

ORGAN/TISSUE DONATION IN AFRICAN AMERICANS:*

A NATIONAL STRATAGEM

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ABSTRACT

In spite of the recent overall improvements in organ donation rates per million in 1990, African Americans (A.A.) continue to be less likely than White Americans (W.A.) to become donors (11.3 vs. 21.8). To improve A.A. donation, the following data were shared with the A.A. community: 1) A.A. renal disease incidence rates are disproportionately high, 1.3 to ten times those of W.A.; 2) the A.A. kidney graft survival rate is 10-20 percent lower.

Sharing these data resulted in: A.A. transplant awareness increasing from 10 percent to 24 percent; A.A. signing donor cards increased from 7 percent to 24 percent (1985-1990 Dow Gallup Polls); the number of A.A. receiving kidney transplants and becoming organ donors doubled nationally (Health Care Financing Administration [HCFA] data 1982-1989). The message was carried by ethnically-similar messengers who form the core of this successful A.A. volunteer community-based grassroots effort, the District of Columbia Organ Donor Project (DCODP).

A national Minority Organ/Tissue Transplant Educational Program (MOTTEP) designed after this volunteer community organization is presented as a model to increase A.A. donor rates nationally.

Introduction

The state of transplantation is problematic for all groups, but most problematic for the African American community as a result of unique medical predispositions, donor difficulties, and harsh socio-economic conditions (1,2). The incidence of end stage renal disease (ESRD) in A.A.s with hypertension continues to rise despite a decline in deaths among A.A.s traceable to hypertension, heart disease, and stroke. The incidence of ESRD is almost seven times greater in A.A.s with hypertension than in their White counterparts. Furthermore, even though A.A.s represent only 12 percent of the American population, they make up 30 percent of patients on dialysis (3,4,5).

**The terms African American and Blacks are used interchangeably throughout this paper.*

Presently, three options are available for patients who develop end-stage kidney disease: peritoneal dialysis, hemodialysis, and organ transplantation. Unfortunately, no group, regardless of race, takes full advantage of transplantation: all groups overwhelmingly choose hemodialysis to combat kidney disease (80 percent Whites vs 90 percent A.A.) (5). These statistics are particularly striking considering the burdensome problems associated with dialysis. Hemodialysis is very costly, it requires attachment to a dialysis machine for 12 hours a week, and unnaturally constrains and dictates the patients lifestyle physically, socially, emotionally, professionally, and sexually.

In 1989 there were 16.1 organ donors per million Americans. African Americans donated 8 percent of the kidneys available for transplantation (11.3 donors per million), but received 23 percent of the available kidneys, almost three times as many kidneys as they donated (3).

Ten years ago, because of a similar situation (1,2,8) and the absence of any prior research on donation among A.A.s, Howard University Hospital sponsored a pilot study to disclose the most salient reasons influencing low Black donorship. The five primary reasons were: 1) lack of transplant awareness; 2) religious myths and superstitions; 3) distrust of the medical community; 4) fear of premature declaration of death after signing an organ donor card; and 5) potential Black donors' preference for assurance of Black receivership (8). Our 2-hour focus sessions provided education on an individual basis which proved to be the key to changing attitudes about donation. Only 10 percent of participants agreed to sign an organ donor card before the interview, while 100 percent signed them at the conclusion of the sessions.

Drawing from the experiences of this pilot study, the District of Columbia Organ Donor Project (DCODP) was developed in 1982. This paper discusses the origin of the DCODP, the first community-based organ/tissue donor program targeted to the Black population, and the development of subsequent initiatives which have been used to eradicate the obstacles to organ and tissue donation and transplantation among A.A.s.

Of vital importance to the success of this project have been the following: 1) an ethnically directed community message, 2) volunteerism, 3) ethnically sensitive and similar messengers, 4) community empowerment, 5) private sector sponsorship and partnership, and 6) coalitions between transplant and community organizations. We propose that the synergistic relationships operating in these programs will significantly increase A. A. donor rates when the National Transplant Educational Program is extended to the Black community. We therefore recommend establishing a National Minority Organ/Tissue Transplant Educational

Program (MOTTEP) coordinated through a national office, with 20 local programs, as an effective national strategy to increase the A. A. organ donor rate per to 16 million by 1993.

