geographic distribution that includes rural and urban areas (Fig. 1).

According to the 1990 U.S. Census, 75.1 percent of the U.S. population was white, as compared with 74.6 percent of the population served by all participating organ-procurement organizations and 77.6 percent of that served by the 16 organ-procurement organizations that submitted complete data for 1997 through 1999 ($P<0.001$ for both comparisons with the U.S. population) (Table 2). There was a smaller proportion of blacks in the participating organizations than in the United States overall (12.3 percent of the population of the United States was black, as compared with 10.7 percent of the populations served by all the participating organ-procurement organizations and 9.1 percent of the populations served by the 16 organizations that submitted complete data; $P<0.001$ for both comparisons with the U.S. population).

We examined the demographic characteristics of brain-dead organ donors in all participating organ-procurement organizations, in the subgroup of the 16 that submitted complete data, and in all U.S. organizations. Given the large sample size, chi-square tests for the difference between proportions were able to detect differences below the 0.01 level

**Table 1. Estimates of the Donor Pool.**

| Variable | 1997 | 1998 | 1999 |
|---|---|---|---|
| | | *no. of donors* | |
| U.S. donors* | 5,477 | 5,801 | 5,849 |
| Donors in the study | 2,763 | 2,628 | 2,399 |
| Potential donors in the study | 6,843 | 6,219 | 5,462 |
| Estimate of national pool | 13,565 | 13,728 | 13,317 |

* Data are from the United Network for Organ Sharing.[2]


**AROR** Arkansas Regional Organ Recovery Agency
**CADN** California Transplant Donor Network
**CAGS** Golden State Donor Services
**CAOP** One Legacy
**CORS** Donor Alliance
**CTOP** LifeChoice Donor Services
**DCTC** Washington Regional Transplant Consortium
**FLFH** TransLife/Florida Hospital
**IAOP** Iowa Donor Network
**ILIP** Gift of Hope Organ and Tissue Donor Network
**INOP** Indiana Organ Procurement Organization
**LAOP** Louisiana Organ Procurement Agency
**MAOB** New England Organ Bank
**MNOP** LifeSource, Upper Midwest Organ Procurement Organization
**MOMA** Mid-America Transplant Services
**MWOB** Midwest Transplant Network
**NJTO** New Jersey Organ and Tissue Sharing Network
**NVLV** Nevada Donor Network
**NYAP** Center for Donation and Transplant
**NYRT** New York Organ Donor Network
**NYWN** Upstate New York Transplant Services
**OHLB** LifeBanc
**OHLP** LifeLine of Ohio Organ Procurement Agency
**OHOV** Ohio Valley LifeCenter
**ORUO** Pacific Northwest Transplant Bank
**PADV** Gift of Life Donor Program
**TNMS** Mid-South Transplant Foundation
**TXGC** LifeGift Organ Donation Center
**TXSB** Southwest Transplant Alliance
**UTOP** Intermountain Organ Recovery Systems
**WALC** LifeCenter Northwest Donor Network
**VATB** LifeNet
**WISE** Wisconsin Donor Network

**Figure 1. Organ-Procurement Organizations Submitting Data from a Review of Death Records.**
Three organizations that submitted data subsequently merged with other organizations.

of significance, but the three groups were similar with respect to the proportion of actual donors who were 18 years of age or younger (19.8 percent among all participating organizations, 19.6 percent among the 16 organizations with complete data, and 19.3 percent among all organizations in the United States), the proportion of donors who were older than 65 years of age (7.4 percent, 7.3 percent, and 7.1 percent, respectively), the proportion who were male (59.1 percent, 60.0 percent, and 59.3 percent, respectively), and the proportion who had died from trauma (43.7 percent, 44.8 percent, and 44.8 percent, respectively).

