#### Social and Behavioral Interventions to Increase Solid Organ Donation Grantees – Fiscal Years 1999-2011

#### Fiscal Year 2011 Grantees

### Grantee:University of PittsburghProject Title:Controlled Trial of Academic Detailing and Web Based Education for Primary<br/>Care Physicians to Increase Consent for Organ Donation

This study will use a 2x2 factorial cluster randomized controlled trial to test the hypothesis that receiving a message about organ donation from a trusted medical provider in a context where it is possible to have questions answered and fears and misgivings addressed will have a direct effect on people's decision to join the organ and tissue donor registry. The intervention (conducted in three modalities and one control) is for physicians and their office staff to ask all adult patients whether they are organ donors, and, if not, provide a brochure and donor card form and offer to answer any questions. The control condition is a conventional poster and brochure placed in the waiting room of participating physician offices.

#### Grantee: Northwestern University

### **Project Title:** Evaluation of a Culturally Competent Website on Living Kidney Donation for Hispanics

The objective of this study is to increase understanding about living kidney donation (LKD) among Hispanic/Latino patients and public by increasing knowledge and positive attitudes about LKD. The study will: develop, test, and evaluate a culturally sensitive, web-based, multimedia educational resource on LKD in Spanish and English tailored to Hispanics. The study will be conducted in partnership with the National Kidney Foundation of Illinois who will host the website.

#### **Grantee:** Donor Network of Arizona **Project Title:** *Partnering with Mexican Consulates to Increase Organ Donor Registrations*

The seeks to increase donation registration among Spanish Language Dominant Hispanics using a portable DVD player to create focused engagement and favorable activation while people wait at the Mexican Consulate. If successful, the results of this study will offer a new context (Consulates) and a new method (portable DVD players with headphones as a means of providing information and placing potential donors in the most efficacious mind frame) for increasing donor registration rates. Also tested is a new approach to addressing myths about donation based on the Risk Communication Framework.

Grantee:Case Western Reserve UniversityProject Title:Patient and Physician Interventions to Increase Organ Donation in Primary Care<br/>Settings

This s seeks to increase discussions between physicians and patients about organ donation by 1) showing a donation video to patients in primary care settings waiting to see their physician and 2) academic detailing of primary care physicians about the topic of donation. Evaluation outcomes include increases in willingness to donate, discussions with physicians, and consent to donate.

**Grantee:** New York Alliance for Donation, Inc. **Project Title:** *Increasing organ donation in New York through Challenge Campaigns* 

This study will promote the formation of competitive teams on to develop and implement outreach strategies to increase organ donor registration. Most teams will be located on college campuses in the New York Metropolitan area. The goal of the study is to register 15,000 new donors.

#### **Fiscal Year 2010 Grantees**

**Grantee:** Emory University **Project Title:** *Living Donation Education for African American ESRD Patients* 

This is an extension project to modify an existing and effective federally-funded educational intervention to increase deceased donation and determine its effectiveness for increasing the understanding of patients who are waiting for organs that can be donated by living individuals of their option to seek a living donor and the process, risks, and benefits of living donation.

Grantee:National Kidney Foundation of MichiganProject Title:Use of Lay Health Advisors to Encourage Dialysis Patients to Give the Gift of<br/>Life

This project will rigorously evaluate the efficacy of a novel intervention to engage dialysis center social workers and dialysis patient peer mentors in encouraging patients in Michigan dialysis centers to sign up in the Michigan Organ Donor Registry.

**Grantee:** St. Vincent Medical Center **Project Title:** *Home-Based patient and Family Education: Hispanic Living Kidney Donation* 

This project will implement and assess the efficacy of a home-based program that directly educates patients, an intervention to educate patients' loved ones about kidney transplantation, and a combined approach educating patients and families for a comprehensive educational experience.

**Grantee:** Lifeline of Ohio Organ Procurement, Inc. **Project Title:** *"Can We Talk/" A Dialogue Intervention to Increase Organ Donation* 

#### Registration Among Older Adults"

This project will conduct a pilot study to implement and evaluate an intervention to increase organ donor registrations among 50-70 year old adults in this OPO's service area who have not already declared their intent to donate, but who are positive toward organ donation (positive potential non-consenting adults). The effectiveness of a dialogue process that involves participants in a participatory discussion about issues related to organ donation that especially related to people their age will be compared to a standard practice community education presentation strategy.

