



minority organ tissue transplant education program

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**“ORGAN DONATION: UTILIZING PUBLIC POLICY AND  
TECHNOLOGY TO STRENGTHEN ORGAN DONOR  
PROGRAMS”**

**Testimony of  
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*"Love Yourself, Take Care of Yourself"*

**“Organ Donation: Utilizing Public Policy and Technology to Strengthen Organ Donor Programs”** Testimony – Clive O. Callender, MD, FACS

The number one problem in transplantation today is the shortage of donors. More than 96,000 people today are on transplant waiting lists. Nearly 25,000 transplants are performed annually leaving an organ donor recipient disparity of 65,000. This disparity results in nearly 20 deaths/day at least seven of which are African Americans (A.A.). In order to answer the questions, what has happened to organ donations in the A.A. population, and how it compares with donations in other ethnic groups? I will share three decades of work (1982-2005) in the African American community which have culminated in the development of a methodology which has narrowed the A.A. donor gap, and which has the potential to help narrow or eliminate other minority health disparities. African Americans represent 13% of the American population, but make up 35% of those on kidney transplant waiting lists. In 1982 when we began our first African American donation campaign, it was stated that Blacks “don’t and won’t” donate organs for transplant purposes. Then the A.A. donations rate in organ donors per million (O.D.M.) was eight compared to eighteen O.D.M. in the Caucasian population. We then began the D.C. Organ Donor Program (DCODP) in conjunction with Howard University and the National Kidney Foundation of the National Capital Area between 1982 and 1990 with five hundred dollars from Howard University. This program began with a two hour community focus group session with forty District of Columbia residents and included one kidney donor and one transplant recipient. Upon completion of these sessions, we identified the five commonest obstacles to organ donation in the District of Columbia. They were: 1). Lack of transplant awareness, 2). Religious myths and misperceptions, 3). Medical distrust, 4). Fear of premature death after signing a donor card, 5). Racism. The second important outcome of those focus sessions was that while only two of forty had signed donor cards at the beginning of the session, forty of forty donor cards were signed by the end of the session. This led us to form the DCOOP in August of 1982; this was a grass roots effort to change behavior in the District and the surrounding Metropolitan Washington area. The cultural and ethnically sensitive presentations to the community were directed at overcoming the five obstacles identified above

By 1990 the number of donor cards signed at the D.C. Motor Vehicle Office increased from 25/month to 750/month and the number of A.A. organ donors in the District of Columbia

doubled. Because of the success of the DCODP, the Dow Chemical Company (1986-1992) sponsored my involvement in national media tours in fifty cities to increase awareness about the need for more Black donors. This initiative merged the community grass roots, face-to-face interaction and mass media approach. Gallup Polls done in 1985 and 1990 identified that the number of Blacks aware of the highly successful nature of transplants and the number of Blacks signing donor cards had trippled during this five year period secondary to this Dow Chemical Company Take Initiative Program directed at the A.A. population. This led us to conceptualize The National Minority Organ Tissue Transplant Education Program (MOTTEP) in 1991 to use this successful community grass root and mass media approach in all minority groups (African American, Latino/Hispanic, Asian, Pacific Islander, Alaskan Native, American Indian).

Congressman Louis Stokes, Secretary of Health and Human Services, Dr. Louis Sullivan and Dr. John Ruffin then intervened and encouraged us to seek NIH funding to allow for the development of fifteen community grass root programs in fifteen cities across the United States (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).

### **WHAT IS THE NATIONAL MOTTEP MODEL?**

The National MOTTEP model was conceptualized based upon the successes of our previous African American education programs such as the local DC Organ Donor Project (DCODP), 1982-1988 and nationally, the DOW Chemical Company Take Initiative Program (DOWTIP), 1986-1992. These successes led us to utilize their successful methodologies with the Latino-Hispanic, Native American, Alaskan Native and Asian-Pacific Islander populations as the National Minority Organ Tissue Transplant Education Program (MOTTEP). This model combines media campaigns and grass roots efforts to disseminate a two-pronged message: preventing chronic diseases particularly hypertension, renal failure, diabetes and obesity while simultaneously increasing organ donation rates. The following is a summarization of the national impact of MOTTEP.

