

# Organ/Tissue Donation the Problem! Education the Solution: A Review

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**T**he 21st century is upon us faster than we thought possible, as is the crisis caused by an ever-increasing incidence of end-organ failure. This has mandated us to focus on the need for organs, the wide donor-recipient disparity, and the widening transplant waiting list. In 1983, this disparity between donors and recipients was nearly 1000; in 1996, it was more than 20,000. Because of this gap and the long waiting time for organs (1 to 2 years), 10 people die every day. What is the solution to this problem? The answer lies in the recognition that this disparity is the number one problem in transplantation today and that it must be given the priority for solution it deserves.

In the past, we have spent wisely, giving the science of transplantation its proper due. Billions of dollars have been spent on basic science and clinical research in transplantation, and consequently, we are blessed with a better than 90% 1-year patient and graft survival rates for most organ transplants. In a sense, this success has been part of the problem because it has made transplantation a more attractive treatment option. Unfortunately, without sufficient numbers of donors, this has resulted in waiting lists with an average wait of 1 year for an organ.

This article underscores the importance of recognizing that the shortage of donors is now the number one priority and that we need to marshal our resources with the same intensity used for the

previously mentioned research efforts. We must now approach this problem with careful educational intervention strategies as well as the appropriate research funding to allow these endeavors to become and remain a top priority. The beginning of the solution is for us to look at the history of our previous organ donation efforts, identify the strengths of each effort, learn from them, and take these building blocks to identify a national strategy for narrowing the donor-recipient disparity.

This strategy must have education as its foundation. Education, be it community-based, personal, or national, is the key to the strategy for "narrowing the gap." A blend of professional, public, majority, and minority efforts must be mixed with grass roots and multimedia campaigns with the targeted message delivered by transplant recipients, transplant candidates, donors, and their families. The eloquence of messages delivered in this fashion will allow us to overcome the obstacles of ignorance and distrust, which are our arch enemies.

## HISTORY OF ORGAN TISSUE DONATION EDUCATIONAL EFFORTS

### Efforts in the Majority Population

*National Kidney Foundation (NKF) (1968 to Present).* Between 1968 and the present, the following occurred:

- Organ donor cards were made possible by the Uniform Anatomical Gift Act, which was developed by the Commissioners on Uniform State Laws in 1968. This model law had to be enacted in every state so that donor cards would be valid in all jurisdictions across the country. Local NKF Affiliates worked actively with their respective state legislatures to pass

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the Uniform Anatomical Gift Act from 1968 to 1973. The Table lists the states that adopted this statute as well as the effective dates.

- House of Representatives (HR)-1 Legislation signed by President Nixon in 1972 authorized Medicare payment for end-stage renal disease. The NKF lobby played a major role in the passage of this legislation.
- The Critical Care Nurses education program entitled, "Making the Critical Difference," educated 10,000 critical care nurses about organ donation and transplantation from 1990 to 1995.

***American Council on Transplantation (ACT) (1985 to 1990).*** The ACT was the first attempt to bridge all transplant efforts with private and public sectors working together as one. The Council emphasized for the first time the power of the voice of the transplant recipient population.

***United Network for Organ Sharing (UNOS) Ad Hoc Donations Committee's White Paper (1990 to 1991).*** The United Network for Organ Sharing (UNOS) Ad Hoc Donations Committee's White Paper reemphasized the need for an umbrella group working together for donation educational purposes. This organization suggested the use of the Advertisement Council (AD) for minimal cost advertisements.

***Partnership on Donation (1990 to Present).*** Partnership on Donation was the first to present data (1991) that emphasized the value of decoupling the death pronouncement and organ donations request.<sup>1</sup> The program recommended a priority shift from donor card signing to family discussion and demonstrated statistical evidence to support the need for change.<sup>1</sup>

***Coalition on Donation (1992-Present).*** This umbrella group for donation emphasized majority population needs (E. Servino, unpublished data, December 1995) and used AD Council and transplant centers to expand and optimize resources.

### **Lessons Learned From These Majority Efforts**

The value of the political, private, and public sectors working together on legislation was demonstrated in 1968 with the passage of the Uniform Anatomical Gift Act (UAGA) and again in 1972 with the passage of HR-1, the Medicare end-stage renal disease medicine reimbursement program. In 1985, the power of the voice of the transplant recipient and the need to work together as one was articulated by the ACT.