Methodology and Results

In 1978, the author was first approached by members of the Southeastern Organ Procurement Foundation (SEOPF) to identify the obstacles to organ donation in the A.A. population and the dichotomy between low Black donorship and high ESRD incidence rates. I have elsewhere described the critical elements of these original efforts (1,2,8,12) but will summarize here the steps which have led to current efforts.

In 1980, the Howard University Organ Donor Pilot Study was organized under the direction of Dr. James A. Bayton. The information yielded from focus session interviews with 40 members of the Black community shaped the concept for the D.C. Organ Donor Project (DCODP). Instituted in August 1982 under the auspices of the National Capital Area's National Kidney Foundation (NKF) and the support of Howard University Hospital, the DCODP worked with representatives from local members of the medical, political, educational, business, and religious communities.

The key founding members and subcommittee chairpersons included Harvey Silver and Preston Englert, Executive Directors, NKF; Curtis Yeager, Transplant Coordinator Howard University Hospital; Paula Barry, Public School Education Chairman and Curriculum Developer; Donovan Gay, liaison between NKF and Bureau of Motor Vehicles and first Chairman of the Financial Affairs and Grants Subcommittee; D.C. Councilman William Spaulding, First Co-Chairman of DCODP, who launched the campaign in Ward 5; Dr. Charles Thompson (first dialysis and transplant patient member) former principal and Public Education Subcommittee member; Garrett Stewart, Jr., transplant patient and liaison with funeral directors; Dr. Clive Callender, Transplant Surgeon, President NKF, Co-Chairman DCODP; Patti Grace Smith, Communication Specialist, First Chairman of the Subcommittee on Media and Community Relations.

The DCODP steering committee met monthly from 1982 to 1984 to present subcommittee progress reports, propose future initiatives, and discuss strategies to raise funds and disseminate the message into the A.A. community to increase the number of A.A. organ and tissue donors. Funds raised paid for communication materials (video tapes, slide presentations, brochures, books, and posters), the salary of a full-time DCODP Program Coordinator, and the development of a strategic plan, with committee input, by ethnically sensitive professional planners. This strategic plan led to the development of ethnically sensitive messages and techniques for effectively communicating to the A.A. community the need for more

A.A. organ donors. The DCODP strategic plan implemented in 1985 has been one of the main building blocks of this effort. All presentations now include either ethnically similar or sensitive donors, recipients, transplant candidates, family members, or health care providers whenever possible.

The message delivered to this target community is ethnically sensitive, appropriate, honest, and direct. It allows time for meaningful dialogue and for evolving answers to key questions. The message is structured as follows:

The Problems:

- 1. The incidence of all types of kidney disease is highest in A.A. patients.**
- 2. A.A.s with hypertension between ages 25 and 44 are twenty times more likely than Whites to have kidney failure.**
- 3. While A.A.s make up 12 percent of the American population, they constitute 30 percent of kidney patients waiting for transplantation.**
- 4. Kidney transplantation is less successful in A.A.s than in Whites because we have so few A.A. donors.**
- 5. A.A.s are transplanted at a rate of 50 percent less than that of Whites.**
- 6. Twenty percent of A.A.s have transplant genetic markers that are rarely found in Whites, hence, the need for more A.A. donors.**

Proposed Solutions:

- 1. The patient is the most important member of the health care team and must feed back to the physician all information about side effects when they occur. The physician, in turn, must respond in a sensitive and caring fashion.**
- 2. A.A.s should have semi-annual blood pressure evaluations after the age of 12 (13,14).**
- 3. If a diagnosis of high blood pressure results, a physician should be contacted and treatment started as soon as possible. The earlier the therapy the less likely that medication will be required and the greater the likelihood that stroke, heart attacks, and kidney disease will be prevented.**

4. Treatment of hypertension is the critical first step in early prevention of kidney failure. The treatment of hypertension decreases the number of deaths from heart attack and stroke, and is likely to decrease the incidence of kidney failure if the diagnosis is made early enough and treatment is begun promptly.