## A 25 YEAR DATA ANALYSIS OF A NATIONAL DONOR EDUCATION PROGRAM

Since 1982 we have participated in a national donor education program emphasizing community education and empowerment requiring the community to be an efficient change agent. As described above, the grass roots approach is combined with mass media aimed to: 1) increase organ donation rates and 2) adopt healthy lifestyle behaviors. The methodology utilizes culturally sensitive and ethnically similar community individuals who are transplant recipients, donors and their family members as messengers. Three distinct eras are evident.

<b>Era I – 1982 –</b>	<b>Present Era II – 1995-2005</b>	<b>Era III – 1995-2005</b>
African American Impact	Hispanic/Latino Impact	Asian Impact

A review of National African American data demonstrated a change from 8 organ donors/million (1982) to 40.8 organ donors/million (2002). A 50 city campaign Gallup Poll (1986-1992) demonstrated a tripling of Black awareness of the success of transplants and the number of Blacks signing donor cards. Locally, donor card signings increased from 25/month to 750/month (1982-1988) and Black donors in the District of Columbia doubled by 1988. Tables 1-3 illustrate increases in donors, donation rates, organ donors/million and the impact on donation rates in cities with a national structured effort versus areas those cities without a national effort.

### **Minorities Donate in Proportion to their Population Distribution** (Table 1)

<b>Ethnicity</b>	<b>Population Percentage (2003)</b>	<b>Donation Percentage</b>
Black	12.7	12.6
Hispanic	10.9	12.2
Asian	3.8	2

### **Cadaveric Donors per 1,000 Evaluable Deaths and Number of Donors by Ethnicity and OPO's, 1995-1998**

**MOTTEP****Non MOTTEP**

(Table 2)

<b>Ethnicity</b>	<b>Donation Rate</b>	<b>Donors</b>	<b>Donation Rate</b>	<b>Donors</b>	<b>p-value</b>
White, Non Hispanic	59.3	4,928	59.2	11,279	0.02
White, Hispanic	106.9	1,055	47.4	886	<.01
Black	43.4	1,263	32.9	1,286	<.01
Other	50.7	228	42.4	272	<.01

(Table 3)

**Number of Donors****Donors/Million****Donation Percentages**

<b>Ethnicity</b>	<b>1990</b>	<b>2000</b>	<b>1990</b>	<b>2000</b>	<b>2000</b>	<b>2005</b>
Black	659	1373	22.4	40.8	11.2%	14%
Hispanic/Latino	518	1319	22.9	40.2	11.2%	13.2%
Asian	73	278	10.3	26.2	2.7%	2.6%
Minority Donor					25.1%	30% (29.8%)
Total						

**National MOTTEP's PAST ACCOMPLISHMENTS**

In the past, National MOTTEP® has used several intervention mechanisms that, because of their success, will be used in our expanded programs. First, MOTTEP® has made extensive use of the media in order to change minority behavior regarding organ and tissue donation and about healthy living. For example, media impressions between 1993 and 2006 have increased from 30 million to more than 8 billion respectively. By reaching an average of one million community persons annually, National MOTTEP has empowered communities to meet the challenge head on by participating in the donor process and adopting healthy lifestyles to prevent the need for transplantation. The figure below lists some milestones throughout MOTTEP's history. Through the expanded efforts, MOTTEP anticipates creating new milestones.

## **MOTTEP Milestones**

### **I.A. 1991 – 1993**

- MOTTEP Conceptualized in 1991 – Callender/Smith.
- MOTTEP Concept and Strategic Plan – Sponsored by Congressman Louis Stokes – 1992.
- MOTTEP authorization approved by Congressional Appropriations Committee – May 1992.
- MOTTEP legislation authorized by President Bush in the Fall of 1992.
- Development of an African American Strategic Plan.
- Development of a Hispanic Strategic Plan.

### **I.B. 1993 – 1995**

- First MOTTEP contract from office of the NIH Director, Dr. Bernadine Healy, and Dr. John Ruffin, Associate Director, NIH Office of Minority Health Research – 1993 to 1995.
- Development of MOTTEP survey evaluation tool – Pre & Post MOTTEP presentations.  
Organ Donation: The Problem; MOTTEP: The Solution – This publication chronicles MOTTEP's evolution.
- Development of National African American Transplant Strategic Plan.
- Development of National Latino Transplant Strategic Plan.
- Development of MOTTEP “Give to Save” Logo and Theme Song.
- Appeared on the Oprah Winfrey Show, BET, CBS Evening News – all national TV shows with audiences exceeding 9 million.
- “Focus on Health” weekly radio talk show on WOL (Washington, DC and Baltimore, MD) from 1993 to 1995.