#### **Fiscal Year 2009 Grantees**

#### **Grantee:** National Kidney Foundation of Michigan **Project Title:** *Take the Pledge: Social Motivation to Join the Michigan Organ Donor Registry*

The need for organs is particularly great among African Americans who make up 12.4% of the U.S. population (14.1% Michigan) but 29% of those on the national waiting list (37.4% Michigan). The primary objective of the Take the Pledge project is to rigorously evaluate the efficacy of a novel intervention in alumni (or graduate) chapters of African American sororities and fraternities in Michigan to increase organ and tissue donation, as assessed by registration in the Michigan Organ Donor Registry. The project will use a cluster randomized design where African American alumni sorority and fraternity chapters are assigned to one of two groups – either an intensive intervention regarding organ donation or a delayed intervention group who initially receive a chronic disease prevention program (comparison chapters). The primary outcome will be actual registrations on the Michigan Organ Donor Registry via mail-in card and internet enrollment. The secondary outcome measure will be determination of differences between pre- and post-test surveys about participants' knowledge and attitudes regarding organ donation.

## Grantee:Saint Barnabas Medical CenterProject Title:Enhancing Living Donor Kidney Transplant Education: A Randomized Trial of<br/>Transplant Center-Based Interventions

The goal of this project is to identify, among a diverse cohort of potential kidney transplant candidates, transplant center-based interventions that will increase understanding of the opportunities for and process, risks, and benefits of living kidney donation. The project team will assess transplant candidates' knowledge of living donor kidney transplant (LDKT), correlates of increased understanding of LDKT, and racial/ethnic differences in the understanding of LDKT. This project will test practical interventions that may efficiently increase transplant candidates'

understanding of LDKT. These proposed interventions should be applicable and replicable at the 245 kidney transplant centers in the U.S.

### Grantee:Upstate New York Transplant ServicesProject Title:Increasing Registry Enrollment via Electronic Medical Record Patient Education

As most people indicate they would like to hear about donation from their physicians and heavy patient loads consume the time of most physicians, this study proposes to use MyChart -- an electronic medical records system for physicians to communicate with patients outside of the office – to promote donation. MyChart allows patients to view their medical records by computer, to receive health information and education from their physician, and to communicate with them via email. Intervention subjects (N=350) will receive information via a multifaceted web-based education program including narrated programs, video of physicians discussing the importance of donation and enrollment, recipient and donor family testimonials and printable materials. A control group of equal size will not receive the intervention. Data will be collected through pre-post surveys and telephone interviews to gather qualitative information.

### Grantee: University of Illinois at Urbana-Champaign Project Title: A Comparison of Campaigns Designed to Increase Organ Donation to African American, Caucasian, and Hispanic 18-Year-Olds

The study seeks to identify the most effective message appeal to encourage 18-year-old African American, Caucasian, and Hispanic adults to join the first-person consent donor registry in Illinois. In doing so, the project will conduct a race-stratified random digit dial phone survey (N = 600) to determine current attitudes, non-cognitive beliefs, controllability, efficacy, knowledge, reactance, subjective norms, intentions, and behaviors as they pertain to joining the first-person consent registry. From this information, the team will develop initial ideas for a mailer and tease out which specific appeals and medium would attract attention, be comprehensible and relevant, and be void of insensitive material. This will be done through focus groups (N = 12) with 18-year-old African American, Caucasian, and Hispanic residents.

#### **Fiscal Year 2008 Grantees**

## Grantee:University of PittsburghProject Title:Instructional Design Approach to Training Department of Motor Vehicle<br/>Customer Service Representatives

This project will incorporate an instructional design approach to develop a clerk training package. The target audience will be West Virginia Division of Motor Vehicles (DMV) Customer Service Representatives. The project will use a randomized design to evaluate the

impact of the web-based training on the probability that the driver's license customer agrees to join the registry.

## Grantee:Virginia Commonwealth UniversityProject Title:A Randomized Trial of the ERRA Intervention to Increase Consent to Organ<br/>Donation

This study will test the use of the Communicating Effectively about Donation (CEaD) training program, a component of the Early Referral and Request Approach (ERRA) intervention, to raise consent rates to solid organ donation from the families of deceased patients when requests are made by organ procurement organizations (OPOs). Eight OPOs, located around the United States, and their OPO coordinators who request organ donation, will participate as study sites and participants (n=80). The proposal has the following specific aims: 1. Test the effectiveness of the CEaD to increase consent rates; 2. Test the OPO implementation of the CEaD training under two conditions to ascertain best practices for implementation.