5. Impotence or decreased sexual libido is a side effect of some anti-hypertensive medications, but many anti-hypertensives do not cause this side effect. If impotence occurs, this information should be shared promptly with the physician, who will adjust or change the medication so that the patient's sex life is not compromised.

6. More compatible A.A. donors are likely to make the success of kidney transplantation in A.A.s equal to the success of kidney transplantation in Whites.

7. The A.A. community is encouraged to start a family tradition: to sign an organ donor card and to have a family discussion about organ donation and transplantation at the dinner table and at family gatherings, and to make this discussion a part of daily living.

These problems and solutions are shared with the medical or lay community as time permits with presentations ranging from 5 - 120 minutes depending on the audience's time frame.

In 1986 representatives of the Dow Chemical Company attended a DCODP presentation at the national meeting of the American Council on Transplantation. They were favorably impressed by the early DCODP results and inquired about possible participation in continuing or expanding this local initiative. That same year, with Dow's support, the Dow Take Initiative Program (Dow-TIP) campaign took the donor education effort on a tour to 22 cities with the largest A.A. populations. This tour was completed in 1989.

The success of these efforts led to the development in 1988 of a joint effort between the National Medical Association (NMA), physicians, and A.A. clergy. This A.A. donor education project was characterized by Black physician and clergy interactions in an attempt to dispel widely held religious myths concerning organ donation. These groups applied the grassroots approach which had proven successful in previous Black donor targeted programs. This effort took place under the direction of Dr. Jesse Barber, Chair of the religious subcommittee and former NMA president, and Dr. Frank Staggers, past NMA president. Subsequent to these experiences, in the summer of 1990 a National Black Physician Education Project was initiated by the NMA and the National Institute for Allergy and Infectious Diseases (NIAID) under the direction of Dr. Vivian Pinn-Wiggins, Immediate Past

President of NMA, to educate as many Black physicians as possible about organ/tissue donation and transplantation.

In the fall of 1989, based upon the previous successes of the DCODP and the Dow- TIP Black Donor Education Programs, the Dow/NAACP Black Donor Education Project was begun in New York City, Saint Louis, Memphis, Detroit, Baltimore, and Houston. These efforts used a successful triad of (1) a voluntary Black community organization, the National Association for the Advancement of Colored People (NAACP) and (2) Regional Organ Procurement Organizations (ROPO) after receiving government-sponsored minority or Black donor targeted educational grants from the Division of Organ Transplantation, and (3) the private sector sponsorship of the Dow Chemical Company which paid for much of the educational materials, public relations and media contacts. This national Black donor targeted educational pilot program (Dow/NAACP) and its early successes are the reason for the creation of the MOTTEP which is proposed as a national strategy to overcome the donor shortages of Black and other minority populations.

The National Minority Organ and Tissue Transplant Education Program (MOTTEP)

MOTTEP Methodology A

Establish and maintain a national office for overall project direction and coordination.

Develop Organ/Tissue Donor Programs within local communities. Use the successful Washington DCODP as a model.

Develop a strategic plan for reaching minority populations.

Identify key minority spokespersons and the appropriate message for their communities.

Establish a program committee of dedicated minority community workers and volunteers committed to increasing the number of organ and tissue donors.

Create and revise national and regional transplant curriculums for medical, nursing, divinity, and mortuary science schools, predominantly minority undergraduate colleges, and elementary and secondary schools.

MOTTEP Methodology B

Build on previous regional and national minority efforts including those of: Dow-TIP, Dow/NAACP, the DOT regional OPO minority grant programs, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institute of Allergy and Infectious Diseases (NIAID), Office of Minority Health Affairs, Department of Health and Human Services, and the Centers for Disease Control (CDC).

