

You Too Can Save a Life

Encouraging Minorities to Become Donors

By Kauthar B. Umar, MA

Closing the Gap, Working Toward Our Goal • August 2003

Since its inception in April 2001, the *Gift of Life* Donation Initiative has proven to be a winner. This five-part national program was developed by the Administration to increase awareness and promote donation of organs, marrow, and tissue for transplantation, as well as blood donation. Although there has been marked improvement in organ donation over the last several years, much more work remains to be done.

Speaking in August 2002 on National Minority Donor Awareness Day, Health and Human Services (HHS) Secretary Tommy G.

Thompson said the *Gift of Life* initiative led to a seven percent increase in overall donations over the past year and a 13 percent increase in African American donors. Hispanic donations accounted for a 14 percent increase. But, according to Secretary Thompson, a more concerted effort remains and these efforts should be directed toward minority communities.

“Because of this marked increase in donors, and because of someone’s selfless act of love and compassion, an additional 1,000 people who needed transplants last year [2001] received them,” Thompson said. “However, we need to continue to reach minority communities with the message that organ donation saves lives,” he added.

In addition to reaching out to the minority communities, a Federal/private partnership was created to help involve employers and their employees. Under the *Gift of Life* Donation Initiative banner, Secretary Thompson mobilized the resources and expertise of the Federal government, the private sector, and local communities in what is known as the *Workplace Partnership for Life* program. This feature involves collaboration with companies and employer groups of all sizes to make information on donation available to employees.

The Problem

There are currently more than 80,000 people waiting for organ transplantation in the United States, and between 20,000 and 30,000 people are diagnosed each year with blood diseases that require marrow donation. According to HHS, about 63 people each day receive an organ transplant, but another 16 people on the waiting list die because not enough organs are available. Compounding matters, minorities are disproportionately underrepresented among available donors—making the survival rate for minorities in need of transplants quite low.

“About 54 percent of those on the waiting list are White, 26 percent are African American, 15 percent are Hispanic, and 5 percent are Asian,” said Lynn Wegman, director of transplantation, Health Resources and Services Administration

(HRSA). “The largest proportion of patients on the waiting list (52,000) are waiting for a new kidney. About 38 percent of those are African Americans, because they are transplanting at a lower rate.”

However, a shortage of minority donors has made it difficult to locate the best matches, and contributes to longer waiting periods for transplants for minorities. Tissue types are inherited, much like hair or eye color. Matching organs between members of the same ethnic and racial group often enhances successful transplantation. Patients are less likely to reject a kidney if an individual who is genetically similar donates it.

“Dying from needing an organ is preventable.”

Paul Schwab, executive director,
Association of Organ Procurement Organizations.

Barriers to Donation

While African Americans have one of the greatest needs for organ and tissue transplantation, they are often reluctant to become donors. Dr. Jeffrey Chell of the National Marrow Donor Program (NMDP), a nonprofit organization based in Minneapolis, Minn., says that there are barriers to transplantation for the general public, however, when race becomes a factor, barriers grow even more. “There are a number of barriers that exist that limit a patient’s access to a transplant. Those barriers differ by racial group. Race matters in transplantation,” said Chell. “The first barrier faced by everyone is having a match and having that person available. Next is access to transplantation. There are economic and sometimes geographic barriers. Both are hardest for minorities in the U.S.”

Misinterpretation of the organ donation process and a lack of knowledge are additional barriers, according to Chell. Mistrust of the medical system and a fear of not receiving appropriate medical treatment are also cited as reasons why many minority families decline donation. Religious and cultural beliefs are additional factors, especially the belief that the body must remain intact after death. Asian Americans, Native Americans, African Americans, and Hispanics have individual cultural and religious beliefs that may deter some families from donating.