Two methods were used to derive an estimate of the number of potential donors per year, which we estimated to be 10,500 to 13,800. First, the conver-

sion rate in the study (the number of actual donors in the study divided by the number of potential donors in the study) was applied to the total number of actual donors in the United States. And second, the number of potential donors in our sample population was extrapolated to the national population. When the annual conversion rate was applied to the number of actual donors in the United States in 1997, 1998, and 1999, the estimated size of the national pool of potential donors was calculated to be between 13,300 and 13,800 (Table 1). The extrapolation technique involved dividing the number of potential organ donors for each year of the study by 28.4 percent (79.9 million divided by 281.4 million), which is the proportion of the U.S. population served by the subgroup of 16 organizations that provided complete data. The resulting estimate of potential donors was 10,845 for 1997, 10,465 for 1998, and 10,754 for 1999. Both estimates are consistent with estimates derived by Nathan et al.[6] and Gortmaker et al.[7] However, extrapolation to the national pool could be misleading if the participating organ-procurement organizations were not representative of all organ-procurement organizations.

**Table 2. Racial Distribution.***

| Population | White | Black | Other |
|---|---|---|---|
| | | *percent* | |
| U.S. population | 75.1 | 12.3 | 12.6 |
| 36 Participating organ-procurement organizations | 74.6 | 10.7 | 14.7 |
| 16 Organ-procurement organizations with complete data | 77.6 | 9.1 | 13.3 |

* Data on the U.S. population are from the Census 2000 summary file of the U.S. Census Bureau.

### POTENTIAL-DONOR OUTCOMES

Forty-two percent of potential donors (7790 of 18,524) became actual donors. Among the identified potential donors in the study, consent for donation was not obtained in 39 percent of the cases, and the families were not asked for organ donations in 16 percent of the cases. In 3 percent of the cases, organs were not donated for other reasons, such as restrictions imposed by the medical examiner, the occurrence of cardiac arrest in the patient, precluding organ recovery, or the lack of a family member who could give consent. The consent rate for the study period was 54 percent (8308 donors for whom consent was obtained out of 15,500 families who were asked to donate).

### FINDINGS ACCORDING TO CHARACTERISTICS OF THE HOSPITAL

The number of beds in the hospital correlated positively with the numbers of potential and actual organ donors. Eighty-nine percent of potential donors and 91 percent of actual donors were cared for in hospitals with 150 or more beds, and 88 percent of all potential donors who did not ultimately donate organs were in hospitals with 150 or more beds. Hospitals with 350 or more beds had an average of 0.015 potential donor per bed per year; hospitals with 150 to 349 beds had an average of 0.012 potential donor per bed; and hospitals with fewer than 150 beds had an average of 0.006 potential donor per bed ($P<0.001$). Despite variation in the frequency of potential donors, the rate of conversion of potential donors to actual donors was similar irrespective of the size of the hospital. The conversion rate was 43.1 percent in hospitals with 350 or more beds, 42.9 percent in those with 150 to 349 beds, 37.3 percent in those with 50 to 149 beds, and 43.1 percent in those with fewer than 50 beds.

The 434 hospitals in our sample with the greatest numbers of potential donors (19 percent of the sample of 2239 hospitals) accounted for 80 percent of all potential donors in the study. The presence of a neurosurgical service in a hospital was directly correlated with the number of potential organ donors, as was the presence of an emergency department. The presence of a transplantation program was not a significant predictor of the number of potential donors, but hospitals with a transplantation program recovered organs from a higher percentage of potential donors than hospitals with no such programs (45.5 percent in hospitals with a transplantation program vs. 40.3 percent in hospitals with no transplantation program).

### RESULTS ACCORDING TO ORGAN-PROCUREMENT ORGANIZATION

Among the 16 organ-procurement organizations that submitted complete data on a minimum of 90 percent of donors for each of the three study years, the number of potential donors per year ranged from 28 to 63 potential donors per million population (mean, 41). The number of actual donors per year ranged from 16 to 28 per million population (mean, 20). The conversion rate, one measure of efficiency, also varied among the 16 organizations

with complete data: 32 to 58 percent of potential donors became actual donors (mean, 49 percent). We found no significant correlation between the number of actual donors per million population and the conversion rate for the study period ($R^2$= 0.124) (Fig. 2).

