



Closing the Gap

A newsletter of the Office of Minority Health, U.S. Department of Health and Human Services

May 1998

Organ Donation

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OFFICE OF PUBLIC HEALTH AND SCIENCE
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Have You Told a Family Member? *National Initiative Promotes Dialogue on Organ and Tissue Donation*

By Jennifer Brooks

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

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"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 Office of Minority Health Resource Center

provides free information on various health issues affecting U.S. minorities including cancer, heart disease, violence, HIV/AIDS and diabetes. Call us to learn about funding sources for minority health programs. *Closing the Gap* is a free monthly newsletter published by the Office of Minority Health, Office of Public Health and Science, U.S. Department of Health and Human Services. Address correspondence to: Editor, *Closing the Gap*, OMH-RC, PO Box 37337, Washington, D.C. 20013-7337. Or call OMH-RC toll-free, 1-800-444-6472.

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Organ Donation...from page one

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. ♦

What can you donate?

blood vessels

bone

bone marrow

corneas

heart

kidneys

liver

lungs

middle ears

pancreas

skin

Minority Health Perspective

Sharing Your Life, Sharing Your Decision

National Organ and Tissue Donation Conference, April 1-2, 1998 in Crystal City, Virginia

Remarks delivered by Kevin Thurm, Deputy Secretary, U.S. Department of Health and Human Services

We are on the verge of a season for health care and medicine that is just beginning. It's a season that began over thirty years ago during a time when most Americans would have considered an organ transplant something akin to a fairy tale. Back then, when Dr. Christian Barnard performed the first heart transplant, the entire world paused to marvel at what was truly a medical miracle. But technology has taken us far beyond fairy tales.

Today, the science of organ transplantation has become more advanced and more successful—and is saving thousands of lives each year. Recently, HHS released a report showing that overall survival rates for transplant recipients are at an all-time high. The one-year survival rate for kidney recipients is now over 94 percent, and the rate for heart-lung recipients is almost 62 percent.

To keep pace with all the technological and medical advances, we also are making great strides toward creating the most equitable and medically appropriate system for allocating scarce organs. Last month, HHS published the final rule regarding Secretary Shalala's oversight of the Organ Procurement and Transplantation Network (OPTN). The rule calls on the OPTN to revise organ allocation policies so that they are based on medical urgency instead of relying on arbitrary geographical limits.

In essence, it means leveling the playing field for patients so that the same medical criteria are used for all patients—no matter where they live—and that organs can be made available to those with greatest medical needs.

But, of course, the ultimate fair system is getting enough organs for everyone who needs them. Because, while our dreams for better transplant results are being realized, and while we are working together to devise the fairest allocation system, the dreams and prayers of thousands of Americans who need organs are still going unanswered.

The real problem is simply a matter of too many patients in need and too few organs. There are now nearly 55,000 Americans on the organ donor waiting list. And 4,000 of those Americans are dying each year waiting for a donated organ that never comes.

The fact is, we are tragically—and needlessly—missing thousands of donation opportunities every year, sometimes because a family is reluctant to donate. But in many cases a death was not identified as a potential donor or the family was never asked.

That is why last December, Secretary Shalala and Vice President Gore officially launched the National Organ and Tissue Donation Initiative. We know we must do every-

thing we can to increase organ and tissue donation, not only to help people choose to give the gift of life, but to get them to share that donation decision with family and loved ones.

Our goal is to increase organ donation nationwide by 20 percent within two years. And it begins with a plain and simple message: Share your life, and share your decision. Like you, it's a message we take very seriously.

It's a message that must be carried into every home, into every community, throughout the country. It's a message that must be delivered in elementary and secondary classrooms, on college campuses, and in communities with unique cultural and linguistic needs. It's a message that must be delivered in hospitals, in doctor's offices, and other health care settings.

And it's a message that will only be delivered with the help of a broad national partnership of public, private, and volunteer organizations who reach out to individuals and families and help them make the decision to donate.

Because we all know that the government—or any organization, large or small—working alone cannot ensure everyone has a chance to share the gift of life. For that to happen, all of us must work together. There is simply too much at stake for us not to work together.

That is really what the National Organ and Tissue Donation Initiative is all about. It's about harnessing the dedication to increasing organ and tissue donation that already exists in the transplant community, and nurturing a spirit of seamless cooperation and teamwork.

That spirit has certainly been indispensable for HHS as we all work together toward finalizing Medicare regulations. These regulations will ensure that hospitals, organ procurement organizations (OPOs), tissue and eye banks, and the rest of the transplant community work together even more closely to bring about organ donation.

And that spirit is necessary as we explore new and innovative ways to increase organ and tissue donation. Secretary Shalala, along with the entire Department, is committed to fostering and strengthening partnerships among government agencies and the private sector—from hospitals to OPOs, from tissue and eye banks to patient groups. And we are committed to making sure that health care professionals like you have the support and tools you need to implement effective strategies that will help us ensure that no opportunity to give the gift of life slips through the cracks.

