

Have You Told a Family Member?

National Initiative Promotes Dialogue on Organ and Tissue Donation

By Jennifer Brooks

Closing the Gap, Organ and Tissue Donation • May 1998

If you were to die in a car accident tomorrow, would your relatives know how you felt about donating your organs? It's a hard question—one that most people don't want to think about. But facing it and talking about it with family members *now* may help save lives later.

Failure to discuss wishes with family members is a major reason families choose not to donate a loved one's organs, said Vice President Al Gore at a Washington, D.C. press conference in December 1997. Vice President Gore and Health and Human Services (HHS) Secretary Donna Shalala presented remarks to launch the National Organ and Tissue Donation Initiative. Signing a donor card is a good step, but it isn't enough, Shalala said. "If we should die suddenly, it is our families who must speak for us on organ donation. And that decision will be much easier for them if they know our wishes."

The initiative, which carries the theme: "Share Your Life, Share Your Decision," has strong support from several organizations including the American Medical Association (AMA) and the American Academy of Family Physicians (AAFP). The AMA and the AAFP will encourage physicians to make donation materials available in their offices and to discuss donation with patients.

According to Neil H. Brooks, MD, president of AAFP, "the Academy has long advocated the importance of patients talking with their family members and personal physician about organ donation and other end-of-life issues."

The American Bar Association has also lent its support to the initiative by pledging to encourage its members to discuss donation wishes during the preparation of wills and estate planning. The American Association of Health Plans will urge plans to provide its members with educational materials on organ donation. And materials from the National Coalition on Donation, including a toll-free information hotline, will be used throughout the initiative.

More than a dozen other groups have agreed to help reach particular audiences.

"Organ transplant techniques today are saving and improving thousands of lives every year," according to Secretary Shalala. "But not enough organs are available to help everyone in need, and more Americans are dying while awaiting an organ transplant."

In 1996, roughly 20,000 Americans gained a new lease on life through organ and tissue transplantation. But more than 55,000 people nationwide remain on the transplant waiting list, and about 4,000 people—10 every day—will die while awaiting a donated organ.

Currently, there are approximately 5,500 cadaveric donors per year, despite the fact that there are an estimated 10,000 to 15,000 deaths each year that could result in organ donation. A 1996 study of all potential donations showed

that in 27 percent of cases, either potential donors were not identified or no request was made to the family. The study further showed that 32 percent of families agreed to donate and 36 percent denied consent for donation. Another 5 percent eventually proved medically unsuitable.

According to U.S. figures, the number of cadaveric organ donors each year has jumped from 4,084 in 1988 to 5,417 in 1996. But despite the increase, the number of people who died while waiting for an organ transplant has actually grown to 4,022—up from 1,507 during the same period. There simply aren't enough organs to go around.

"If a significant number of potential organ donors are being missed because these deaths are not identified or the family is not asked, then we need to work with the

transplant community immediately to address this problem, said Secretary Shalala.

HHS also announced proposed Medicare regulations to ensure that hospitals notify an organ procurement organization (OPO) of those deaths that could potentially result in organ donation.

As part of the initiative, HHS worked with providers, consumers, the organ and tissue transplant community and all other interested parties in developing the final regulation to help increase donation.

In an effort to eliminate the known barriers to donation, the initiative will:

- Create a broad national partnership of public, private and volunteer organizations to encourage Americans to agree to organ and tissue donation. The partnership will emphasize the need to share personal decisions on organ donation with family members.
- Work with health care providers, consumers and physicians to ensure that deaths are reported to OPOs whenever there is potential for donation.
- Research and evaluate methods that work to bring about donation.

As part of the final component to the initiative, HHS recently sponsored a special conference to help identify other significant barriers to organ and tissue donation, as well as practices that work to encourage donation.

"We are missing literally thousands of opportunities for donation every year," said Secretary Shalala. "We need to do better."

For more information on the National Organ and Tissue Donation Initiative, contact the Health Resource and Services Administration's press office at 301-443-3376, or 301-443-6652. Or call the National Coalition on Donation's hotline numbers at, 1-888-90-SHARE, or 1-800-355-7427. ❖

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