### **II. 1995 to 1999**

- National Minority Transplant Hall of Fame Inaugurated – September 1, 1996.
- Inaugurated National Minority Donor Awareness Day – August 1, 1996.
- Evaluation reports on findings of the program effectiveness study using data from matched sets of pre- and post- questionnaires for all youth and adult participants showed that: 1) statistically significant increases ( $P < 0.5$ ) occurred in the levels of knowledge on organ/tissue

donation; and 2) participants significantly more likely to state their willingness to become organ/tissue donors after hearing the MOTTEP presentations.

- Implementation of the First National Model Minority Transplant Strategic Plan – 1995.
- Implementation of the First National Latino Transplant Strategic Plan – 1995.
- Developed the First National Asian-Pacific Islander Transplant Strategic Plan – 1995.
- Developed the First National Minority Community Transplant Information Resource Center – 1995.
- Under the influence of MOTTEP, African American organ donors per million (O.D.M.) increased from 8 in 1982 to 20 O.D.M. in 1995 and to 28 O.D.M. in 1998.
- Likewise, Hispanic/Latino O.D.M. increased from 9 in 1994 to 18 in 1998.
- During this same time period, Asian/Pacific Islander O.D.M. doubled.
- African American/Black recipients of African American/Black organ donors increased from 3% in 1985 to 23% in 1998.
- Total Number of Media Impressions from July 1, 1995 – 1999; 3 Billion.
- Total Number of People Reached Through Face-to-Face Presentations since July 1, 1995 equaled 4 Million.
- Generated 492 publications and presentations; 46 academic publications and 23 videos;
- Total number of requests for materials – 1009.
- Organ and Tissue Donations Directly Linked To MOTTEP Presentations As of June 1, 1999: 38 donors from MOTTEP presentations. Birmingham – 2 donations (4/2/98 and 1/3/99); Atlanta – 2 donations, Detroit – 2 donations (1/29/99 and 5/28/99), Honolulu – 1 donation (1/99), Nashville – 1 donation (5/12/99), Chicago/NW Indiana – 30 donations (since beginning of grant in 1995).
- Total number of pre/post surveys (youth and adult) – 7048.
- The number of National or International – publications on MOTTEP and minority transplant education efforts since 1995 is thirty.
- Two Institute of Medicine presentations 1999; one presentation to Secretary Shalala’s “Forum on Liver Allocation and Organ Donation” – 1996; two MOTTEP presentations (testimonies) before the Congress of the United States (April 18 and June 18, 1999).

- Development Of The First National Minority Donation Education effort – Community-based with a grass roots and multimedia combined approach – 1993.
- Produced and Hosted “Focus on Health” – a weekly two-hour radio call-in talk show on WOL (Washington, DC and Baltimore, MD) – 1993 to 1995.
- MOTTEP modus operandus identifies – donors and donor families, transplant recipients, transplant candidates of local community origin and ethnically and culturally similar and sensitive – as the most effective messengers – 1993 to 1995.

**Other “Firsts” Accomplishments Include (1993-1995):**

- First to identify community as the most potent and cost efficient “change agent” – 1993 to 1995.
- First to emphasize the importance of the combination of “Prevent the Need” and “Increased Need for Organ/Tissue Donors” as the most efficient mode of community outreach and education (1993-1995).
- Implementation of the First Model National Minority Transplant Strategic Plan.
- Implementation of the First National Latino/Hispanic Transplant Strategic Plan.
- Developed the First National Asian and Pacific Islander Transplant Strategic Plan.
- First to identify community as the most potent and cost efficient “change agent”.
- First to emphasize the importance of simultaneously promoting the messages of “Preventing the Need” and “Increasing the Number of Organ/Tissue Donors” as the most efficient mode of community transplant-related outreach.
- First to take the fruits of the first minority donor education programs of the District of Columbia Organ Donor Program (DCODP) and the Dow Chemical Company Take Initiative Program (DOWTIP), and apply them to all ethnic minority groups via funding by the National Institutes of Health – Office of Research on Minority Health and the National Institutes on Diabetes and Digestive and Kidney Diseases (1993).
- First to inaugurate National Minority Donor Awareness Day (August 1, 1996).
- First to establish the National Minority Transplant Hall of Fame (September 1, 1996).