Three factors in the donation process appeared to affect the conversion rate: the rate of hospital referral, the rate of requests made to families, and the rate of consent by families. The mean referral rate was 80 percent in our sample, and the mean request rate was 84 percent (Fig. 3). The mean consent rate was 54 percent.

A variety of factors were associated with lower rates of conversion, including older age, nonwhite race, and death from causes other than trauma. The mean (±SD) age of actual donors was lower than that of nondonors (35.8±18.3 among 7775 donors vs. 42.9±19.3 among 10,771 nondonors, P<0.001). A total of 49 percent of white potential donors (6422 of 13,074) became actual donors, as compared with 25 percent of potential donors of other races (1368 of 5450, P<0.001). Donations occurred in the cases of 55 percent of potential donors who died from trauma (3766 of 6901), as compared with 35 percent of potential donors who died from other causes (4023 of 11,621, P<0.001).

## DISCUSSION

Our data confirm previous estimates that the pool of brain-dead potential organ donors in the United States comprises between 10,500 and 13,800 patients per year. With the broad participation of organ-procurement organizations, the large number of hospitals they serve, and the multiyear data we collected, our study supports the observation that the pool of brain-dead potential organ donors is, at best, stable.

Organ-procurement organizations, hospitals, transplantation professionals, and the government have made substantial progress in improving the efficiency of the organ-procurement system over the past decade. During the 1990s, the rates of identification of potential donors and referral to organ-procurement organizations increased, as did the rate of requests for donation. Gortmaker et al. reported that, in 1990, organs were not recovered from 27 percent of potential donors because they had not been identified as potential donors or because no one requested an organ donation from the patient's family.[7] Our data indicate that by the time of our study period (1997 through 1999), this proportion had been reduced to 16 percent of potential donors. This improvement is probably attributable, at least in part, to the implementation of the Medicare Conditions of Participation for hospitals concerning organ donation. These conditions require that all deaths be reported to an organ-procurement organization for consideration and that requests for donation be made by trained "expert" requesters.[10]

The rates of consent and conversion have increased as well. Gortmaker et al. reported a 33 percent conversion rate for 1990,[7] whereas we found an average conversion rate of 42 percent for 1997 through 1999. Similarly, the 1990 consent rate from the study by Gortmaker et al. averaged 48 percent, whereas data from 1997 through 1999 suggest that the consent rate had increased to 54 percent.

Although chart review is seen as the gold standard for the assessment of the number of potential organ donors at the levels of the hospital and the organ-procurement organization, it may be fairly criticized because the data are self-reported and are collected by many chart abstracters. To address this limitation, efforts were made in our study to ensure consistency in data collection through the use of didactic and case-based training of abstracters. High degrees of interrater reliability in the review of death records, as measured by the re-review of medical records by independent reviewers, have been reported by Gortmaker et al.[7] and Christiansen et al.[11] In addition, the wide variation among the 36 organ-procurement organizations in the rate of conversion of potential donors to actual donors (range, 26 percent to 65 percent) suggests that there was

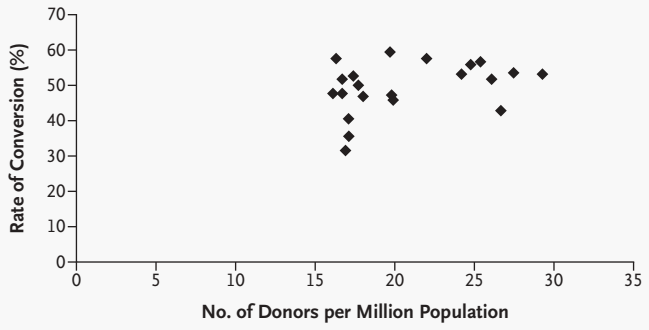


**Figure 2. Relation between the Number of Donors per Million Population in the Service Area of an Organ-Procurement Organization and the Rate of Conversion of Potential Donors to Actual Donors, 1997 through 1999.**
$R^2$=0.124; P for trend=0.12.

no systematic bias in the collection of data by staff members.