I ask you to always keep close to heart the courage and sacrifice of organ and tissue donors and their families, and those still waiting anxiously for their own fairy tale and medical miracle to come true.❖

New HHS Rule Calls for Organ Allocation Based on Medical Criteria, Not Geography

By Jennifer Brooks

The demand for organs for transplantation in the U.S. far exceeds the supply. Despite technological advances in preserving organs, the current system for allocating scarce organs—especially livers—is based largely on local organ allocation, rather than broader regional or national allocation according to medical need. This means a patient who is less ill in one geographic area with a short waiting list may get a matching organ before a patient whose condition is more medically urgent in another area with a longer waiting time.

In March 1998, Secretary of Health and Human Services, Donna E. Shalala, announced a new regulation to improve the nation's organ transplantation system. The new rule will assure that the allocation of scarce organs will be based on uniform medical criteria with less reliance on geographic location.

"Patients who need an organ transplant should not have to gamble that an organ will become available in their local area, nor should they have to travel to transplant centers far from home simply to improve their chances of getting an organ," Secretary Shalala said in a press statement. "Instead, patients everywhere in the country should have an equal chance to receive an organ based on their medical condition and the judgement of their physicians."

The new regulation builds on medical technology advancements; it looks to the medical community for leadership in policy development with participation by patients, donors and their families; and it sets performance goals for fair and effective use of donated organs.

Transplant Recipients International Organization, Inc. (TRIO), an

organization representing more than 4,000 organ and tissue donors, recipients and transplant candidates, released a statement that hailed the new regulation as "a tremendous step towards an equitable distribution of this life-saving resource." Bruce Weir, national president of TRIO, said based on his initial review and a briefing he attended, he believes TRIO's major areas of concern affecting patients have been addressed.

"TRIO's preeminent concern is the fair sharing of organs among the nation's 58,000 transplant candidates. We believe these new regulations can ensure more equitable sharing of organs while leaving delicate medical decisions with physicians because the guidelines place medical urgency over geography," said Weir, who received a heart transplant in 1988.

But not everyone is happy about the new rule. Larry Hunsicker, MD, president of United Network for Organ Sharing (UNOS), feels "in the long run, fewer people will get liver transplants and fewer lives will be saved. The regulations would require doctors to put a greater emphasis on providing liver transplants to the very sickest patients, a sentiment with which we sympathize," Hunsicker said. "But there is a dire shortage of organs, and many of the very sickest patients would not be able to survive without a second or even a third transplant. This means that fewer livers will be available and over time thousands fewer lives will be saved."

Hunsicker also added that many liver transplant programs would have to shut down because "the regulations would divert livers from many smaller transplant programs to a few large centers."

According to Shalala, "HHS does not want to choose which patients

receive scarce organs. Those choices must be made by transplant professionals," she said. "But this regulation will help assure that organs are allocated on the basis of medical need, and that availability of organs will not be impeded by arbitrary geographic lines."

The new rule calls on the Organ Procurement and Transplantation Network (OPTN) to develop revised organ allocation policies that will reduce the current geographic disparities in the amount of time patients wait for an organ. Specifically, the OPTN is to develop uniform criteria for determining a patient's medical status and eligibility for placement on a waiting list. The criteria will be aimed at assuring that patients with greatest medical need will receive scarce organs based on medical judgement and common medical criteria, no matter where they live or in what transplant center they are awaiting treatment.

Current medical criteria for listing patients and assessing their status vary from one transplant center to another, making it difficult to objectively compare the medical need of patients awaiting organ transplantation in different centers and different areas of the country.

Under the new regulation, performance goals would be established to guide the OPTN as it modifies existing organ allocation policies. Under the current policies, matching organs are usually made available to all listed patients in a local organ procurement area before they are made available to other patients outside the area. This, according to HHS officials, means less ill patients in the local procurement may receive a transplant while patients with more

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New Rule...from previous page

urgent medical need in another area continue to wait.

Three new sets of criteria for organ allocation would be developed by the OPTN under the new regulations. Development of the criteria would include public input and comment and final HHS approval. Secretary Shalala emphasized that the regulation looks to transplant professionals in the OPTN to develop the revised policies.

“We are not substituting our judgement for the judgement of medical professionals,” she said. “We are asking them to make the system fairer, and we are setting clear performance goals to guide their work.”

The OPTN is responsible for developing:

- Criteria aimed at allocating organs first to those in the highest medical urgency status, with reduced reliance on geographical factors. HHS officials said this should reduce disparities in waiting times for patients at different transplant centers in different areas of the country. Today, there is a wide variation in waiting times, with patients in some areas waiting five times longer or more for an organ than in other areas. The new criteria is expected to provide for wider sharing to assure organs were made available to patients with greatest medical need.

- Criteria to be followed in deciding when to place patients on the waiting list for an organ. Currently, each transplant center establishes its own criteria, with the result that patients listed at one center may not be as ill as patients not yet listed at another center with more stringent medical listing criteria. Under the regulation,

the OPTN would develop medically objective criteria to be used by all transplant centers.

- Criteria for determining the status of patients who are listed. Medically objective, uniform criteria would help ensure a “level playing field” in selecting among patients and determining which have the greatest medical need. The OPTN is already developing uniform criteria of this kind.

“Together, these new uniform criteria will add up to a fairer and more understandable system which will serve both patients and the transplant system better,” Secretary Shalala said.

OPTN is the non-profit private sector system created by the National Organ Transplant Act of 1984. Originally, OPTN membership and policies were voluntary. But with the enactment of the Omnibus Budget Reconciliation Act of 1986—adding Section 1138 of the Social Security Act—all hospitals that perform transplants and all organ procurement organizations were required to abide by the rules and requirements of the OPTN in order to receive Medicare and Medicaid reimbursement.