Organ Procurement

HRSA plays an instrumental role in funding and overseeing Federal efforts to improve the national system of procuring, distributing and transplanting organs, tissue, bone marrow, and blood stem cells. President Bush’s fiscal year 2003 budget included nearly \$25 million, an increase of \$5.2 million, for HRSA’s organ procurement and transplantation efforts. The requested level is targeted to increased efforts to encourage organ donation and education.

continued on page 2 >>>>



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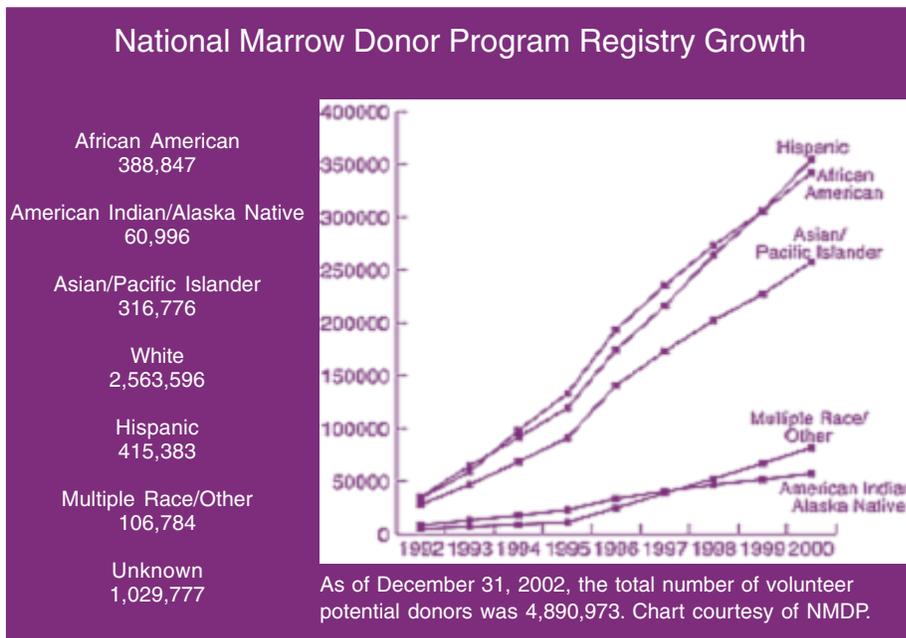
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The United Network for Organ Sharing (UNOS) administers the nation's only Organ Procurement and Transplantation Network (OPTN). It collects and manages data about each transplant event occurring in the U.S., facilitates the organ matching and placement process, and oversees the national waiting list. In addition, UNOS links all transplant centers and organ procurement organizations (OPOs). OPOs are responsible for approaching families about the option of donation when they have lost a loved one. OPOs evaluate the medical suitability of potential donors, coordinate the recovery, preservation, and transportation of organs donated for transplantation, and educate the public about the critical need for organ donation.

The LifeCenter Northwest Donor Network of Bellevue, Wash., the largest organ procurement organization in the U.S., says cross-racial donations can, and do, occur successfully when the matches are available. Genetic makeup is a crucial factor when matching a specific donor and recipients. As a result, an individual of Hispanic descent may match better with an organ from another Hispanic versus a different racial or ethnic group.

In addition, organ donations can be collected from both the deceased and the living. "Last year, there were 6,500 living donors in this country. For the first time, the number of living organ donors surpassed the number of deceased organ donors," said Wegman. "Living organ donors are traditionally relatives or friends of the organ recipient, making the donors more inclined to donate because the recipient is a loved one," she added.

Wegman further mentioned that there were nearly 6,100 deceased donors in 2002. Despite the surprising increase in living donors, the disparities in terms of race and ethnicity were equally as shocking as they were for deceased donors. Seventy to 72 percent of living donors are White, 12 to 13 percent are African American, and another 12 to 13 percent are Hispanic.



Increasing Minority Donors

There are a number of national programs and initiatives created to break down the barriers and make donations easier and more attractive to minorities. NMDP has developed a strategic approach to increase the number of transplants, improve transplant outcomes for patients, and in particular, service the needs of minority patients. The initiative addresses racial disparities and revolves around recruitment, education, patient advocacy, research, and NMDP organizational diversity.