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As previously mentioned, National MOTTEP was the first program of its kind in the country that was designed to: 1) educate minority communities on facts about organ/tissue transplants and how to maintain the health of key organs and tissues; 2) empower minority communities to develop programs to increase awareness; and 3) increase minority participation in organ/tissue transplant endeavors including signing organ donor cards, encouraging family discussions and involving parents in the decision to retain the health of kidneys, livers, hearts, lungs and other organs.

National MOTTEP was also one of the first organizations in the country to work to expand its original grassroots efforts to include a health promotion and disease prevention component that exclusively targeted youth as well as adults. The disease prevention aspect was added to decrease the disproportionate rate of hypertension, diabetes and other diseases that affect minority populations. More specifically, a comprehensive, intensive outreach campaign focused upon uncontrolled or untreated diabetes mellitus, hypertension, proper nutrition, increased physical activity and avoiding the use of alcohol and other substances by minorities.

However, National MOTTEP's primary activities have remained the design, implementation, and evaluation of educational programs for national use in order to increase the number of minority Americans who take active roles in organ and tissue donation and who hold family discussions. National MOTTEP also provided leadership in educating the public about how to maintain sound organs. To support these campaigns, MOTTEP utilized the following strategies: Established networks of speakers, (i.e., youth, parents, celebrities, transplant recipients, donor family members, transplant candidates, health care professionals) who were available to religious and community-based organizations to promote organ and tissue health; Identified, accessed and utilized print media and radio technology to increase awareness among minority audiences of organ and tissue health; Supported and sponsored national and local forums which targeted public, private and community leaders who then disseminated information to minority communities on organ and tissue health; Established a library of audiotapes, videotapes, print and other materials which were made available for duplication; Followed up on any media coverage related to organ and tissue health to generate a greater knowledge of issues related to organ/tissue health; and Collaborated with an exceptionally large range of other community-

based organizations in order to implement health promotion and public awareness campaigns at each of the sites in the targeted cities.

### **MOTTEP of HONOLULU - Accomplishments**

The goal of this project is to expand educational efforts across all ethnic, religious and age groups to increase the number of individuals consenting to donate organs and tissues and to increase the supply of organs for waiting transplant recipients through the expansion of a public education program on organ and tissue donation.

The Minority Organ Tissue Transplant Education Program (MOTTEP) is a nationwide program designed to educate ethnic minority communities about organ and tissue donation and transplantation to increase the number of donations from these communities. The Organ Donor Center of Hawaii (ODCH) implemented MOTTEP of Hawaii in 1995. The program currently focuses on Hawaii's local Filipino community which had the highest number of individuals on the organ transplant waiting list (36%) and the lowest number consenting to donation (3%). In 2002, the University of Hawaii – Cancer Research Center of Hawaii (CRCH), in collaboration with ODCH and various Filipino community organization was awarded a five-year grant to continue MOTTEP. Funding of the program will end in June, 2007.

The program's objectives, as it remains focused on the Filipino community and extends its outreach to Hawaiian and Pacific Islander communities, are to:

- Increase the number of individuals designating themselves as organ donors via driver's license, state ID and/or donor card
- Assure that family discussions occur to inform their loved ones of their wishes
- Increase the number family consents for organ and tissue donation
- Increase education and awareness about organ and tissue donation in the community.

Organ Donor Center of Hawaii will continue to focus on Filipino community and plans to expand the MOTTEP to the Hawaiian and Pacific Islander Communities. Currently 49 of the 375 Hawaii residents on the Hawaii Transplant Waitlist are Pacific Islanders, the second largest group after Asians (which include Filipinos) who represent the largest ethnic group in the waitlist. Over the past 3 years, the Hawaiian and Pacific Islander groups represent the third largest potential organ donor group, but the lowest consenting ethnic group.

Since implementation in 1995, the Organ Donor Center of Hawaii has been working within the Filipino community through MOTTEP. The program's success is documented through an increase in the Filipino donor consent from 3% to 27% during that time period. Over the past 3 years, organ donation consent rates among Filipinos have steadily increased: 40% in 2004, 67% in 2005, and 71% in 2006. It is evident that MOTTEP's public education efforts to improve organ donation rates among the Filipino population have been effective and we wish to sustain this success. The result of this successful program is evidenced in increased donor consent in the Filipino community from 3% to 71%.

MOTTEP is a national model that has shown to be culturally effective in the Filipino Community and will be adapted and expanded to include other Hawaiian Pacific Islander communities.