Partnership on Donation's educational strategies of decoupling and emphasizing family discussion, and deemphasizing the signing organ donor cards in 1990 were significant breakthroughs. Finally, the Coalition on Donation reemphasized the need for an umbrella group and put into practice the concepts first espoused by the UNOS Ad Hoc donations committee in 1991.

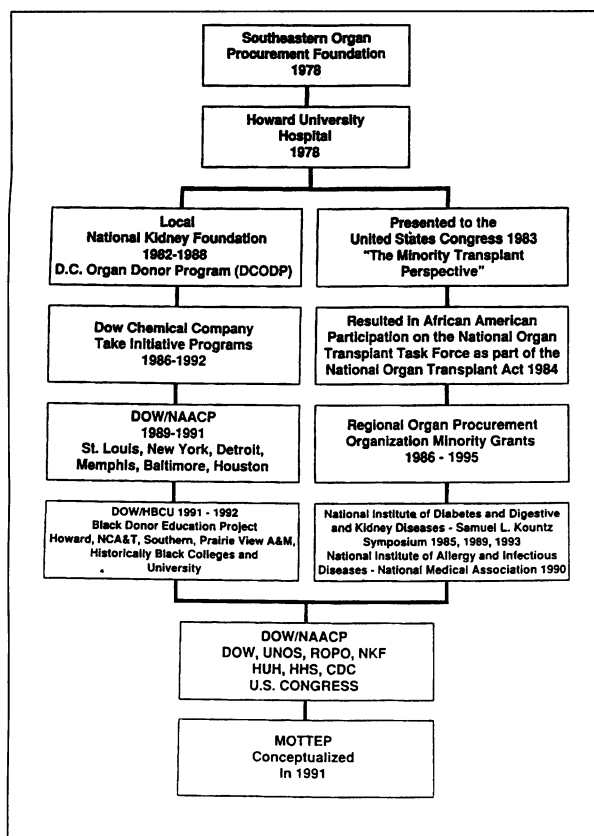
### **Efforts in the Minority Population**

***The District of Columbia Organ Donor Program (DCODP).*** The DCO DP was sponsored by Howard University Hospital and the National Capital Area's NKF from 1982 to 1988.<sup>2-4</sup> This effort resulted in the following black donor education contributions:

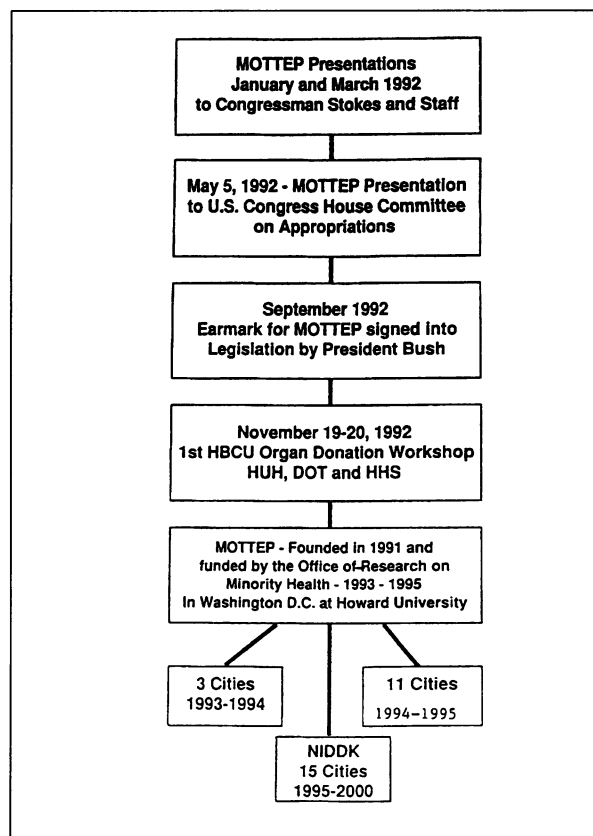
- first to identify and document the five most common reasons for African-American reluctance to donate organs,<sup>4</sup>
- first to develop an African-American donation strategic plan to form a targeted message with short- and long-term plans for increasing African-American donor rates,
- first to apply the face-to-face dialogue and grass roots approach in organ donor education efforts to educate and empower this community,
- first to highlight the effectiveness of transplant recipients, transplant candidates, and donor families as community educators and messengers,
- first to develop black donor community education brochures encouraging organ and tissue donation, and
- first to target the Washington, DC Motor Vehicle agency and document an increase in donor card signings from 25 per month to 750 per month between 1982 and 1988.