## Grantee:Washington UniversityProject Title:Training Dialysis Provided to Promote Living Donation: A Four-State Explore<br/>Transplant Intervention

This intervention will assess whether training dialysis providers to present Explore Transplant, an education program designed to address dialysis patients' fears and questions about deceased and living donation, effectively with their own patients can significantly increase the rates of living donation in four states. During the one-year intervention, the research team will conduct all-day Explore Transplant provider trainings in every state, staff a transplant hotline, provide monthly podcasts and transplant newsletters, and offer center visits from transplant coordinators, kidney recipients, and living donors.

#### Fiscal Year 2007 Grantees

Grantee:Upstate New York Transplant Services, Inc.Project Title:Increasing Declaration of Intent to Donate Through HMO Patient Education

The intervention to be studied involves members of a large health maintenance organization (HMO). The intervention encourages HMO subscribers to declare their donation intention by enrollment in the State's donor registry and will encourage family notification of the intention to donate. Also, the study will determine which modalities for the HMO delivery of donation education are most effective.

Grantee: Upper Midwest Organ Procurement Organization, Inc.

### **Project Title:** Barbershop Conversations: Increasing Organ Donation among African American Men

A culturally specific community-based education program will be developed for African American barbers who serve as trusted messengers for some aspects of health education for their customers. The project will determine whether this grassroots intervention can influence African American men, over age 18, to make the commitment to organ donation.

## Grantee:Washington University, St. Louis, MOProject Title:Educating Missouri Patients about Preemptive Living Donor Transplantation: A<br/>Randomized Clinical Trial

This project explores whether improved transplant education for renal patients, not yet on dialysis, could increase the patients' willingness to pursue preemptive living donor transplant (PLDT). Research shows that PLDT, where a living donor transplant is done before the recipient's kidneys fail, offers better graft survival and lower mortality than living donor transplants following dialysis. The study will look at rural and minority patients' access to transplant education and assess racial, social, economic, and other influences on a patients' willingness to participate in the study.

#### Grantee: Donor Network of Arizona

Project Title: Swap Meets as a Context for Increasing Organ Donation Among Hispanics

Nearly 80 percent of Hispanics in the Southwest support organ donation and 35 percent want to be donors but have not registered their decision. The proposed project offers a context, the swap meet, for an educational intervention on organ donation. Hispanics represent 99 percent of the populations at the swap meet sites targeted in the study. A swap meet manual is expected to be prepared.

#### **Grantee:** St. Vincent Medical Center, Los Angeles, CA **Project Title:** *Hispanic Living Donation: Kidney Health Literacy and Education*

The purpose of this project is to increase the number of living kidney donor consents among Hispanics in Los Angeles using two interventions: (1) a Kidney Health Literacy Intervention to increase comprehension of living kidney donation, and (2) a Living Donor Educational Intervention to facilitate the initiation of discussion between Hispanics in need of a kidney and a potential living donor.

#### **Fiscal Year 2006 Grantees**

## Grantee: Johns Hopkins UniversityProject Title: Culturally Sensitive behavioral Interventions to Enhance Living Kidney Donation and Living Kidney Transplantation

This project will develop culturally sensitive materials for end stage renal disease patients and families considering living donation and will test the effectiveness of a culturally sensitive social worker led intervention to enhance rates of communication, donor evaluations, and transplantation. The social worker will distribute educational materials, facilitate discussion, and use problem-solving techniques to enable families to make decisions about living donation.

### Grantee:Lifeline of Ohio Organ ProcurementProject Title:Increasing Older Adult Registration in 1st Person Consent Ohio Donor Registry

The purpose of this project is to increase registration rates through informational and educational interventions targeted at 50 to 70 year old rural and urban Ohio residents who are not registered to donate. To address a lack of registry rate increase in this group when compared to the overall population, a unique message brochure will be designed based on identified barriers to donate and evaluated for effectiveness.