In December 1989, HHS issued a *Federal Register* notice indicating that all OPTN rules and requirements would remain voluntary until the Secretary announced regulations to define the roles and policymaking procedures of the OPTN and HHS. A Notice of Proposed Rule Making containing these definitions was published on September 8, 1994.

After two extensive comment periods, including three days of special hearings in December 1996, HHS announced a final rule providing a framework for the operation of the

OPTN, and aimed at assuring that the Nation’s organ procurement and transplantation system operates for the greatest benefit of transplant patients.

The final rule includes a new 60-day comment period and becomes effective 90 days after publication in the *Federal Register*. The OPTN would have another 60 days to propose new criteria for livers, and a year for development of criteria for other organs.

For more information, contact HHS’s Health Resources and Services Administration at 301-443-3376. Or browse their Web site at <http://www.brsa.dbhs.gov>. ❖

Did you know?

Every 16

minutes, a new

name is added

to the national

organ transplant

waiting list.

HRSA's Division of Transplantation: Reaching Out to Minorities

By Jean Oxendine

Minorities should be concerned about organ donation and transplantation because they are disproportionately affected by diabetes, kidney disease, high blood pressure, heart disease, and other conditions that can lead to organ failure, according to Mary Ganikos, chief of the HHS Health Resources and Services Administration (HRSA) Division of Transplantation (DOT's) Public and Professional Education Branch. Members of different racial and ethnic groups are usually more genetically similar to members of their own groups than they are to others, Ganikos said. Increasing the minority donor pool increases the likelihood that good matches can be made for minority patients.

Promoting organ donation in minority communities is a priority for DOT. In order to educate the public on DOT, it is important to understand its activities. Since the National Organ Transplant Act of 1984 was passed, HRSA has overseen our national transplant system. DOT has a contract with the Richmond-based United Network for Organ Sharing (UNOS) to administer the following programs:

- **The Organ Procurement and Transplantation Network (OPTN):** The OPTN maintains a national computerized list of the more than 51,000 patients waiting for organ transplantation, as well as a 24 hour-a-day computerized organ placement center that matches donors and recipients. The goal is to ensure equitable access to organs and to guarantee that scarce organs are recovered and used safely and efficiently. The network includes all 280 transplant centers, 64 organ procurement organizations, and other health and medical organizations.

- **The Scientific Registry of Transplant Recipients** has information on all recipients of kidney, heart, liver, heart-lung, and pancreas transplants since October 1, 1987. The registry tracks all patients from the time of transplant to hospital discharge, and also follows those cases that end in transplant failure or death.

- **The National Marrow Donor Program (NMDP):** The NMDP is a non-profit organization in Minneapolis. The program is a network of 99 donor centers, 111 collection centers, 106 transplant centers, and 12 recruitment groups. The NMDP also studies the effectiveness of marrow transplants and related treatments. The program has undertaken a national effort to increase the number of potential donors who are African American, Asian American and Pacific Islander, Hispanic, and American Indian.

Other HRSA activities:

- **Education:** DOT conducts public and professional initiatives to improve awareness of organ and tissue transplantation. This includes spreading the word through exhibits and seminars, and collaborations with the Coalition on Donation and the American Association of Motor Vehicle Administrators.

- **Grant Program:** Since 1986, DOT has awarded 95 grants to organizations that work to improve public and professional education on organ donation. Since 1989, special emphasis has been on minority organ donation.

Promotion and outreach efforts towards minorities are on the increase. The NMDP is concerned about the

need for volunteer marrow donors from African Americans, Asian Americans and Pacific Islanders, Hispanics, and American Indians and Alaska Natives. To address this need, the NMDP is currently conducting four specially targeted national recruitment campaigns to increase Registry representation of minority volunteers. By reaching each community through ethnic and mainstream media, community groups and individuals, the NMDP will ensure that patients of every racial and ethnic background will have a better chance of finding a matched donor.

An insert on DOT and its activities was included in a recent issue of *The Journal for Minority Medical Students*. That issue, which focuses on transplantation, was published in Winter 1998 (Vol. 10, No.2). To order a back issue, call Spectrum Unlimited Publishing at 504-488-5100. DOT also plans on participating in a meeting of the Congress of National Black Churches (CNBC) on May 12-13, 1998. "We hope that the CNBC network will assist us in promoting donation in African American communities," Ganikos said.

If you'd like to play a role in educating minorities about organ donation, Ganikos suggests letting friends, family, professional contacts, patients, and others know about the unique need in minority communities. You may help save lives.

