

## policy points

**Reorganizing Organ Allocation** As the gap grows between the number of patients on organ transplant waiting lists and the number of transplantations, the federal government has adopted new rules to try to allocate organs more equitably.

BY JEFF ATKINSON



A man is killed in an auto accident in New Jersey and his liver becomes available for transplantation. Two suitable recipients are identified. One is a resident of New York with a Status 1 liver condition (fulminant liver disease with less than seven days to live without a transplant). The other potential recipient is a resident of New Jersey with a Status 3 condition (requiring continuous medical care, but the patient is not in immediate danger and could live for years without a transplant). Who

should receive the liver?

Under the old system of organ allocation, the healthier New Jersey patient probably would receive the transplant. Under the new system, the sicker New York patient is more likely to receive the transplant.

In the last two years, the federal government and private organizations concerned with organ transplantation have been studying ways of

improving the organ donation system. The result is new regulations which became effective last year with more detailed regulations likely to follow this year.

Before the new regulations became final, Congress referred the issue of organ transplantation to the Institute of Medicine, which is part of the National Academy of Sciences in Washington, DC.

### **Allocation based on need**

A key recommendation from the Institute of Medicine, which has been adopted as a federal regulation, is to require that organs, particularly livers, be allocated to patients who are most in need of a transplant rather than to patients located nearer the donor. In years past, it was common for livers to be allocated to patients who lived near the donor rather than to patients with the most need. If there are two prospective recipients with the same level of need, one recipient local and the other recipient in another state but in the same region, the local recipient still can be preferred.

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**Organs on Ice**

The following is the amount of time solid organs can be preserved after removal (cold ischemic time with appropriate preservation fluids) and still be suitable for transplantation. The times are based on a survey of peer-reviewed literature by the Institute of Medicine. Preservation times vary, and may be somewhat longer, depending on the donor's age and health at the time of donation.

| Organ         | Time (hours) |
|---------------|--------------|
| Liver .....   | 12           |
| Pancreas..... | 17           |
| Kidney.....   | 24           |
| Heart .....   | 4            |
| Lung .....    | 6-8          |

SOURCE: INSTITUTE OF MEDICINE

**Organ Donation Waiting List**

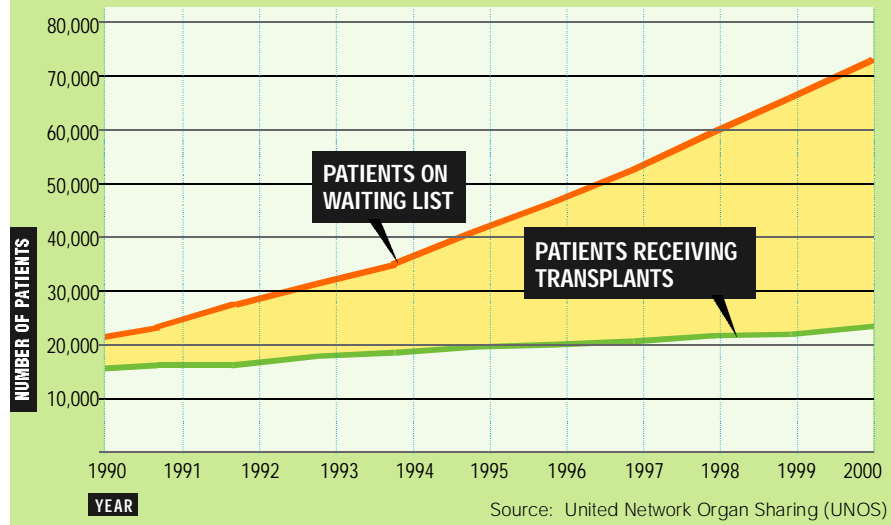
The United Network Organ Sharing (UNOS) National Patient Waiting List for Organ Transplant included the following on its March 31, 2001 list:

| Type of Transplant             | Patients Waiting for Transplant |
|--------------------------------|---------------------------------|
| Kidney transplant              | 48,474                          |
| Liver transplant               | 17,376                          |
| Pancreas transplant            | 1,099                           |
| Pancreas islet cell transplant | 187                             |
| Kidney-pancreas transplant     | 2,471                           |
| Intestine transplant           | 175                             |
| Heart transplant               | 4,271                           |
| Heart-lung transplant          | 210                             |
| Lung transplant                | 3,720                           |
| <b>TOTAL PATIENTS:*</b>        | <b>75,614</b>                   |

\* Policies of UNOS and the Organ Procurement and Transplantation Network (OPTN) allow patients to be listed with more than one transplant center (multiple-listing), thus the number of registrations is greater than the actual number of patients. Also, some patients are waiting for more than one organ, which would make the total number of patients less than the sum of actual patients waiting for each organ.

Source: United Network Organ Sharing (UNOS)

**Growing Gap Between Waiting List and Transplants**



**Transplants Performed in 2000**

| Type of Transplant                | Number        |
|-----------------------------------|---------------|
| Kidney alone transplants .....    | 13,261        |
| Liver transplants .....           | 4,933         |
| Pancreas alone transplants .....  | 433           |
| Kidney-pancreas transplants ..... | 919           |
| Intestine transplants .....       | 79            |
| Heart transplants .....           | 2,197         |
| Heart-lung transplants .....      | 48            |
| Lung transplants .....            | 957           |
| <b>TOTAL .....</b>                | <b>22,827</b> |

**Medical information regarding transplants can be found at <http://transplantation.medscape.com>**

Source: United Network Organ Sharing (UNOS)

The old system gave "seniority points" to persons based on the length of time they had been on the waiting list. This encouraged physicians to place patients on the waiting list early in the stages of a chronic disease before the patient was truly in need of a transplant. Under the new system, the time a patient spends on a waiting list at a low level classification (such as Status 3) will not be counted for the purpose of liver allocation if the patient moves to a higher priority classification (such as Status 1).

ification (such as Status 1).