#### **Grantee:** New York Center for Liver Transplantation **Project Title:** *Increasing Liver Donation through Peer-Developed Education*

Living liver donor self-reports will inform the development and implementation of an educational process targeting potential recipients and living donors. The intervention addresses knowledge of living liver donation, post-donation quality of life, and ability to communicate relevant information to loved ones. Outcome measures include actual living donor consent rates, post-donation living liver donor health, and knowledge of living donation. For the population of individuals consenting to donate but found to be unsuitable, intent to donate upon death will be measured.

#### **Grantee:** LifeNet **Project Title:** Increasing Organ Donation Among the 50 Plus Age Demographic: Piloting an Age-Demographic Tailored Message

To counter the misperception that people over age 50 are medically unsuitable to donate, age tailored marketing style messages, rather than the traditional healthcare message, will be delivered to 50-65 years olds in several geographic clusters. The messages are intended to change perceptions about who can donate thereby increasing organ donation entry into the Virginia Donor Registry. The message and the medium of delivery will be evaluated with behavior change and donor registration rates as outcome measures.

#### Grantee: South Dakota Lions Eye BankProject Title: Sharing the Gift of Life: A Multi-state American Indian Tribal College Intervention to Increase Organ and Tissue Donation

A multi-state, culturally-targeted intervention utilizing the Native-American tradition of storytelling and gift giving among the Plains tribes will be delivered to tribal colleges in the US Great Plains to address the need for kidney transplantation and the corresponding low donation consent rate. The intervention incorporates print, video, and web site materials. Outcomes measures include improved readiness to be an organ donor, the move to action, and family notification.

Grantee:Purdue UniversityProject Title:The Drive for Life Campaign and Evaluation: The Impact of Just-in-TimeInformation, Public Education, and DMV Clerk Training on Donor Registrationsand Family Notifications

DMV/Circuit Court Clerks will be trained to provide simple, accurate information about organ donation and the DMV registry when Kentuckians are obtaining their driver's license. Additional approaches include stocked brochures, mailings with driver's license renewal materials, and outreach and mass media events. This campaign is intended to increase donor registrations and self-reported family discussions.

#### Fiscal Year 2005 Grantees

**Grantee:** Center for Organ Recovery and Education **Project Title:** *West Virginia Organ Donor Project: A Model for Campus Intervention* 

A mass media campaign and a grass roots advocacy program will be integrated to improve declaration of intent and family notification. The intervention takes place on a large university campus and consists of a media component, in-class presentations, and support from local religious leaders.

Grantee:Donor Network of ArizonaProject Title:Translating Attitudes into Action: A Multi-Site Test of Various Community<br/>Forums

A three-phase intervention will target the 80% of the population that is in favor of donation through structured implementation of focus groups, community forums, and talk radio programs. It is intended to increase donor registration by creating contexts where positive attitudes are

accessible, social norms support donation, and perception of difficulty in registering is minimized.

### Grantee:New York Alliance for DonationProject Title:Promoting Organ and Tissue Donation through Medical Education

Medical students and medical residents in New York State will receive an educational intervention intended to positively affect knowledge, self-efficacy, and outcome expectations with respect to donation and for residents, to improve communication with patients and families about donation. The intervention will be delivered via video, lecture, discussion groups, standardized patients, and online learning vignettes.

## Grantee:Upstate New York Transplant ServicesProject Title:Incorporation of Declaration of Intent to Donate Organs in Cemetery Pre-<br/>Arrangements

Cemetery professionals will participate in a program to prepare them to educate their clients, in the context of end-of-life decisions during pre-arrangement meetings, about the importance of donation and methods to declare intent. In addition to increasing rates of declaration of intent, the project is intended to establish effective collaboration among cemeterians, professional organizations, and organ procurement organizations.

### Grantee:Washington University School of MedicineProject Title:Increasing Living Donation in Transplant-Eligible Dialysis Patients

In this group randomized trial, a living donation education program will be implemented to increase dialysis patients' transplant knowledge, willingness to pursue living donation, and rates of living donation. This health education intervention consists of video and print material, exercises, and interactive discussion with health educators and is intended to promote the benefits of and reduce the fears associated with living donation.

#### **Fiscal Year 2004 Grantees**

Grantee:National Kidney Foundation of IllinoisProject Title:Increasing Organ and Tissue Donation in the Service Industry/Factory<br/>Workplace: A Peer Educator Approach

This project will implement an evidenced-based workplace intervention designed to increase intentions to donate organs and tissues among lower socioeconomic and minority populations, mainly African-Americans, and Hispanics. The project will use peer educators and a group of

multifaceted interventions to increase intentions to donate among employees, to promote communication of this decision with family members, and to persuade family members to become donors themselves.