For more information on DOT, call 301-443-7577. The division distributes several publications including: *Q & A About Organ Donation* (includes organ donor card); *Financing Transplantation-What Every Patient Needs to Know*; and *Organ Donor Cards*. DOT is also on the World Wide Web: <http://www.hrsa.dhhs.gov/osp/dot>

FULL PAGE AD

Facts About Minorities and Organ Donation

Compiled by Jean Oxendine

- The number of minority deceased donors increased from 16 percent in 1988 to 23 percent in 1995.
- Twelve percent of all deceased donors are Blacks, but 27 percent of those on the organ transplant waiting list are Black.
- Minority organ recipients increased from 20 percent in 1988 to 26 percent in 1995. The number of Hispanic organ recipients more than doubled during that time period.
- Minorities comprised 50 percent of the kidney waiting list in 1995, compared to 43 percent in 1988. Most are Black.
- The decrease in graft survival rates among Black recipients of kidney transplants is more pronounced than for other races.
- Blacks on the kidney waiting list wait longer than Whites for transplants. This is primarily because a) the blood group distribution among Black registrants differs from the donor pool, which is predominately white; b) Blacks have a higher sensitivity to donor organs than any other race; and c) Some HLAs are more rare among Blacks than Whites.
- HLAs, human leukocyte antigens, are the genetic information encoded on white blood cells.
- Five-year patient survival rates for Black recipients of living donor kidney transplants are lower than for other racial groups. Asian survival rates are highest.
- Minority registrants comprised 14 percent of all kidney-pancreas waiting list registrants in 1995, up from 11 percent in 1992.
- Black registrants wait longer for kidney-pancreas transplants than candidates of other races. In 1995, the median waiting time for all races overall was 298 days, and 345 for Blacks.
- Patient survival rates for Black and Asian liver recipients are lower than for other races.
- The number of minorities waiting for hearts increased from 13 percent of all registrants in 1988 to 18 percent in 1995.
- Minorities comprised 13 percent of lung recipients in 1995, up from 3 percent in 1988.

Source: UNOS. ❖

Lions Clubs International (Eye Banks)

Lions Clubs International provides referrals to some 60 Lions Eye Banks in the U.S. and abroad. The organization serves as a liaison between donor families and recipients. They receive, process and disperse corneal tissue to surgeons who perform corneal transplants. They provide education programs for the public and health care professionals. They also provide eye tissue for medical education and research. *For more information, call (630) 571-5466, ext. 318.*

National Minority Organ Tissue Transplant Education Program

The National Minority Organ Tissue Transplant Education Program (MOTTEP) was established in 1993 by Clive Callendar, M.D., head of the transplant department at Howard University Hospital in Washington, D.C. The program aims to increase organ and tissue donations in minority communities and to empower minorities to develop transplant education programs.

With funding from the HHS National Institute of Diabetes and Digestive and Kidney Diseases, and the Office of Research on Minority Health, MOTTEP has expanded to 15 cities: Anchorage, Alaska; Birmingham, Alabama; Los Angeles, California; Washington, D.C.; Miami, Florida; Atlanta, Georgia; Honolulu, Hawaii; Chicago, Illinois; Detroit, Michigan; Albuquerque, New Mexico; Brooklyn, New York; Cleveland, Ohio; Nashville, Tennessee; Houston, Texas; and Richmond, Virginia

Program accomplishments in the various MOTTEP cities include implementing school programs on organ and tissue donation, sponsoring organ donor days at major league baseball games, and sponsoring tree planting ceremonies in memory of those who died while waiting on the transplant waiting list. National program accomplishments include establishing National Minority Donor Awareness Day (August 1) and collaborating with more than 150 organizations to promote organ and tissue donation. MOTTEP also established the National Minority Transplant Hall of Fame.

For more information about MOTTEP, call 202-865-4888. The program is housed at Howard University Hospital, 2041 Georgia Ave., NW, Suite 3100, Washington, D.C. 20060. ❖

After Two Month Wait, African American Teen Gets New Heart

By Michelle Meadows

Waiting indefinitely was a horrible feeling, said Noah Wynn, a 14-year-old African American from Muskegon, Michigan. He went on the heart transplant waiting list as a "status 1-urgent" at the end of October 1997. "I just kept thinking that I'd be in the hospital forever, and I'd never be able to go back home again," he said.

The wait ended on January 24, 1998, and it was a time of mixed emotions. Knowing that death in one family means life for another family is tough, said Delores Wynn-Hendricks, Noah's mother. Because of confidentiality rules, Noah's family doesn't know many details about the donor or the circumstances of the death.

The family does know that the donor was African American and was close to Noah's age. "We also know that the donor's family was concerned about how Noah was doing, and we

appreciate that," Wynn-Hendricks said.

The first sign of trouble for Noah began last summer when he experienced an upset stomach and loss of appetite. He'd always been a big eater, so the sudden change in eating habits sent him in to his doctor's office.

Three days later, Noah found out he had cardiomyopathy, a serious disease that causes the heart muscle to become inflamed, and not work as well as it should. Other symptoms can include shortness of breath, dizziness, fatigue, and chest pain.

Medication, the usual treatment for cardiomyopathy, was ineffective in Noah's case. He needed a heart transplant to live. "This was really the last effort," said Francis Pagani, M.D., the doctor who performed Noah's transplant operation at the University of Michigan Medical Center in Ann Arbor. "It's used when we've exhausted all other options."

Noah's operation was successful. He was able to go home three weeks later. "I'm already feeling like my old self," he said. But he understands that life is different. He's had to cut out basketball and other strenuous activities for the next several months. And he'll be on immunosuppressive medications for the rest of his life to prevent rejection of the organ.

"Taking the medication properly is critical," said Dr. Pagani. Failure to take the medication increases the risk of rejection, and taking too much medication can damage Noah's kidneys. Doctors will perform biopsies of his heart over the next few months. This involves removing pieces of the heart to inspect them.

