

Mrs. Sudie Hilliard (Testimonial)

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BLACKS HESITANT TO DONATE ORGANS CULTURAL BELIEFS, MISINFORMATION, MISTRUST MAKE IT A DIFFICULT DECISION

As her 14-year-old son lay dying from a head injury after falling from a school auditorium catwalk three years ago, Sudie Hilliard sat in the hospital waiting room thinking. The African-American youth who had led the school band's percussion section "was so young and vibrant and active and agile," Hilliard said recently, recalling her thoughts that day in November 1991. "His life hadn't even begun. There must be some way to preserve him, all his vitality." Then Hilliard made up her mind: She would donate her son's body for organ transplants. "Are you sure?" asked the minister beside her. So did the nurses. They cautiously urged Hilliard to take 24 hours to think it over. But her mind was made up. "I felt very comfortable doing it," she said. Most African-Americans don't make the decision to donate organs with such ease. In fact, many don't consider it at all.

For many blacks, fundamentalist religious beliefs, mistrust of the white medical establishment, burial custom and tradition, and even myths from Black Muslim Minister Louis Farrakhan obstruct decisions to donate a loved one's organs for transplant, say those who work in the field. Because transplants are far more likely to succeed if the donor and recipient are of the same racial and ethnic background, the shortage of black donors leaves blacks waiting up to 2 1/2 times longer than whites for kidney, heart, liver and bone marrow transplants. As a result, a higher percentage of blacks die while waiting for organs, according to the United Network for Organ Sharing in Richmond. Of about 35,000 people nationwide awaiting transplants, 37 percent are African-American. The percentage is high partly because of a higher incidence among African-Americans of hypertension and diabetes, which can cause kidney malfunction. But blacks give about 11.5 percent of all organs, while whites donate about 85 percent, said Joel Newman of UNOS. Hispanics, Asians and other ethnic minorities give the rest. Organ transplants are more successful when donor and recipient match by both blood and tissue type. Tissue cells have six markers, or HLA antigens. Two of these, known as the DR antigens, are unique to blacks. So it is difficult to match organs from persons of different racial backgrounds. To debunk the myths, educate the ignorant, and proselytize nonbelievers, a 177-member Black Task Force has been mobilizing an organ donor awareness campaign throughout eastern Virginia since February.

Led by Baxter Harrington of Life-Net Transplant Services in Virginia Beach, the grass-roots campaign is blitzing black schools, colleges, churches, civic groups and community events with speeches, panel discussions, pamphlets and radio public service announcements on what they call the "gift of immortality." Harrington hopes the effort will yield successes like those of Life-Net's Central Virginia campaign launched 3 1/2 years ago. By the end of 1993, that region's black donation rate had risen from 8 percent in 1990 to 74 percent, Harrington said. "We are listening to what people's fears are and not making them feel like they are ridiculous or stupid," Harrington said. "For example, someone religious might tell me that they won't make it through the Pearly Gate without a heart. Or St.

Peter will only give them one wing if they have only one kidney." "We can't laugh at that. We ask them, 'What do you base that on?' They say the doctrines of their faith."

When a member of the Jehovah's Witnesses faith explained that he couldn't sign a donor card because "The body comes from Jehovah and must go back to Jehovah," Harrington encouraged him to check that with the elders of the church.

He learned that the Jehovah's Witnesses interpretation of the Bible forbids blood donation. But organ donation is a matter unaddressed in the scripture and therefore left up to the individual believer's conscience.

Mary M. Clark's heart had deteriorated so badly from hereditary cardiomyopathy that her legs swelled, her hands and feet turned blue and cold, and her body bloated with fluid.

"I couldn't comb my girls' hair. I couldn't cook. I didn't feel like laughing," said the 35-year-old Chesapeake mother of three young children and a teenager. "I didn't know how dead I had become until that new heart began pumping in me."

She glows with gratitude for the heart she received in December 1993 after waiting a year and a half. As soon as her heart healed, Clark dove into task force activities.

"We sat outside two showings of 'The Lion King,' telling people about donation," she said. "I didn't run into a lot of negative stuff. A lot of people are misinformed or not informed at all. A lot of information is available, but it's not reaching people," she said. "We need a permanent booth in the malls. In the church, we need to introduce people to other ways of giving life besides food and shelter for the poor."

Clark is also using a study under way at Sentara Norfolk General Hospital to spread the good news about organ donation. So far, she's gotten her husband and children involved. And she's talked her neighbors into at least thinking about it.

Sponsored by the National Institutes of Health, the study needs 20 local African-American families with two to three children age six and above to take part in a nationwide investigation of tissue types involving 500 black families. The study seeks to identify unknown African-American antigens, the cell markers that determine a match. The findings could improve the quality and speed of matches for blacks languishing on the waiting list. "Since most organ donors are white, a lot of research has identified Caucasian antigens," said Kay Keatley, one of two medical technologists assisting in the study. "But because not much research has been done on African-Americans, all of their antigens haven't been identified." Awareness is the other aim of the study, said Tracy Thompson, the other technologist. "If we got more black donors we could do a better job of matching."

And that means myth-busting.

When Levester H. Gaines used to go for dialysis in the Greenbrier section of Chesapeake, not exactly a black neighborhood, he used to notice that all the patients were black.

"I think it's some kind of phobia in the black community that prevents them from donating," surmised the 42-year-old building code specialist who last month received a kidney from his sister, Lucy G. Majors. "If they haven't been touched by it, they have no appreciation for it."

Now Gaines is always encouraging other blacks to give organs like the one that saved his life after diabetes and hypertension ravaged his own. But he doesn't get much of a reaction.

He has arrived at various theories as to why. "Take Minister Farrakhan," Gaines said. "He had put out a suspicion in the black community that black organs were being donated to white recipients.

There is already a certain fear of death involved in donating organs, and this just adds to it."

Black mistrust of the overwhelmingly white medical establishment may be justified in some cases. Whites have a history of using blacks as guinea pigs. For example, in the infamous 1930s Tuskegee Study, 400 black men with syphilis went untreated, even after a cure for the disease was known.

Blacks should educate themselves more on medical advancement and technologies, said William A. Lassiter, who received a heart transplant in June after a nine-month wait in the intensive care unit of Sentara Norfolk, more than double the normal time. "People need to understand that it is almost as if the body is recyclable."

Instead, Lassiter suspects that black funeral or burial customs, which hold the intact body in high reverence, may hinder donation. "You're talking about culture," said Lassiter, a deeply religious man. "There are those who believe that when you are born with organs, when you leave this earth,

those organs should go right with you. That's a hard thing to change in the mind of the black community."

MEMO: For more information on Sentara Norfolk General Hospital's study on African-American tissue types call 1-800-SENTARA
A blood sample will be taken. Participants will receive \$30.

ILLUSTRATION: Color staff photo by L.TODD SPENCER/
Sudie Hilliard of Virginia Beach holds a picture of her son, Rosecelious, who died in 1991. She donated his body for organ transplants, a decision many African-Americans wouldn't consider.
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