## Grantee: National Kidney Foundation of MichiganProject Title: Validation of the Impact of Lay Health Advisors on Intent to Donate in the African American Community

This study will assess the effectiveness of African American lay health advisors to educate their clients about organ and tissue donation and encourage clients to join the Michigan Donor Registry. The main outcome indicator is measured the number of organ donor registry cards returned to the Michigan Donor Registry. Changes in knowledge about and attitudes towards donation will be assessed using pre- and post-tests.

#### Grantee: National Kidney Foundation of North CarolinaProject Title: Community and Individual Interventions to Increase Organ and Tissue Donation Intent Among African Americans

This project attempts to advance understanding of donation decision-making, evaluate individually tailored and community-based interventions, and refine these interventions aimed to increase organ donation among African Americans. The project will measure intent to be an organ/tissue donor and documenting that intent, e.g., by signing an organ donor card, and informing the family of the intent to donate.

#### **Grantee:** New Jersey Organ and Tissue Sharing Network **Project Title:** *The New Jersey Workplace Partnership for Life Campaign and Evaluation*

The purpose of this program is to create a significantly higher rate of signed organ donor cards, driver's licenses, and/or New Jersey organ donor registry entries and a significantly higher rate of family notification donation intent among employees of organizations in New Jersey who receive the Workplace Partnership for Life Campaign interventions.

### Grantee:Tulane UniversityProject Title:Home Care Association of Louisiana DONATE LIFE Worksite Partnership

This project will implement and evaluate a workplace partnership model for donor registration in Louisiana that can be incorporated into the existing infrastructure of home care professional organizations without substantially increasing personnel or operating costs.

Grantee: University of Maryland Surgical Associates

#### Project Title: Evaluation of an Early Educational Program to Increase Live Kidney Donation

This project proposes to optimize access to live kidney transplantation for End Stage Renal Disease (ESRD) patients and to assess whether the implementation of an educational program early in the ESRD treatment process, i.e., in dialysis facilities, increases the number of ESRD patients who identify at least one certified willing live kidney donor. The project also will measure the proportion of patients who request a kidney donation from family or friends and the number of completed donations.

## Grantee:Upstate New York Transplant ServicesProject Title:Life Lessons: Development and Implementation of a Comprehensive Program<br/>Teaching Teens to Educate Their Peers on Organ and Tissue Donation

This project will establish an ongoing education program for teens on organ and tissue donation in order to increase the number of high school students committed to donation and to encourage discussions with their families about donation. Students who have been trained to provide organ donation information to their peers will establish high school donation organizations. The project will measure outcomes by the increases in family discussions about donation and increases in the declaration to donate, e.g., organ donor registrants.

#### **Fiscal Year 2003 Grantees**

**Grantee:** Arizona Kidney Foundation, Phoenix, and University of Arizona, Tucson, AZ **Project Title:** *Hispanic Live Organ Donation: A Strength-Based Approach* 

This two-year project intends to implement a dual-featured intervention. The investigators will develop and implement a live organ donor media/community campaign as well as replicate a deceased donor campaign that was implemented in Tucson and Phoenix. The project will appeal to the enhanced sense of family and community within the Hispanic culture to increase the number of live and deceased donors. Surveys and focus groups will evaluate the project's effectiveness.

#### Grantee: Case Western Reserve University and LifeBanc Organ Procurement Organization, Cleveland, OH Project Title: Testing the Early Referral and Request Approach (ERRA) Model

This three-year project will test the ERRA Model to increase solid organ donation from brain dead patients. The model consists of hospital-tailored intervention modules plus communication modules based upon the information needs of family decision-makers. The intervention will target OPO requesters, family decision-makers, and health-care providers. The investigators will

evaluate hospital barriers to time-sensitive referrals, a health care provider's ability to discuss organ donation with patients' families, and OPO requester's ability to optimize their approach to discussions of donation with families.