When asked about the need for more organ donors, Noah said: "All I can say is it's a worthwhile cause. It's why I'm here. When you donate, you're helping someone else." ❖

Raising Awareness Among African Americans in Muskegon

By Michelle Meadows

Joe Mattox, executive director of the Muskegon Heights Housing Commission, read about Noah's situation in the local paper. "I was very concerned when I read that the average wait for a heart in Michigan is six months," Mattox said. He already knew Noah from when he participated in the housing commission's summer "Kids in Training" program in 1994 and 1995.

"The article in the paper was a fine article," Mattox said. "But it didn't say anything about the need for more organ donors in the African American community." Members of

racial and ethnic groups share similar genetic markers with members of their own group, so an African American recipient is more likely to have good match with an African American donor. Increasing the minority donor pool increases the likelihood of a good match.

Mattox started asking around to find out how people feel about organ donation. "A lot of people say they won't donate because of religion," he said. "They say they want to go to heaven whole." But according to the National Transplant Assistance Fund, all major religions support donation as

a beneficial act, especially since one donor can save the lives of as many as 40 transplant patients.

In an effort to spread the word about the need for more African American donors, Mattox sent an article to several Michigan papers. He's received positive feedback from readers, and he continues to distribute material on organ donation at the housing commission. "People have all different opinions about organ donation," Mattox said. "But we need to call more attention to the fact that Black people should think harder about this issue." ❖

National Conference: Increasing Donation and Transplantation

The following articles are reports on the recent national conference on organ donation and the challenge of evaluation, April 1-2, 1998 in Crystal City, Va. Sponsors included HHS's Office of the Assistant Secretary for Planning and Evaluation, the Agency for Health Care Policy Research, and the National Institute of Allergy and Infectious Diseases.

Researchers Apply Behavioral Psychology To Organ Donation Consent

By Michelle Meadows

Some of us have our pens out, ready and willing to sign an organ donor card at the first opportunity. Some are willing to think about signing. Others are turned off completely. So what factors put us in one category over another? And what pushes us from one stage to the next?

The South-Eastern Organ Procurement Foundation (SEOPF) and The University of Rhode Island (URI) Cancer Prevention Center have teamed up to answer such questions. The Health Resources and Services Administration, HHS, helped bring the two organizations together.

SEOPF has contracted with URI for studies that would apply the Transtheoretical Model of Behavior Change to organ donation consent. Phase 1 of the work resulted in the development of a detailed questionnaire that was administered to 158 donor next-of-kin. That data will be used to construct a short questionnaire that organ procurement coordinators will use to "stage" donor families at the time of consent. The idea is to determine someone's stage of readiness to donate so that stage-appropriate interventions can be used.

The Transtheoretical Model of Behavior Change views the stage of change, the decisional balance (pros and cons), and the processes of change as interrelated parts of successful behavior change, said Mark Robbins, PhD, of URI's Cancer Prevention Center. The stages of behavior are precontemplation, contemplation, preparation, action, and maintenance.

"The assumptions that we're using," Dr. Robbins said, "are that multivariable models are needed to influence behavior change, that interventions are action oriented, and that interventions need to be matched to a person's level of readiness."

The decisional balance part of the model involves how people weigh the pros and cons of donating. A pro would be trying to get some positive outcome from a person's death. A con might be thinking that the doctor won't try hard to save a patient's life if another patient is waiting for a

transplant.

The processes of change part of the model looks at how people change and progress through the stages. For example, dramatic relief is the process that can move people to change by touching their emotions. This would include personal testimonies from an organ recipient. The social liberation process encourages change by focusing on empowerment. And self-liberation focuses on the belief that one can change and make a commitment to act on that belief. An example would be a New Year's resolution.

SEOPF has contracted with URI for Phase 2 studies that would develop curricula and training materials for organ procurement coordinators. Phase 3 will lead to the development of multimedia computer systems that enhance this work.

For more information, contact Mark Robbins at the University of Rhode Island, 401-874-5082. ♦

National Organ Waiting List

Kidney.....	38,760
Liver:.....	10,059
Pancreas.....	367
Pancreas Islet Cell.....	88
Kidney/Pancreas.....	1,653
Intestine.....	95
Heart.....	4,020
Heart/Lung.....	235
Lung.....	2,756
Total.....	58,033

Source: United Network for Organ Sharing, March 1998

National Conference: Increasing Donation and Transplantation

California Transplant Donor Network Improves Hispanic Marketing Efforts

By Michelle Meadows

In 1996, only 9 Hispanic families in the Fresno area, from a potential of 37, consented to organ donation. “We started to think that maybe we weren’t putting out the right message to Hispanics, or using the right messenger, or even using the right language,” in our outreach efforts, said Denise Kinder, regional manager of the California Transplant Donor Network (CTDN).

To better understand low consent rates among Hispanics, CTDN surveyed 520 Hispanic households in several northern California counties. Results showed a need for bilingual public awareness programs that highlight stories of Hispanic transplant recipients and donor families. There was also a need to target the large population of Mexican immigrants. Using a Hispanic marketing firm, CTDN:

- Broadcast, in Spanish, testimonials from Hispanic transplant professionals, recipients, and donor families.
- Honored a Hispanic donor family during donor awareness week.