Proposed Local Programs

Local programs will be implemented in 20 cities, whose Regional Organ Procurement Organizations (ROPO) have received DOT minority educational grants and Dow/NAACP Black donor targeted Organ Donor Programs (ODP). The following cities are proposed as initial sites:

New York City - Dow
Baltimore - DOW
Philadelphia - OPO
Washington, D.C. - DCODP
Detroit - DOW
Houston - DOW
St. Louis - DOW
New Jersey - ROPO
San Antonio - ROPO
Chicago - ROPO

Atlanta - ROPO
Jackson, Mississippi - ROPO
San Francisco - ROPO
Los Angeles - ROPO
Jacksonville, Florida - ROPO
Miami, Florida - ROPO
Memphis - DOW
New Mexico - ROPO
Arizona - ROPO
Columbia or Charleston,
South Carolina - ROPO

Local Program Costs*

Local program cost per year	\$ 35,000
Local program cost for 20 cities (20 x \$35,000)	\$ 700,000
Total for 20 local programs over 5 years	\$3,500,000

* costs include local program coordinator salary, consultant fees, equipment and supplies, travel and miscellaneous.

MOTTEP National Office Operational Activity Costs.**

Total national office operation per year	\$ 142,572
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** Costs include national coordinator, research assistant, consultant fees, office space, equipment, telephone, postage, supplies, travel and miscellaneous.

MOTTEP National Marketing Costs

Cost for national office activities, services, and products	\$ 285,000
Three videotapes (production, reproduction, and shipping)	\$ 108,750
Two national slide shows (production, reproduction, and shipping)	\$ 56,525
Three national displays	\$ 15,000
Four national posters	\$ 35,000
National brochure	\$ 15,500
Organ donor cards	In Kind
Revision of National Transplant information Curriculum for elementary and secondary schools (revision, production, and shipping)	\$ 53,000

Total MOTTEP National Office Costs

National office operations (\$142,572 per year X 5 years)	\$ 712,860
National Office activities, services and products (\$285,000 per year X 2 years)	\$ 570,000
Local program costs (20 programs for 5 years)	<u>\$3,500,000</u>
Total costs for MOTTEP for 5 years	\$4,782,860

Results

Since the development of the District of Columbia Organ Donor Project in 1982, there have been some outstanding results, including:

1. Development of a list of experts who could be called upon to speak at various organizational groups, and church meetings.
2. Widespread distribution of "A Gift of Life Poster" featuring organ donor cards signed by Black role models, professional basketball star Rick Mahorn, and former Senator Edward Brooke the most recent Black senator.
3. Introduction of a curriculum on kidney disease that has been included since 1985 in the District of Columbia public school system at the high school level.
4. Presentations to hundreds of civic and social groups including sororities, fraternities, neighborhood advisory councils, funeral directors, lodges, women's organizations, and other community-based organizations. Similar presentations have been made to more than 100 of the 1000 Black churches in the Metropolitan D.C. area.
5. Collaboration or cooperative ventures with organ donor programs in Georgia, Florida, Chicago, California, New Jersey, and Pennsylvania. Educational materials produced by the Organ Donor Program have been shared with at least 40 cities and 20 States interested in initiating their own programs.
6. Initiating a program within the District of Columbia Motor Vehicle Administration licensing unit whereby drivers could indicate their intention to become an organ donor. A symbol would be placed on their license as an indication of their intent. This effort increased the number of organ/tissue donor symbols appearing on licenses from 25 per month in 1982 to 750 per month in 1989 (15).
7. Since 1982 the number of Black organ donors and transplant recipients has increased significantly -- locally, regionally, and nationally (15).
8. Seven Black organ donor targeted videos have been produced since 1987 for use in local and national Black organ donor education efforts. These are shown to Black lay and medical groups.
9. The Dow/NAACP Black Donor Education program has been launched in six cities: New York and St. Louis in 1989, and in Memphis, Detroit, Baltimore, and Houston in 1990.

10. Since launching the above program in 1986, information concerning Dow Black Donor Education Media efforts has been featured in more than 275 newspapers and magazines, including USA Today, the St. Louis Post-Dispatch, the Detroit News, the New York Daily News, the Houston Post, Newsweek, Parade, Jet, Ebony and the Journal of the National Medical Association. In addition, information concerning Blacks and organ donation has been included on 60 local and national television broadcasts and 70 local radio stations, generating approximately 300 million media impressions.