### Grantee: Life Alliance Organ Recovery Agency, Miami, and University of Miami, Coral Gables, FL

**Project Title:** A Model Intervention for Increasing Intent of a New Immigrant Population (Haitians in Miami-Dade County, Florida) to Donate Organs and Tissues

This two-year project will develop and evaluate a health campaign intervention designed to increase intent to donate among Haitians living in Miami-Dade County. The four-phased intervention will look at the use and effectiveness of a theory-driven media and community outreach campaign to enhance intent to donate in immigrant populations. The campaign will use native language, focus groups, and trusted community health providers to develop culturally tailored messages. The evaluation will help establish replicability in other immigrant populations.

**Grantee:** Life Point Organ Procurement Organization and Medical University of South Carolina, Charleston, SC

**Project Title:** A Comprehensive Approach to Organ Donation by Incorporation of Family Support Counselors as Members of the Hospital Critical Care Team

This three-year project will develop and evaluate an intervention that will implement a hospitalbased requestor model in which counselors will provide emotional and bereavement support to families of patients dying in the ICU. The intervention also will provide education on brain death and the value of donation to families. The effectiveness will be measured by the number of families consenting to organ donation, counts of potential donors, and changes in attitude and knowledge of organ donation amongst health care providers.

Grantee: Mount Sinai School of Medicine and New York Organ Donor Network, New York, NY

Project Title: Improving Organ Donation in Chinese Communities in New York City

This three-year project will compare two types of interventions aimed at increasing willingness to become an organ donor among Chinese Americans. Grassroots campaigns and a paid-media advertising campaigns will be implemented in three Chinese neighborhoods in New York City. The investigators will design culturally sensitive interventions that respect local institutions, persons, and beliefs. The relative effectiveness and cost-effectiveness of the interventions will be measured by the number of new registrants on the organ donor registry and by survey.

#### Grantee: New York Alliance for Donation, Albany, NY, and University at Buffalo, Buffalo, NY

#### Project Title: A Multi-Campus Classroom Intervention to Increase Organ and Tissue Donation

This three-year project aims to increase the number of college students in New York who communicate their intent to donate their organs and tissues by enrolling in the State's donor registry and notifying their family of their enrollment decision. Students will participate in a public communication course promoting organ and tissue donation that requires them to devise and execute campus-wide campaigns to increase declaration rates and family discussion. The project will evaluate the impact of participation in the course on knowledge and changes in registry enrollment.

## Grantee: Organ Procurement Agency of Michigan, Ann Arbor, MI, and University of Michigan-Dearborn, Dearborn, MI Project Title: A Culturally Sensitive Intervention to Increase Organ Donation Registration

Among Asian Pacific Americans

This project will study the Asian Pacific American community from three perspectives: 1) behavior, attitude, willingness, and obstacles to organ donation; 2) receptivity to an organ and tissue donation intervention, and 3) change in organ and tissue donation registry sign-ups if culturally sensitive interventions are administered. The project will implement culturally appropriate interventions and will evaluate their effectiveness by changes in awareness, attitude, intent to sign a donor card, and informing family about their decision.

Grantee:	South Dakota Lions Eye Bank, Sioux Falls, and South Dakota State University,
	Brookings, SD

**Project Title:** A Culturally-Competent Intervention to Increase Organ, Eye, and Tissue Donation on South Dakota's Indian Reservations: A Collaborative Project by the SD Lion's Eye Bank and SD State University, College of Nursing

The three-year project will pilot-test a cultural intervention that includes printed materials, videos, and social marketing methods that will be implemented within reservation schools, organizations, and activities. The intervention will be developed within the context of Sioux Indian cultural beliefs and values. The investigators will help ensure culturally sensitive methods by using Sioux Indian personnel. The project's effectiveness will be measured by changes in donor card completion, driver's license designation, and family notification.

#### **Fiscal Year 2002 Grantees**

Grantee: Albany Medical College and Center for Donation and Transplant, Albany, NY

### **Project Title:** Social Support for Families Considering Organ Donation: Transferability of the MOD (Mothers of Donors) Squad Volunteer Intervention Program

This project will evaluate the effectiveness of a hospital-based peer support intervention on consent rates, family satisfaction, and coping in three regions with markedly different population characteristics. The project builds on the successful implementation and testing of the MOD Squad program-- entailing support by mothers of donors to families faced with the death of a loved one -- in Upstate and Western New York, also sponsored by a HRSA grant. This expanded initiative will allow the grantee to evaluate the transferability and generalizability of the outcomes of the intervention.