- Placed newspaper articles about the heroic aspects of being a donor family.
- Presented Spanish-language organ donation material at rural clinics and special events such as Mexican Independence Day activities.
- Presented organ donation materials at classes on English as a Second Language.
- Developed relationships with Hispanic religious, social, and professional organizations.

As a result of these efforts, the Hispanic consent rate in the Fresno area rose from 24 percent to 46 percent by the end of the program. To track consent rates of Hispanic families, the network used a donor tracking tool—a database containing 29 fields of information. They looked at age, language spoken, the hospital where the request was made, and previous exposure to organ donation.

The survey of Hispanic households will be repeated in the year 2000. *For more information, call 1-800-553-6667.* ♦

ICFA Encourages Funeral and Cemetery Counselors to Provide Organ Donation Education to Those Planning Own Funerals

By Michelle Meadows

The International Cemetery and Funeral Association (ICFA) announced in March a new program that encourages funeral and cemetery counselors to include organ donation in their “pre-need” presentations.

Through pre-need counseling, cemetery and funeral counselors advise consumers on making their own funeral arrangements. This lifts the time constraints and emotional pressure that relatives typically face when a loved one dies, said Linda Christenson, executive vice president of ICFA.

ICFA estimates that thousands of pre-need sessions take place each day. Counselors discuss a range of end-of-life issues, such as veterans’ benefits, the advantages of having a will, and the importance of sharing final instructions with family members.

The association’s organ donation awareness program recommends that pre-need counselors discuss the process of becoming an organ donor, and provide free organ donor registration information.

Due to the long-term nature of pre-need counseling, ICFA representatives are optimistic that this program will boost the number of organ donors. “Unlike with other consumer transactions, the relationship between pre-need

counselors and customers often continues over a number of years or even decades,” Christenson said.

ICFA plans to distribute training materials and organ donation information to its member cemeteries and funeral homes. “We anticipate working closely with the U.S. Department of Health and Human Services and other parties in developing an effective method of evaluating or intervention program,” Christenson added.

This evaluation would include conducting a baseline survey of 100 ICFA members to find out which ones provide some organ donation information already, and whether customers have registered. Fifty of the 100 members would then receive educational materials and forms on organ donation. Later, a follow-up survey would determine whether donor registration rates have increased.

The ten members with the highest registration rates and the ten with the lowest rates would be identified and evaluated, Christenson said. “Then we could look at certain elements that could have contributed to the different rates, such as counselor participation and attitude.”

For more information, contact the International Cemetery and Funeral Association in Reston, Virginia, 703-391-8400. ♦

National Conference: Increasing Donation and Transplantation

Legislative Briefs From Transplant Recipients International Organization (TRIO)

Immunosuppressive Drug Coverage Under Medicare (H.R. 1061 & S.1481): In 1997, Rep. Charles T. Canady (R-FL) reintroduced H.R. 1061 to amend Title XVIII of the Social Security Act. The bill would eliminate the time limitations on benefits for immunosuppressive drugs under the Medicare program. Sen. Mike DeWine (R-OH) introduced the companion bill in the Senate (S.1481).

Gift of Life Medal Act (H.R. 1505 & S.636): Rep. Pete Stark (D-CA) introduced the Gift of Life Congressional Medal Act of 1997 to the 105th Congress. Sen. Bill Frist (R-TN) introduced the companion bill in the Senate. The legislation would award a Gift of Life medal to donor family members for their donation.

Lifetime Cap Discrimination Prevention Act (H.R. 1807 and S. 1114): In 1997, the Lifetime Cap Discrimination Prevention Act was introduced by Rep. Anna Eshoo (D-CA), Sen. James Jeffords (R-TV), and Sen. John Rockefeller (D-WV). Lifetime insurance caps or limits are currently set at an average of \$1 million per person. But TRIO says, this limit discriminates against those who need coverage the most, driving the chronically ill out of the private insurance market. The legislation would amend the Employee Retirement Income Security Act and the Public Health Service Act to raise the lifetime cap from the existing \$1 million limit to \$5 million in 1998 and \$10 million in 2002. Businesses with fewer than 20 employees are excluded from the requirements.

Amendments to Bolster Donor Efforts: In 1997, the U.S. Senate unanimously passed two amendments aimed at bolstering hospital efforts to increase organ and tissue donation (Sen. Bill 1061). The first amendment, sponsored by Sen. Carl Levin (D-MI) is to ensure "that hospitals that have significant donor potential shall take reasonable steps to assure a skilled and sensitive request for organ donation to eligible families. The second amendment, sponsored by Levin and Sen. Richard Durbin (D-IL), calls for a nationwide survey of hospitals' donor practices. The appropriations bill is before Congress, and the final bill language will be worked out in conference committee.

Congressional Task Force on Organ and Tissue Donation: In 1996, members of the House and Senate formed this task force to increase donor awareness and dispel myths about donation. The group holds briefings with health experts, donor families, recipients, and other members of the donation and transplant community.

TRIO distributed these legislative briefs at the national conference on organ donation and transplantation. For more information on legislation affecting donors and transplant recipients, contact TRIO at 202-293-0980; 1000 16th St., NW, Suite 602, Washington, D.C. 20036. ♦

"Life Takes Guts" Campaign Attracts College-Aged Donors

By Michelle Meadows

Sometimes the key to pulling off a good health awareness program is a tactic that always draws a big crowd. Free food, for instance. It's one way the "Life Takes Guts" campaign attracts college students to events that promote organ donation education. The campaign also holds donor drives in high-traffic areas, adds organ donation information to curriculum, and makes organ donor registration an option when students register for classes.