11. A Black donor awareness guidebook, based on the DCODP experience was created and copyrighted in 1987 for the Dow/NAACP Black Donor Education Program.

12. A Dow/NAACP Black Donor Question and Answer Brochure was created in 1989 and more than 5,000 copies have been distributed.

13. The publication of Organ Donation: A Minority Dilemma - Howard University Hospital. More than 250 copies have been distributed since 1988.

14. Publication of "Start A Family Tradition", A Black Organ/Tissue donor targeted brochure. More than 10,000 copies have been distributed since 1988.

15. The conduct of the First and Second International Symposia on Renal Failure and Transplantation in Blacks, in Washington, D.C. in 1985 and 1989, respectively. Both symposia were sponsored by the Howard University Hospital and the National Institute of Diabetic and Digestive and Kidney Diseases. The symposium now bears the name of the Samuel L. Kountz Symposium and the third Symposium is scheduled for 1993 in Washington, D.C.

16. The development in 1988 of two slide tapes which are targeted at A.A. audiences: one for the lay community and one for the medical community. Both are available to interested cities.

17. A comparison of the Dow Gallup Polls of 1985 and 1990 demonstrates a heightened awareness in Blacks of the highly successful nature of organ transplantation as well as a tripling of the number of persons signing organ donor cards during that interval. This dramatic increase is at least partially the result of the intensive Black donor education efforts described above.

Discussion

Between 1983 and 1989, the gap between the supply (donors) and the demand (patients waiting) for organs in the United States has widened from 1,050 to 9,903. Most of this change has occurred since 1986 (16). Furthermore, as of

June 1990, 20,828 people were waiting for organs for transplantation and three people die every day because of this shortage (3). Thus, the scarcity of organs has become the major limiting factor in transplantation today (7). This appears to mandate a priority shift for the transplant community and a critical need for their innovative and creative energies to be directed toward solving this dilemma. This has not yet occurred. In an effort to address this concern, the author has made the shortage of organ and tissue donors one of his highest priorities for the past 10 years. Reasons for low donorship in Black and White communities have been examined and found to be very similar (1,17,18,19,20,21). Thus, efforts successful in the Black community may be successful in communities of other ethnic origins.

Before this pioneering effort, no Black community transplant education effort had been researched or attempted. In addition, efforts to enlist the Black community in solving this problem could not be found in the literature. The solution was therefore approached in a grassroots fashion. The grassroots approach has a unique meaning for the Black population when considering historical factors and present socio-economic conditions. The approach has been unwittingly employed throughout Black history but most prominently during the civil rights movement in the 1960s. It was effective in mobilizing Mississippians to form the Mississippi Freedom Democratic Party and in garnering support for the freedom bus rides throughout Alabama. A sense of community empowerment is generated because organizers discuss the problem, consider the factors surrounding the issue, and most importantly illustrate each individual's ability to effect change (15,22,23,24).

This is particularly important when considering the lack of access to health care and health care professionals as well as the malicious history of health care officials using Blacks as agents of disease states as in the Tuskegee experiment (25). This method clearly is not restricted to the political sphere, but can be applied to the medical problems of the Black community as we have shown here.

The positive results of organ donor campaigns from 2 to 5 years after their initiation is proof that the Black community when appropriately challenged will respond (1,8,12). We attribute this success to grassroots organizing. Whether grassroots organizing is employed in research or education, an atmosphere of reciprocal learning is created which is especially necessary for the interdependency between the medical and the lay communities. Coalitions are developed and ethnically sensitive role models are generated to reach all areas of the A.A. community to help members of the community realize their equally important roles in organ donation. This may be particularly crucial in the A.A. community where a combination of socio-economic factors produces a more pronounced schism or

social distance between the medical and lay communities (22,23,24). Therefore, programs like required request may be ill-fated due to the untrained or insensitive approach of hospital personnel, compounded by the untimely nature of the request (26).

The face-to-face approach utilized by the DCODP was responsible for increasing the number of signed Black organ donor cards from 25 per month, in 1982, to 750 per month in 1989 and the Black organ donor consent rate from 10 percent in 1978 to 40 percent in 1989 (15).

