

Striking a chord with Hispanics in quest for organs

Donor groups focus on big population

BY SAMANTHA MARSHALL

After Celina López's 17-year-old son, Paul, was hit by a drunken driver in 1998, she waited until he was taken off life support and declared dead before telling his doctors she wanted to donate his organs.

"I was afraid if they knew before then, the doctors were going to let him die," she says.

Paul López's organs ended up saving five other lives. But misperceptions such as the one that delayed his mother's decision have long stymied efforts to increase organ donations.

Now, facing a huge and growing need for organs, advocacy groups have decided on a new tactic. In addition to conducting general awareness campaigns, they are going to target specific ethnic groups. Topping their list are Hispanics, because they represent such a large percentage of the population and because so many Hispanics are in need of donated organs.

Disseminating the facts

"We want to dispel the myths out there and give people the facts," explains Bob Spieldenner, a spokesman for the Coalition on

Donation, a national group based in Richmond, Va., that is working with New York organizations to educate the public about organ donation.

Widespread shortfall

The shortfall isn't just in the Hispanic community. More than 8,000 people in the metro area are waiting for transplants, while the general supply of organs is flat at best.

8,000 are awaiting transplants in the NYC area, but supply is flat

In part because of lower crime rates and higher drug use, there are relatively few potential donors in New York City. In the first quarter of 2002, the New York Organ Donor Network—the group federally designated to recover organs in the metro area—procured only 52 organs, up from 48 in the same period last year.

"The increase is not even a drop in the bucket," says Julia Rivera, spokeswoman for the donor network.

Donor groups decided to start by focusing on Hispanics in part because they make up 13% of the population nationally, and more than 25% in New York City. The city needs big numbers of donors

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LIFE PRESERVER: A co-worker's transplant prompted Celina López to donate her organs. Advocates hope educating Hispanics about donation will boost participati

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to even begin to make a difference.

In tackling the organ donation issue, advocates are confronting a deep-seated reluctance among many Latinos to discuss death. A recent study by the Coalition on Donation found that many potential donors don't share their intentions with family members, fearing that the morbid topic will bring misfortune. Some respondents expressed concern that the body of their loved one would be mutilated, preventing them from having an open-casket funeral.

Superstitions and spiritual beliefs play a role as well. For instance, some of the respondents said that bodies need to be buried whole. The research even uncovered the notion among some that the eyes are windows to the soul—hence a reluctance to donate corneas.

The study also revealed that many newly arrived Hispanic immigrants do not understand the difference between a coma and brain death. Rumors of a black market in trafficked organs, which may indeed be valid in some Hispanics' countries of origin, increase the reluctance to consent to organ donation.

"In Mexico, people believe that kids are being kidnapped and killed for the Yankees in the north," points out Mr. Spieldenner. He says a woman working as a missionary in Central America was recently stoned to death because the villagers thought she was kidnap-

A marketing edge

Aside from the number of Hispanics in New York, there is another good reason for donor groups to focus on them: Even though ethnicity doesn't make much difference in matching organs, the fact that many Hispanics are awaiting organs gives donor groups a marketing edge as they design their campaigns.

The number of Latinos awaiting organs has climbed 300% nationally during the past decade; now, just under 1,000 Hispanics are waiting in New York City. That's in part a reflection of the growth of the population. In addition, Hispanics have relatively high rates of diabetes, hypertension, and liver and heart disease because they often lack access to good preventive health care. By the time they end up in the health system, many have suffered organ failure, says the Organ Donor Network's Ms. Rivera.

The national coalition's study

shows that many Latinos who have registered as donors did so because they knew someone in their community who needed a transplant. New York's organ donor advocates expect that their new campaign, which focuses on Hispanics' needs, will give their efforts a boost.

Plans are also under way for an effort aimed at African-Americans. Advocacy groups hope that the campaign targeting Hispanics will be useful, since the fears and misperceptions uncovered by the

from Asia, Eastern Europe and Africa—where rumors of black markets for organs are rife—are afraid to become donors for many of the reasons that are outlined in the study.

Common concerns

"These fears are typical of any relatively undereducated population—whites and blacks as well," says Dr. Vivian Tellis, head of the kidney transplant unit at Montefiore Medical Center in the Bronx.

Ms. López, who has been a volunteer for the New York Organ Donor Network since her son

died, says that showing Paul's photograph while she's out campaigning has prompted many to register on the spot. Ms. López became friends with the parent of her son's liver, a fellow Puerto Rican.

Ms. López had never considered the idea of organ donation until a colleague in the post office where she worked received a liver transplant 13 days before her husband was killed. Having learned firsthand what a difference offering her son's organs could make, "I knew it was the right thing to do," she says.

Still, it was difficult to con-

Reluctant Donors

New York City has a lower rate of cadaveric organ donation than other areas.

DONORS PER 1 MILLION POPULATION

New York City	17.1
Upstate New York	31.6
United States	22.04

2000 data, based on 1999 population figures
SOURCE: UNITED NETWORK FOR ORGAN SHARING

vinced her husband that it was the right decision, and she's not sure her mother will ever forgive her. "She thinks God gave you these organs and you should take them with you," Ms. López says. ■