***Dow Chemical Company Take Initiative Program (DOWTIP).*** From 1986 to 1992,<sup>5-9</sup> the Dow Chemical Company and the National Association for the Advancement of Colored People (DOW-NAACP) (1989 to 1991), and the Dow Chemical Company's Historically Black Colleges and Universities Black Donor Education Program (DOW/HBCU) (1991 to 1992) resulted in the following black donor education contributions:

- From 1986 to 1992, a black donor education mass media tour encompassed 50 cities.
- The first national donor education program to blend a grass roots approach with a multimedia campaign was instituted in six cities (St Louis, Memphis, New York, Houston, Detroit, and Baltimore).
- The Dow Chemical Gallup Poll showed a tripling



**Figure 1.** Events from 1978 to 1991 that led to the conceptualization of the National Minority Organ and Tissue Transplant Education Program (MOTTEP).



**Figure 2.** Events from 1992 to 1995 that led to the institution of the National Minority Organ and Tissue Transplant Education Program (MOTTEP).

of African-American transplant awareness and signing of donor cards between 1985 and 1990.

- National Historically Black Colleges and Universities (HBCU) including Howard University, Washington, DC; North Carolina A&T University, Greensboro, North Carolina; Prairie View A&M University, Prairie View, Texas; and Southern University, Baton Rouge, Louisiana, began black donor efforts between 1991 and 1992. These educational programs increased family discussions on HBCU campuses from 22% to 51% and generated 10 million media impressions.

These national mass multimedia campaigns created the following:

- *Black Donor Awareness Guidebook* (copyrighted in 1991),
- black donor awareness video entitled *Second Chance* (1990),
- black donor education brochure with questions and answers (1990), and
- articles featured in more than 275 newspapers

and magazines, 60 local and national television broadcasts, and 70 local radio stations generating more than 300 million media impressions by the fall of 1991.

**National Minority Organ Tissue Transplant Education Program (MOTTEP).** The success of the previously mentioned programs DCODP and DOWTIP culminated in the development of MOTTEP in 1991 (Figure 1). This Howard University Hospital and Office of Research on Minority Health-National Institutes of Health (NIH)<sup>10,11</sup> effort was first conceptualized in 1991 and initially funded from June 1, 1993 to July 1, 1995 with a \$1.2 million contract by the NIH Office of Research on Minority Health to develop a model minority donor strategic plan (Figure 2). The initial program involved three cities the first year and eight additional cities in the second year. This initiative produced the following outcomes:

- the first national minority transplant strategic plan,

**Table. States That Adopted the Uniform Anatomical Gift Act and Effective Dates**

State	Effective Date
Alabama	May 14, 1969
Alaska	Jan 1, 1973
Arizona	June 11, 1970
Colorado	April 24, 1969
Delaware	May 20, 1970
District of Columbia	May 26, 1970
Florida	June 14, 1969
Georgia	June 14, 1969
Illinois	Oct 1, 1969
Indiana	March 13, 1969
Iowa	July 1, 1969
Kansas	July 1, 1969
Kentucky	June 18, 1970
Louisiana	July 31, 1968
Maine	Oct 2, 1969
Maryland	July 1, 1968
Massachusetts	Aug 12, 1971
Michigan	March 20, 1970
Mississippi	April 6, 1970
Missouri	May 28, 1969
Nebraska	Aug 27, 1971
New Hampshire	Aug 29, 1969
New Jersey	Sept 9, 1969
New Mexico	March 29, 1969
New York	May 5, 1970
North Carolina	Oct 1, 1969
Ohio	Nov 6, 1969
Oklahoma	July 29, 1969
Oregon	Aug 22, 1969
Pennsylvania	July 1, 1972
South Carolina	July 1, 1969
South Dakota	March 14, 1969
Tennessee	March 25, 1969
Texas	May 29, 1969
Virgin Islands	Jan 19, 1984
West Virginia	March 10, 1969
Wyoming	Feb 19, 1969

- the first Hispanic transplant strategic plan,
- the first Asian Pacific Islander transplant strategic plan,
- the first information center for community outreach minority transplant education materials, eg, videos, brochures, posters, slides, and public service announcements,
- 200 million media impressions generated as of

July 1995, and

- a \$5.8 million NIH-National Institute of Diabetic, Digestive, and Kidney Disease (NIDDK) from July 1, 1995 to July 2000 grant for a 15-city MOTTEP to reach all minority groups, including Native Americans, Asian Pacific Islanders, Hispanics, and African Americans under one umbrella.