The Dow-TIP, born directly out of the success of the DCODP, utilized several principles of grassroots mobilization at a national level. A media campaign using magazines directed towards the Black community like Ebony, Jet, Essence, Black Enterprise, Black Health and other ethnically oriented community newspapers and national print media played a crucial role in illuminating the urgency and necessity for the Black community's involvement. Such articles, along with TV/radio broadcasts and numerous community discussions, laid the foundation for the increase in Blacks who signed donor cards from 7 percent in 1985 to 24 percent in 1990, and in transplant awareness from 10 percent in 1985 to 32 percent in 1990, as seen in the Dow Gallup Poll of May 1990. No less impressive has been the increase in Black organ donors as shown in the SEOPF, Washington Regional Transplant Consortium (WRTC), HCFA, and Terasaki data (15). The WRTC data demonstrates a marked improvement (10 percent - 1978; 43 percent - 1989) from the 10 percent Black organ donor consent rate which existed in 1978 (15) before these efforts began (1,2,8,11,12). It also reveals for the first time data which depicts highly statistically significant differences between Blacks and Whites in medical unsuitability (9 percent Whites, 30 percent Blacks) and willingness to donate in one locale (15).

A Dow/NAACP coalition formed in October 1989 nurtures the seeds planted by the efforts of the Dow-TIP project. Even though it is too early to quantify its performance, two promising letters have been received, one from the Mid-American Transplant Association and the second from the Wisconsin Organ Procurement Organization. Since the launching of this project, data indicate that Black organ donations in the first 6 months of 1990 jumped to 39 percent from 15 percent for all of 1989. Similarly, the Dow/NAACP initiative was started in Memphis, Tennessee in April 1990. One month later, a person who heard one of the presentations on organ donation experienced a family member's tragic death. The family decided to donate their relative's liver, in part because one family member had learned about the critical need for organs during one of the organ donor talks and concluded they should participate in giving the "gift of life." As a result, a patient in Wisconsin with chronic Hepatitis B, in intensive care, received a successful liver transplant.

The most obvious benefit of these initiatives is an increase in the available organ and tissue pool across the racial spectrum, significantly increasing the likelihood that a Black transplant candidate can be successfully transplanted. A report recently released from the DHHS Office of the Inspector General reveals that Blacks wait twice as long as Whites to receive kidney transplants (10). One of the factors in this discordance is the shortage of Black organ donors. Consequently, an increase in the Black organ donor pool may help reduce long waiting times. Immunogenetic studies have also indicated that mismatches for certain major histocompatibility antigens, such as HLA-DRW6, are found with greater frequency in Blacks than in Whites (27) and have been associated with a decreased kidney graft survival (27,28). Recovering more organs from Black organ donors with similar antigens may therefore be crucial to increasing graft survival in Black transplant recipients (4,5,19,27,28,29).

The message on transplantation and organ donation that we take to the Black community is ethnically sensitive, appropriate, honest, and direct. Moreover, time for meaningful dialogue is allowed because questions and answers are key. As significant as the message is, the author has observed that ethnically similar or sensitive organ donor families, patients awaiting transplantable organs or tissues, and successful transplant recipients are the most effective and credible messengers and we use them as often as possible as the critical members of the messenger team. When possible the messengers should be the same ethnicity as the community addressed. Since transplant coordinators are specially trained to talk with family members and communities about donation and transplantation, when addressing the Black community, Black transplant coordinators are preferable. Since only 5 percent of the transplant coordinators in the United States are Black (16), the expertise of the Black coordinators must be maximized. In their absence, other Black health care providers, such as psychologists, social workers, nurses, physician assistants, etc., must be educated as ethnically similar messengers (which is preferable) or ethnically sensitive non-Black transplant coordinators must be trained to talk with Black families and communities.