**Summary:**

Since 1982 we have participated in the growth and development of a national donor education program which relies on a grass roots strategy that emphasizes community education and empowerment requiring the community to be an efficient and economically appropriate change agent. **Methodology:** The data presented provide compelling evidence of the efficiency of a community-based grass roots approach combined with mass media to deliver a two-pronged message aimed at: 1) increasing organ donation rates and 2) promoting the adoption of healthy lifestyle behaviors and practices. The key for its success is utilizing a methodology emphasizing the use of culturally sensitive and ethnically similar community individuals who are transplant recipients, donors and their family members as messengers. Three distinct eras are evident.

Era I – 1982 – Present	Era II – 1995-2005	Era III – 1995-2005
African American Impact	Hispanic/Latino Impact	Asian Impact

**Results:** African American data emphasized here reflects the impact of national education efforts resulting in an increase from 8 organ donors/million (1982) to 40.8 organ donors/million

(2002). Regionally, a 50 city campaign Gallup Poll (1986-1992) demonstrates a tripling of Black awareness of the success of transplants and the number of Blacks signing donor cards. Locally, the number of donor cards signed increased from 25/month to 750/month (1982-1988) and the number of Black donors in the District of Columbia doubled by 1988. Tables 1-3 below illustrate the increases in donors, donation rates, organ donors/million and the impact on donation rates with a national structured effort versus areas without a national effort.

**Minorities Donate in Proportion to their Population Distribution** (Table 1)

<b>Ethnicity</b>	<b>Population Rate</b>	<b>Donation Rate</b>
White	71.7	72.1
Black	12.7	12.6
Hispanic	10.9	12.2
Asian	3.8	2

**Cadaveric Donors per 1,000 Evaluable Deaths and Number of Donors by Ethnicity and OPO's, 1995-1998**

(Table 2)

<b>Ethnicity</b>	<b>National Effort</b>		<b>No National Effort</b>		<b>p-value</b>
	<b>Donation Rate</b>	<b>Donors</b>	<b>Donation Rate</b>	<b>Donors</b>	
White, Non Hispanic	59.3	4,928	59.2	11,279	0.02
White, Hispanic	105.9	1,055	47.4	886	<.01
Black	43.4	1,263	32.9	1,286	<.01
Other	50.7	228	42.4	272	<.01

(Table 3) **Number of Donors** **Organ Donors/Million** **Donation %**

<b>Ethnicity</b>	<b>Number of Donors</b>		<b>Organ Donors/Million</b>		<b>Donation %</b>	
	<b>1990</b>	<b>2000</b>	<b>1990</b>	<b>2000</b>	<b>2000</b>	<b>2005</b>
Black	659	1373	22.4	40.8	11.2%	14%
Hispanic/Latino	518	1319	22.9	40.2	11.2%	13.2%
Asian	73	278	10.3	26.2	2.7%	2.6%

**Conclusion:** Since the half lives for kidney transplants range from 5.3 (A.A.) to 12.2 (Asian), and 50% of all grafts survive at least 5 years and most more than 9 years, it is clear that the financial benefit to the government supporting a national donor education program such as this would save millions of dollars. Since outpatient dialysis costs are in excess of \$40,000.00/yr per patient and transplants break even after 3 years, this would provide an average savings of at least \$30,000.00/yr for each year the grafts survives over 3 years. Assuming a graft survival rate of 6 years, each donor (living or deceased) organ would save at least \$135,000.00 per donor (1.5 x

\$30,000.00 x 3 years. Deceased donors provide an average of 3 organs/donor while living donors provide 1 organ/donor). Assuming out patient kidney transplant costs after 3 years = \$10,000.00/yr, looking at the graphics presented above, it is clear that the cost benefit ratio of a model national donor education program such as the one presented here is a worthy investment whose benefits greatly outweigh the under-funded support currently provided.

These data are based upon the current census that identifies 25% of the American population as minorities. The MOTTEP goal is by 2010 to have 35% of the donors being minorities and to have African Americans (A.A.) and Latino O.D.M. to increase from 41 O.D. M. to 50 O.D.M. This would allow for the recovery of 1750 minority donor organs and save the Government 236 million dollars.

While MOTTEP has received a total of \$16 million dollars from the Federal Government between 1992 and now. None of these dollars have been allocated for organ donation after 2007. This would mean this unique program which has made a national contribution to the donor shortage would cease to exist after midyear 2008. Currently MOTTEP exists in 11 sites. Only 5 of which are partially funded. To optimize this unique community grass roots education program, funding for 15-25 sites would require 3-5 million dollars a year for an additional 5 years.