The greatest opportunity for increasing the rate of donation from the pool of brain-dead potential donors lies in increasing the consent rate. Many studies have attempted to determine what factors influence families' willingness to donate a patient's organs.[12-15] The organ-procurement community needs to understand how and why a patient's age and ethnic background, as well as how he or she died, influence the likelihood that families will consent to donate organs. Legislation in several states has created donor registries that allow the living to record their wishes regarding organ donation electronically for easy retrieval; such registries may hold promise for increasing the rate of consent. Other strategies that have been considered for increasing the rate of consent include the presumption of consent or offers of financial gifts to families who donate organs. Although it is impossible to predict the effect of any new initiative on the willingness of families to donate organs, it is also imperative to assess the potential effect of their implementation.

Our finding that the highest proportion of potential organ donors is found in hospitals with 150 or more beds suggests that a total of 1000 hospitals in the United States care for the majority of potential donors and already account for more than 80 percent of actual organ donors. The theory that there are institutions with a large undiscovered potential for organ donation is not supported by our findings.[16] Thus, resources should be invested in those hospitals where organs are already being recovered. The development of strong relationships between hospitals and organ-procurement organizations and the implementation of clear standards of practice for the obtaining of consent and the handling of organ donations should result in increases in the rate of donation. In addition, the Centers for Medicare and Medicaid Services should hold hospitals accountable for active and timely participation in the process of identification of potential donors, referral to organ-procurement organizations, and collaboration with these organizations.

Even in an ideal world in which all brain-dead potential donors became actual donors and the demand for organs remained constant rather than increasing, the supply of organs from brain-dead donors could not meet the needs of all the patients on waiting lists. The situation varies somewhat depending on the organ needed. For example, if all potential donors became actual donors, the supply of cadaveric kidneys and hearts could accommodate the number of new patients added to the waiting list in 2002 and help to reduce the current backlog. However, even if livers were successfully recovered from all potential donors at the same rate at which they are currently recovered from actual donors, the supply would be insufficient to meet the demand of the annual additions to waiting lists.

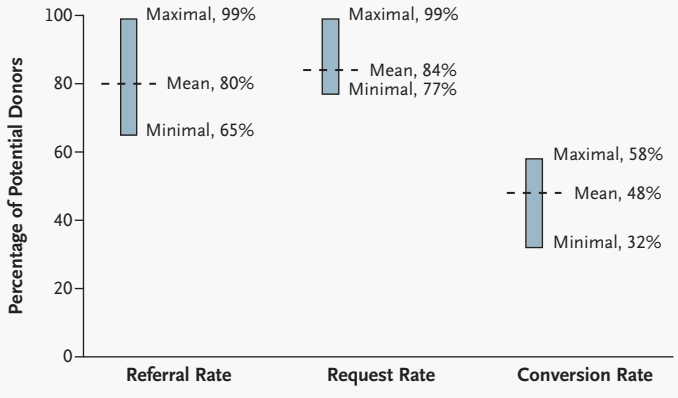


**Figure 3. Range of Rates of Referral, Requests, and Conversions among the 16 Organ-Procurement Organizations with Complete Data for 1997 through 1999.**

The referral rate is the number of medically suitable patients referred by hospital staff to the organ-procurement organization divided by the number of potential donors; the request rate is the number of families that were asked to donate a family member's organs divided by the number of potential donors; and the conversion rate is the number of actual donors divided by the number of potential donors. The overall consent rate (the number of donors for whom consent was obtained divided by the number of families that were asked) was 54 percent; consent rates for particular organizations ranged from 42 percent to 69 percent.

Our study suggests that the assessment of the performance of organ-procurement organizations on the basis of the number of donors per million population could lead to the miscategorization as underperformers of some organizations facing smaller numbers of potential donors. Since the number of donors per million population correlates only weakly with the proportion of potential donors who become actual donors, organ-procurement organizations should not be evaluated solely on the basis of the number of donors per million population.

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