In 1993, NMDP developed a series of initiatives to address recruitment in minority communities. Programs like, *African Americans Uniting for Life*, *Keep the Circle Strong for American Indians and Alaska Natives*, *Asian Pacific Islander Donors Can Save Lives*, and *Hispanics Giving Hope* were remarkably successful and several components of these initiatives continue today.

"Each of these programs was developed with direct involvement and consultation from people in those communities," said NMDP's Isaac Fordjur, legislative representative. "The programs also included the de-

velopment of very culturally centered materials that were translated into the proper languages. A team of what we call ethnic marketing associates helps make sure that NMDP is addressing the needs of the community in terms that the community can appreciate," added Fordjur.

NMDP has also developed a series of recruitment groups that work with NMDP donor centers across the country. In these groups are individuals who are involved and highly visible within their communities and work to recruit donors to the registry. Language assistance is available in 26 different languages, and written materials are available in six languages.

Projects at Historically Black Colleges and Universities (HBCU), in collaboration with African American fraternities and sororities, have also worked well for NMDP. "The *Touchdown for Life* campaign which is sponsored by 3M Corporation, in partnership with our donor centers, recruits about 6,000 donors a year to the registry on HBCU campuses," said Fordjur. The Asian Pacific American Medical

continued on page 3 >>>>



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Student Association recently finished a campaign that recruited approximately 3,500 donors. In addition, Mu Kappa Alpha, a national Hispanic fraternity, recruited approximately 3,000 donors in 2002.

Working with students and universities to address the need for donors in minority communities has also proven to be a sound tactic for the National Minority Organ Tissue Transplant Education Program (MOTTEP).

In 1991, Dr. Clive O. Callender, chairman of the Department of Surgery at Howard University Hospital, helped develop the first minority-directed dialysis and transplant center, and histocompatibility and immunogenetic laboratory in the U.S. He envisioned an organization that would target minorities and educate them on the importance of organ donation while encouraging them to become donors. This was done using a grassroots effort—an endeavor that had not been used in targeting minorities in the past. Just three years later, the official MOTTEP office was opened at Howard University Hospital. Today there are 15 additional sites throughout the U.S. and its territories. The efforts of MOTTEP have expanded to other minority communities including, Hispanics/Latinos, American Indians/Alaska Natives, and Asian Americans/Pacific Islanders.

As the first program of its kind in the U.S., MOTTEP is designed to educate minority communities on facts about organ and tissue transplantation. It empowers minority communities to develop transplant education programs that allow them to become involved in addressing the shortage of donors. MOTTEP increases minority participation by encouraging and increasing family discussions related to organ and tissue donation.

MOTTEP's mission recently expanded to include a prevention message. It created a new theme to reflect the change, "Love Yourself, Take Care of Yourself." This message is meant to encourage individuals to adopt healthy behaviors, including eating balanced, nutritious meals, exercising, and avoiding unhealthy behaviors such as eating a diet high in fat and cholesterol, being overweight, and abusing drugs and alcohol—behaviors that could lead to the need for a transplant.

A Look to the Future

Along with the *Gifts of Life* Donation Initiative, Secretary Thompson also unveiled a model organ and tissue donor card that incorporates proven elements from existing donor cards. He also commissioned a national medal to honor donors and their families at national and regional ceremonies.

"Dying from needing an organ is preventable," said Paul Schwab, executive director, Association of the Organ Procurement Organizations.

"The opportunity to save the life of a stranger is a heroic act. Sometimes it takes more of a personal sacrifice to get the job done," added Secretary Thompson.

For more information on organ and marrow donation and Federal initiatives, go to <http://www.organdonor.gov> ❖

For more information on the National Marrow Donor Program, go to <http://www.nmdp.org> ❖



*You Too Can Save a Life is based on the Summit workshop
"Organ Donation and Marrow Donation Program—Now More Than Ever"*