After discovering a study that showed how many people's values take shape during the ages of 18 and 24, the Georgia Coalition on Donation created the college program in 1996. The coalition supported five campus programs in 1996 and ten programs in 1997. Fifteen colleges are being targeted for 1998.

More than half of Georgia's college audience has been exposed to "Life Takes Guts" through special events and media placements. A Greek life campaign has reached 20,000 fraternity and sorority members.

For more information, contact Mr. Von Roebuck at the Georgia Coalition on Donation, 404-851-5849. ♦

College Students' Attitudes Toward Organ-Tissue Donation

By Jennifer Brooks

Almost two-thirds of students surveyed desired to become organ donors, according to a study conducted by Joye M. Carter, MD, Harris County Chief Medical Examiner in Houston, Texas. But only about a third of those individuals communicated their wishes to their family members, the study revealed.

The 1997 study examined student's attitudes about organ donation knowledge, personal decision, family communication, public education, discrimination, rapid organ recovery, presumed consent, and mandated choice. Ninety-two percent of respondents felt that public education was inadequate, and almost a half—47 percent—felt that the donation process was not fair to all people.

"We cannot allow a lack of education limit our supply of potential donors," said Carter. "Educational efforts involving the community must be implemented to solve this dilemma."

There was mixed support for rapid organ recovery (56 percent for versus 42 percent against). Seventy-eight percent of the students were against full presumed consent. There was, however, substantial support for mandated choice (79 percent), which suggests, according to Carter, "that we must revamp the present system and try to solve this crisis."

Overall, the study showed that students fail to consider organ and tissue donation. In addition, students feel that the public is improperly educated on the topic of organ donation.

The study involved a written survey that was administered to 516 students, age 18 or older, at the Philadelphia College of Pharmacy and Science. The survey was completed voluntarily and anonymously. *For more information, contact Dr. Joye M. Carter at 713-796-6789.❖*

NKF Teaches Elementary-Aged Students About Kidney Donation

By Michelle Meadows

To hold the attention of third graders, get them involved in hands-on activity. This approach is working for the National Kidney Foundation's (NKF) new school education program. The program, which is targeted to students in grades 3-5, is designed as an interactive 30 to 60 minute class period.

A volunteer medical professional and a kidney recipient present the program. One student is designated as the patient who needs a kidney from one of several potential donors. Different students acting as potential donors wear vests with "removable" kidneys attached. Also provided are flash cards indicating the donor's age, blood type, and willingness to donate. Then the NKF representatives talk

about kidney function, kidney failure, and its treatments. After students select the best donor, the student doctor in the class performs the "operation", removing the kidney from the donor and attaching it to the recipient.

After the program, students create quizzes on the topics covered, administer them to family members and friends, and grade them. Students then take the quiz results and create posters of their findings. A post test is administered several months later to evaluate how much students learned about kidney donation..

This school program is in the pilot test phase, and will be launched nationally in February 1999. *For more information, call Cornelia Cavanagh at NKF, 212-889-2210.❖*

Organizations with Minority Outreach Programs

American Society of Minority Health and Transplant Professionals

19480 Burlington Drive
Detroit, Michigan 48203
Tel. (313) 369-0398; Fax (313) 369-0497

Association of Organ Procurement Organizations

Regional Organ Bank of Illinois
800 South Wells, Suite 190
Chicago, Illinois 60607
Tel. (312) 431-3600; Fax (312) 803-7643

One Cambridge Court
8110 Gatehouse Road, Suite 101 West
Falls Church, Virginia 22042
Tel. (703) 573-2676; Fax (703) 573-0578

California Transplant Donor Network

Tel. 1-800-553-6667

Delaware Valley Transplant Program

2000 Hamilton Street, Suite 201
Philadelphia, Pennsylvania 19130
Tel. 1-800-KIDNEY, or (215) 557-8090

Donor Network of Arizona

3877 North 7th Street, Suite 200
Phoenix, Arizona 85014
Tel. 1-800-943-6667, or (602) 222-2200

Georgia Coalition on Donation

1201 Peachtree Street
400 Colony Square, Suite 1550
Atlanta, Georgia 30361
Tel. 1-800-355-SHARE, or (404) 266-8864

Lifeline of Ohio

770 Kinnear Road, Suite 200
Columbus, Ohio 43212
Tel. 1-800-525-5667, or (614) 291-5667

Louisiana Organ Procurement Agency

3501 North Causeway, Suite 940
Metairie, Louisiana 70002
Tel. 1-800-521-4483, or (504) 837-3355

Mississippi Organ Recovery Agency

12 Riverbend Place, Suite B
Jackson, Mississippi 39208
Tel. 1-800-362-6169, or (601) 933-1000

MOTTEP

National Minority Organ/Tissue Education Program
2041 Georgia Avenue NW, Suite 3100
Washington, D.C. 20060
Tel. (202) 865-4888; Outside Washington (800) 393-2839

National Coalition on Donation Hotline

1-888-90-SHARE (1-888-907-4273)