The amount of time that a patient spends in a new classification, however, will be considered when allocating livers between patients in the same classification. The goal, according to the regulators at the U.S. Department of Health and Human Services is to allocate organs on the basis of "medical urgency...in accordance with sound medical judgment and avoidance of futile transplants and organ wastage."

**Help for the most ill**

Some were concerned that the willingness of people to donate organs would decrease if the organs were sent out of state rather than used for local recipients. The Institute of Medicine concluded that the location of the recipient was not a major factor in the decision to donate an organ. Although there is not a great deal of data on the subject, a 1998 Gallup Poll found that three-quarters of the respondents reported that the location of the recipient would make no difference in their decision and, in fact, many respondents would want the organ or organs to go to the most seriously ill patient.

The Institute of Medicine Report, "Organ Procurement and Transplantation" (2000),

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254 pages, is available on line at <http://books.nap.edu/catalog/9628.html>

The Institute of Medicine also studied the size of the areas within which organs are allocated and concluded that each area should have a population of at least nine million people. This will increase the likelihood that organs can be provided to the patients who need them most. Currently, there are 62 Organ Procurement Areas in the United States, each served by an Organ Procurement Organization (OPO). The Institute does not propose dismantling the current system, but it does suggest that the existing organizations work together more closely for allocating organs. Exactly how the existing organizations will mesh with the larger areas is still under consideration.

If organs that would have gone to Status 3 patients now will go to patients in Status 1 or 2, the patients in Status 3 are not likely to experience a higher mortality rate since they are able to survive a longer time without a liver transplant. Status 3 patients still will be eligible for transplants, but they generally will receive them only when there are no matching patients in Status 1 or 2.

### Limiting racial inequity

When Congress referred the issue of organ allocation to the Institute of Medicine, it sought input on how the new regulations would affect access to organs by racial minority and low income patients. The Institute noted that African Americans had more than twice the incidence of end-stage renal disease as whites. This was due to a variety of factors including increased incidence of hypertension and diabetes in African Americans.

African Americans and low-income patients of all races are slower to be placed on waiting lists than white patients. This is related more to a lack of access to

health care than the transplantation system per se.

Once on the waiting list, African Americans receive liver transplants at the same rate as whites. For kidney transplants, however, African Americans receive transplants at a slower rate than whites. Among the reasons for this, the Institute said, is "African Americans exhibit much greater heterogeneity in their histocompatibility antigens than whites, which makes it much more difficult to locate a fully matched organ in the pool of available donors." Due to the histocompatibility issue, organs from other African Americans are much more likely to be compatible for African American patients.

In addition, African Americans are less than half as likely as whites to donate organs. Reasons for this may include distrust of the health-care system, failure of health-care personnel to ask, or failure to ask in an effective way. An increase in outreach programs and hiring minorities for outreach and coordinator positions has been found to help increase the level of donations by members of minority groups.

Medications, including immunosuppressive drugs, are available to low income persons either through Medicare or Medicaid.

### Increasing donations

The number of organ transplantations grew 52 percent in the last decade, from 15,004 in 1990 to 22,827 in 2000. Meanwhile, the number of people on waiting lists for organ transplantations grew by 269 percent from 20,481 to 75,614. (See sidebars on page 10.) Last year, approximately 5,500 patients died while waiting for transplants.

To increase the number of organs available for transplantation, the federal government enacted a regulation in 1999 re-

quiring hospitals to notify the Organ Procurement Organizations (OPO) serving their area of all deaths or deaths that are imminent within the hospital. The OPO or a trained member of the hospital staff then may approach the family of a patient whose organs would be suitable for transplantation. Federal law allows Medicare and Medicaid funds to be withheld from hospitals that do not comply with these and other rules related to organ procurement, but this penalty has not been used.

**The U.S. Department of Health and Human Services published a guide for obtaining organ donations. Among the observations and suggestions in the guide:**

- Families are more likely to give consent to organ donation if they believe that they and their loved one have been treated appropriately and respectfully.
- The OPO should be notified as soon as possible.
- The OPO representative and a person who has rapport with the family (such as a physician or nurse) should work together on how best to approach the family.
- The family needs to comprehend the death of the patient before donation is sought, particularly in cases of brain death. Those who approach the family need to be sensitive to family members who may not be able to fully listen or absorb information during a time of crisis.
- Studies show that the greater the percentage of hospital staff that has received training regarding organ donation, the higher the hospital's donation rate.

**The publication is entitled "Roles and Training in the Donation Process: A Resource Guide" (2000) (36 pages). It is available on line at <http://www.organdonor.gov:80/finalresourceguide1.pdf>**

### Effect on cost

As more people are willing to donate organs and as the organ donation system focuses on providing organs to the sickest patients, costs to the health-care system will increase. Charges for average liver transplants, for example, are in the range

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of \$140,000 to \$300,000 (using figures from 1995 through 1998). Status 1 patients, who require longer hospitalizations both before and after transplantation, are at the high end; Status 3 patients are at the low end.

As the new allocation system directs more livers to Status 1 patients, the costs of transplantations, and retransplantations, will rise. The Institute of Medicine comments: "The committee was unable to estimate the magnitude of the increase, but believes it would be marginal compared to the total expenditures for transplantation. The committee also believes the health benefits of implementing broader sharing will substantially outweigh any increase in expenditures."

Organ transplantation increases the length and quality of life for many recipients, and for now the cost to society seems affordable. If resources become more limited, and the demand for transplantation and other high-cost medical services increases, society may need to make difficult decisions about how medical resources are allocated. ■

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