When delivered by the appropriate messengers, this message increases awareness about the transplant dilemma and also publicizes the need for frequent blood pressure checks, fulfilling a preventive health community need. As individuals and the lay community realize the significance of their role in giving the gift of life and the control they can exercise over their own health by acts as simple as taking heart medication or having regular BP checks, the schism between the medical and the lay communities should become less pronounced. The impetus for these initiatives must come from public organizations, health care professionals, and the private sector. With impetus from well-informed public and private sectors, volunteer efforts of the community completes the team necessary for the

successful grassroots approach. This team can then help empower communities to actively participate in facilitating their own health care. The approach is economical, appropriate, and feasible.

Below is a schemata which details the evolution of the MOTTEP. This program, based on successful Black donor-targeted community efforts that began in the District of Columbia in 1982, now can be expanded nationally with the support of the private sector: e.g., Dow, Sandoz, Ortho, UpJohn, Burroughs Wellcome, Dupont, etc.; the public sector: e.g., DHHS, Regional Organ Procurement Organizations, CDC, NIH (NIDDK, NIAID), UNOS, the Red Cross, etc.; and Black community volunteer organizations such as the NAACP, the Urban League, Sororities, Fraternities, the Links and Black Women coalitions and organizations including churches. As detailed analyses are performed for each of the six pilot cities in the Dow/NAACP project, the successful correlates should be incorporated into the additional 20 cities targeted for donor education programs. The cost for such a program approximates \$5 to \$10 million over a 5-year period. This is relatively inexpensive when one considers that \$5 billion is spent annually on end stage renal disease and 30 percent of the patients with end-stage renal disease are A.A.

The minority organ/tissue donor program could increase organ donation by 5 per million per year. Because there are 50 million Hispanics and Blacks in the United States (1990 census) this would mean 250 more donors and 1000 more organs (500 kidneys, 250 livers, 250 hearts) per year, and 5,000 organs after 5 years. Translated into socioeconomic impact, this would save 9,230 patient years. Phillip J. Held, Urban Institute health economist, suggests that American society values a life at \$110,000 per year. Thus, a yearly increase of 250 organ donors would, over a 5-year period, save life years valued at over \$1 billion.

Increased organ donation through this program would have an enormous economic impact on Black kidney patients, who, as a group, have the poorest graft survival rate (33 percent lost in the first year, 18 percent lost each year thereafter). Graft life expectancy among Black kidney patients is 26 months; among Whites it is 4 years. The per-patient cost of direct medical care for dialysis and related medical expenses is \$100 per day. The cost of kidney transplantation is \$30 per day per patient. The approximate average cost benefit from this organ donor program therefore, would be \$70 a day per patient (dialysis expenses minus transplantation expenses). If we assume that 2,500 kidney patients in 5 years would receive transplants because of increased organ donation through this program, the total cost savings would be \$43.5 million for Black kidney patients, and \$87 million for White patients. However, if we add the cost-benefits derived from additional transplants (for example, hearts and livers) and the resulting savings of 9,230 patient years, we would realize an additional cost savings of \$1.15 billion.

Recommendations:

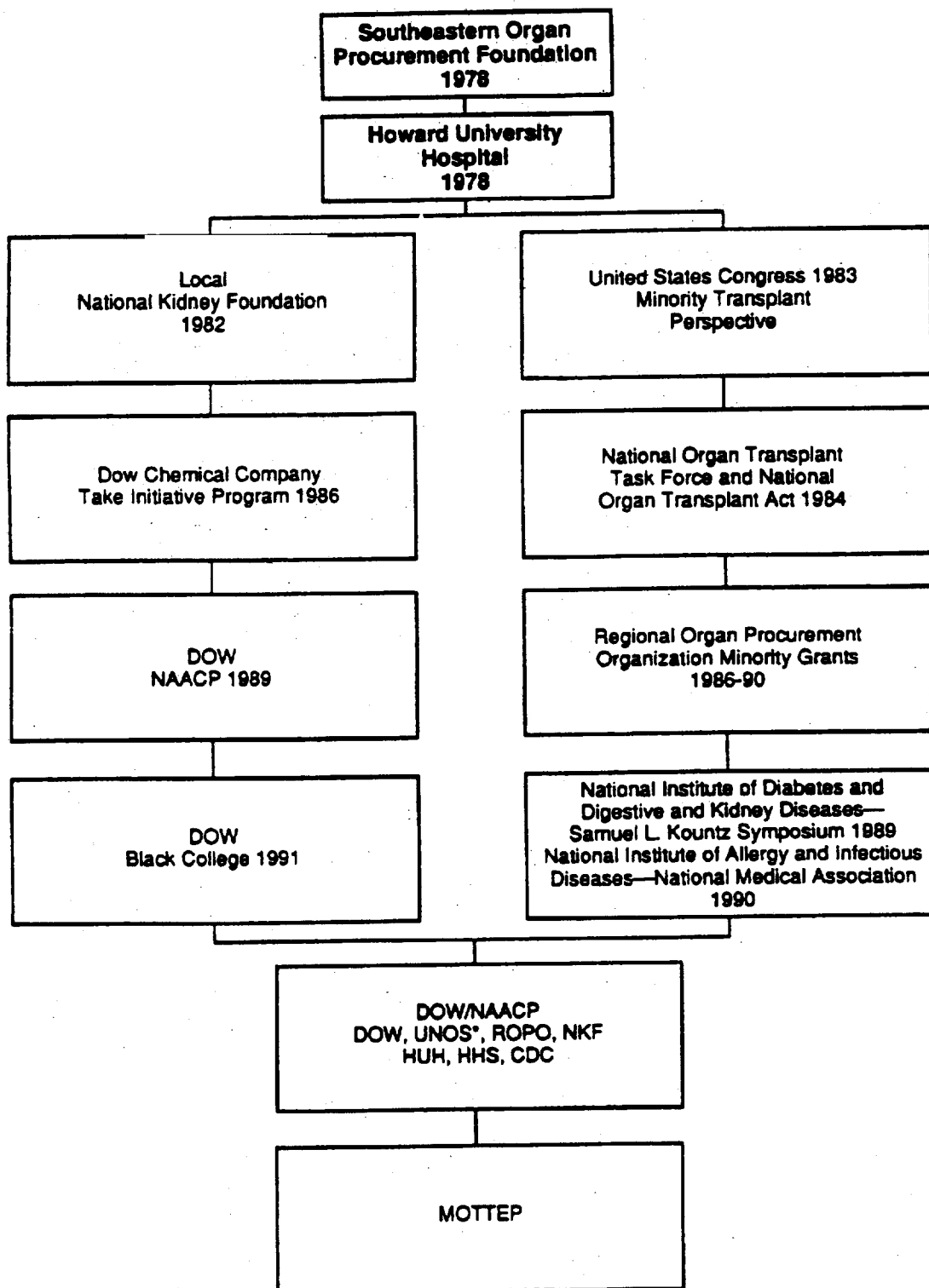
We have described a successful grassroots approach in the African American community which has: 1) heightened transplant awareness, increased the number of A.A.s signing organ/tissue donor cards and increased the number of A.A. organ donors; 2) emphasized a synergistic relationship between the public sector, the private sector and volunteers in the African American community; 3) been successful locally (DCODP), regionally (Dow-TIP), and nationally (Dow-TIP and Dow/NAACP); 4) emphasized the use of ethnically similar and sensitive community role models, ethnically similar organ donor families, successful transplant recipients and patients waiting for organs/tissues for transplantation, as very credible and effective community educators.

Conclusions:

We propose MOTTEP as a program targeted to the minority population which will provide an increase in the number of minority organ donors and a subsequent potential savings to the government of \$43.5 million if Black kidney patients are transplanted and \$86 million if White kidney patients are transplanted. Overall savings resulting from the increased organ donation would extend to the benefits of 9,230 patient years and \$1.2 billion. These benefits would be well worth the \$5 million required for the 5-year, 20 city program.

It is time now for a national expansion of the modus operandi of the DCODP into 20 cities (MOTTEP) taking advantage of the lessons learned from the previous successful efforts. The principles outlined in this report are applicable across the entire racial spectrum of organ donors and may be useful in the resolution of the current acute shortage of transplantable organs and tissues.

The Evolution of The National Minority Organ and Tissue Transplant Education Program



* UNOS - The United Network for Organ Sharing

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