National Kidney Foundation

30 East 33rd Street
New York, New York 10016
1-800-622-9010, or (212) 889-2210

Regional Organ Procurement Agency (ROPA)

11150 W. Olympic Blvd., Suite 770
Los Angeles, California 90064
Tel. 1-800-933-0440, or (310) 206-0222

Southern California Organ Procurement Center (SCOPC)

2200 West 3rd Street, Second Floor
Los Angeles, California 90057
Tel. (213) 413-6219, or (619) 756-3136

Tennessee Donor Services

1714 Hayes Street
Nashville, Tennessee 37203
Tel. 1-800-969-4438, or (615) 327-2247

Texas Transplantation Society

Tel. 1-800-880-1300

Transplant Recipients International Organization (TRIO)

1000 16th Street NW, Suite 602
Washington, D.C. 20036
Tel. 1-800-TRIO-386 or (202) 293-0980

U.S. Department of Health and Human Services, Health Resources and Services Administration, Division of Transplantation

5600 Fishers Lane, Room 729
Rockville, Maryland 20857
Tel. (301) 443-7577

United Network for Organ Sharing (UNOS)

1100 Boulders Parkway, Suite 500
Richmond, Virginia 23225
Tel. 1-800-355-7427

Virginia Transplant Council

P.O. Box 2448
Richmond, Virginia 23218
Tel. 1-800-52-DONOR, or (804) 786-5589

Wisconsin Donor Network

9200 West Wisconsin Avenue, Room 113
Milwaukee, Wisconsin 53226
Tel. 1-800-432-5405

Other Organizations

American Association of Blood Banks

8101 Glenbrook Road
Bethesda, Maryland 20814
Tel. (301) 907-6977; Fax (301) 907-6895

America's Blood Centers

725 15th Street NW, Suite 700
Washington, D.C. 20005
Tel. (202) 393-5725; Fax (202) 393-1282

American Society of Nephrology

1200 19th Street NW, Suite 300
Washington, D.C. 20036
Tel. (202) 857-1190; Fax (202) 223-4579

American Society of Transplant Physicians

Vanderbilt University Medical Center
S-3305 Medical Center North
Nashville, Tennessee 37232-3272
Tel. (615) 322-6976; Fax (615) 322-7156

American Society of Transplant Surgeons

2000 L Street NW, Suite 200
Washington, D.C. 20036
Tel. (202) 416-1858; Fax (202) 833-3843

Central New York Eye Bank and Research Corp.

P.O. Box 21
Syracuse, New York 13201
Tel. 1-800-EYES-4-US, or (315) 476-0199

Emory University Hospital Center for Transplantation

1364 Clifton Road NW, Room F-310
Atlanta, Georgia 30322
Tel. (404) 712-4444

International Cemetery and Funeral Association

1895 Preston White Drive, Suite 220
Reston, Virginia 20191
Tel. (703) 391-8400

Lions Club International

300 22nd Street
Oak Brook, Illinois 60523-8842
Tel. (630) 571-5466, ext. 318

North American Transplant Coordinator's Organization

Laurie Williams, RN, MSN, CCTC, President
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600 South 42nd Street
Omaha, Nebraska 68198-3285
Tel. (402) 559-4076; Fax (402) 559-6107

Diedre Panjeda, Executive Director

P.O. Box 15384
Lenexa, Kansas 66285-5384
Tel. (913) 492-3600; Fax (913) 541-0156

South-Eastern Organ Procurement Foundation

Thomas Peters, MD, President
Jacksonville Transplant Center
580 West 8th Street, Suite 8008
Jacksonville, Florida 32209
Tel. (904) 366-7900; Fax (904) 366-7903

Thomas Armata, Executive Director

5004 Monument Avenue, Suite 101
Richmond, Virginia 23230
Tel. (804) 342-1414; Fax (804) 342-1404

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Closing the Gap

Meetings & Conferences: 1998

May 15-17: National Farmworkers Health Conference in Houston, TX. Sponsored by the National Association of Community Health Centers. Contact: (202) 659-8008.

Jun. 1-4: AARP Biennial Convention, "Connecting with the Future," in Minneapolis, MN. Sponsored by the American Association of Retired Persons. Contact: (202) 434-2760.

Jun. 10-13: 12th Biennial Conference on Hispanic Health and Human Services, held in Dorado, Puerto Rico. Sponsored by the National Coalition of Hispanic Health and Human Service Organizations (COSSMHO). Call: (202) 797-4327.

Jun. 28-Jul. 4: 68th Annual Convention and National Training Institute held in Dallas, TX. Sponsored by the League of United Latin American Citizens. Contact: (202) 408-0060.

Oct. 1-4: National Conference on "Quality Health Care for Culturally Diverse Populations," sponsored by the New York Academy of Medicine, Office of Minority Health, and Resources for Cross Cultural Health Care. Contact: (212) 822-7276

Oct. 22-24: TRIO Annual Conference in Washington, D.C., "Building Partnerships for the Future. Call (202) 293-0980.

Video Conference on Minority Health

July 12-17, 1998

The University of North Carolina, Chapel Hill, School of Public Health is sponsoring the *Summer Public Health Research Video Conference and Institute on Minority Health*. The video conference will be broadcast live throughout the country.

For information on video sites or on-site registration, contact Pam Duncan at (919) 966-7082.