

States fight over rights to organs

BY TRUDI MATTHEWS

New federal rules on the allocation of donated organs remain up in the air two years after Donna Shalala, secretary of the U.S. Department of Health and Human Services, unveiled them in March 1998. Soon after the rules were first proposed, a fight broke out among states and transplant centers around the United States over whether the old system or the new proposed rules were better. States, including Oklahoma, Louisiana, Wisconsin and Ohio, passed laws or resolutions favoring the old system. Louisiana went so far as to file a suit in federal court objecting to the new rules.

At issue is how to allocate scarce organs to more than 64,000 people on the national transplant waiting list. Currently, a private, nonprofit organization, the United Network for Organ Sharing, administers the national transplantation network. It divides the nation into 11 regions. The sickest patients within a region receive first priority for a donated organ, even though there may be medically needier patients in other regions.

This system resulted in the sickest patients generally having comparable waiting times across the country, but great disparities in waiting times resulted for patients who had a less urgent need for an organ. In some areas in the Midwest the waiting time would average only a few months, while in the East patients might wait years for a transplant.

The new federal rules would significantly restructure the system for allocating organs. The new rules seek to ensure that the sickest patients regardless of their location receive organs and to smooth out inequities in the waiting time for transplants. The new rules call on the United Network for Organ Sharing to develop uniform medical criteria for ranking transplant candidates.

Meanwhile, the U.S. Department of Health and Human Services has amended the rules, but congressional leaders and President Clinton weighed in on the issue, postponing the rules' implementation for 90 days until March 16.

One long-term solution to this dispute is to increase the number of organ donations. In 1998, fewer than 10,000 people donated organs, and more than 4,000 people died awaiting an organ transplant, according to the U.S. Health Resources and Services Administration. Thousands of deaths could be averted if there were more organ donors. States are beginning to experiment with ways to do just that.

Most states already allow drivers to indicate their desire to donate organs on their drivers' licenses. Thirteen states have gone a step further and created donor registries. Registries in Florida, Illinois, Louisiana, Maryland, Michigan, Missouri, New Jersey, Ohio, Pennsylvania, Tennessee, Virginia and West Virginia are up and running. New York begins its registry in April. Wisconsin and South Carolina are beginning the process.

People who indicate their desire to donate an organ are entered into a state-wide computer database. Doctors and hospitals then have access to donation

information. This is important because many times donors do not inform their families about their donor status and drivers' licenses are not always available at the time of a person's death.

Illinois has shown that getting the word out can increase donations. It has put \$1 million a year into ads that promote organ donation. And, the investment has paid off — Illinois has more donors in its registry than any other state.

Another novel approach is a Pennsylvania law that authorizes the state to pay \$350 of funeral costs for donors. This law has yet to be implemented, and it may run into problems. A 1984 federal law bars the exchange of any "valuable consideration" for organs.

The Council of State Governments is doing its part. In partnership with the Health Resources and Services Administration, the federal agency that oversees transplant policy, and the National Conference of State Legislatures, CSG is developing a resource guide for state officials that discusses model legislation, best practices, potential barriers and recommended strategies to increase organ donations. The three organizations have begun work on the project and expect it to be completed by the fall of 2000.

For more information about the organ donation project or the resource guide, please contact Trudi Matthews, health policy analyst, at (606) 244-8157. Matthews is a member of CSG's CLIP, which promotes policy development, leadership training and innovative state programming. CLIP develops state problem-solving initiatives with intergovernmental, philanthropic and corporate partners. ★

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