**Lessons Learned From These Minority Donation Education Efforts**

The five most common obstacles to minority donation were identified. A grass roots community-based approach was developed that emphasized a customized minority-targeted message delivered by members of the community who are culturally and ethnically similar and sensitive. The minority donation education efforts demonstrated the synergy that results when grass roots and multimedia efforts are combined. The most eloquent messengers were found to be community members who were transplant recipients, waiting transplant candidates, donors, and their families or significant others who accompanied the health-care providers and gave them the aura of sensitivity and credibility to enhance their presentations.

These efforts highlighted the need for more minority coordinators as well as the need for other minority health-care role models and demonstrated the value of the private and public sectors and cooperative educational endeavors. The power of the community as a change agent, even in the complex area of community behavior and attitudes, was reinforced. Minority donation rates increased locally, regionally, and nationally by the coordination of these efforts.

**Lessons Learned From All Efforts**

National efforts and coalitions involving the public and private sector are very beneficial. American donation rates will increase if the message is understandable, customized, and delivered in a trustworthy, sensitive, and compassionate fashion by the appropriate messengers. Moreover, public and professional efforts are essential. Lobbying where feasible and involvement with political action groups is mandatory, especially in the proactive mode. Finally, the most eloquent messengers are ethnically and culturally similar, sensitive community donors, and transplant recipients and candidates, and their families.

## CONCLUSIONS

The number one priority in transplantation today is the donor-recipient supply-demand disparity. This disparity contributes to the deaths of 10 people per day. The resources allocated to impact on the donor-recipient disparity must be commensurate with the magnitude of the problem. Professional and public education is mandatory for us to overcome the donor-recipient supply-demand disparity and must be the highest priority. Moreover, the majority and minority population must be approached with equal vigor and appropriate financial support. The community is a relatively untapped and powerful resource that must be maximally utilized in the future, and community-based educational efforts must be recognized as a cost-effective and powerful tool. Finally, transplant recipients, candidates, donors, and their families are the most eloquent, believable messengers and educators, and their use is strongly encouraged.

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## **A Review of Racial Differences in Geriatric Depression: Implications for Care and Clinical Research**

*David C. Steffens, MD, Dave L. Artigues, MD, Katherine A. Ornstein, MD, and K. Rama Ranga Krishnan, MD*

This study examines the racial composition of a clinical research center (CRC) in geriatric depression and discusses possible explanations for low participation of African Americans in such programs. During the first year of the CRC project, minority enrollment varied from 5% to 10%, at least one third of the African-American population of the area. Active efforts to improve minority recruitment increased this percentage to 15% by the end of the project's second year. Likely explanations for low minority participation rates include: 1) elders may recognize depressive symptoms, but do not seek or cannot obtain medical treatment, and 2) depressive symptoms may be attributed to a crisis of the spirit (so help is sought through prayer and the church), the "slowing down" process of aging, or part of life's burden to be endured. Future attempts at both treatment and clinical research efforts will need to address these possibilities.

## **Attitudes, Beliefs, and Practices Regarding Smoking and Smoking Cessation Among African-American Physicians and Dentists**

*Holly A. Hill, MD, PhD, and Ronald L. Braithwaite, PhD*

African-American physicians and dentists in metropolitan Atlanta were surveyed to assess smoking cessation practices and perception. Questionnaires were mailed to 373 physicians and 90 dentists. Results were examined by type of practitioner, year of graduation, and gender. A total of 154 questionnaires were returned for an overall response rate of 33.3%. More physicians than dentists considered smoking a "very serious" threat to patients' health, and physicians were more likely to document smoking status in charts and to counsel smokers to quit. Physicians also were approached more frequently by patients seeking cessation advice. Both types of practitioners considered the nicotine patch, formal cessation programs, and behavior modification/psychotherapy to be among the most effective cessation methods, and nicotine gum and acupuncture to be among the least effective. African-American physicians are much more involved than dentists in promoting smoking cessation among patients. Advice of health professionals generally is viewed as a powerful influence for African-American patients. Further work is needed to fully utilize the power of health-care providers, especially dentists, in the fight against tobacco-related morbidity and mortality.