**Grantee:** Donor Network of Arizona, Phoenix, and University of Arizona, Tucson, AZ **Project Title:** *Maximizing Donor Registry Utility via Full Service Kiosks* 

The purpose of this project is to test the effectiveness of a media campaign in promoting "all-inone" kiosks to encourage individuals to register as donors.

Grantee: Johns Hopkins Medical Institutions, the Transplant Resource Center of Maryland, and Johns Hopkins University, Baltimore, MD
 Project Title: Dissemination of an Interdisciplinary Experiential Training Program for End-of-Life Care and Organ Donation

The purpose of this project is to evaluate the reproducibility of a model training intervention that has been shown to increase organ donation by 20 percent at a single hospital by implementing it at three additional hospitals in Maryland. The model training intervention uses the standardized patient method with simulated families to teach an organized, interdisciplinary family-centered approach to care, with particular attention to the processes and communications skills for end-of-life decision making and the decoupled model of presenting the option of organ donation. Based on the results of this project, the grantee will prepare training materials for dissemination of the model training intervention to hospitals, health systems, and organ procurement organizations throughout the United States.

Grantee:	Lifeline of Ohio Organ Procurement Organization, Columbus, and University of
	Cincinnati, Cincinnati, OH
<b>Project</b> Title:	Chio's First Person Consent Donor Registry – A Help or Hindrance: Comparing
	Organ Donation Through a First Person Consent Donor Registry and Statewide
	Donation Campaign

The project will use a retrospective and prospective design to compare the impact of Ohio's first person consent donor registry and a statewide media campaign on Ohioans' donation attitudes and behaviors.

### Grantee: LifeQuest Organ Recovery Services and the University of Florida, Gainesville, FL

#### **Project Title:** Increasing Living Kidney Donation: Evaluating the Effectiveness of a Home-Based Intervention

The primary objective of this research is to implement and evaluate a home-based educational intervention designed to increase living kidney donation rates. Adult patients who have been wait-listed for kidney transplantation will be randomized to receive either standard clinic-based education about living kidney donation or clinic-based education plus a home-based intervention involving family members and significant others. It is hypothesized that the clinic-based education plus home-based intervention will reach more people, reduce barriers to living donation, and contribute to higher rates of living kidney donation and transplantation.

#### **Grantee:** Mid-America Transplant Services and Research & Planning Group, St.Louis, MO **Project Title:** *The Mobile Learning Center: Is it More Effective than Traditional Educational Efforts?*

The purpose of this grant is to study the effectiveness of three different educational interventions – a Mobile Learning Center, OPO presentations, and teacher taught curriculum – on donation attitudes and behaviors of children in grades six to eight. In addition, the grantee will evaluate the project's impact on the attitudes, acceptance, and involvement of the teachers who implement each intervention.

Grantee: The Sharing Network Organ and Tissue Donation Services, Springfield, and Rutgers University, New Brunswick, NJ
 Project Title: The University Worksite Organ Donation Promotion Campaign: Targeting Administrators, Faculty, Staff, and Students Using the Organ Donation Model

This university worksite project will target the willingness of faculty, staff, administrators, and students to sign organ donor cards and discuss organ donation with family members. In addition to increasing the rates of signed cards and family discussion, this project seeks to increase knowledge about the most effective channels for organ donation promotion messages. This is a six-site project with three quasi-experimental conditions: Two sites will receive only mass media messages, while two others will receive a mass media campaign supplemented with an interpersonal component. These campaign sites will be contrasted with two control sites. In sidebar studies at the control sites, a series of qualitative studies will examine the factors that

impact real-life family discussions about organ donation, with a particular focus on African American families.

## Grantee: Thomas Jefferson University, Philadelphia, PA, and University of Michigan, Ann Arbor, MI Project Title: Targeted Intervention to Increase Living Kidney Donation

**Project Title:** Targeted Intervention to Increase Living Kidney Donation

This project seeks to increase the number of living kidney donations by targeting the intervention to each patient's and potential donor's stage of cognitive-motivational readiness to consider living donation.

### **Grantee:** University of Washington and Hope Heart Institute, Seattle, WA **Project Title:** *A Multicultural Urban High School Intervention Program*

Building upon previously published piloted studies conducted by the investigators, a culturallysensitive health education intervention will employ quasi-experimental techniques to evaluate the effectiveness of a 40-minute health education session design to measure students' knowledge, opinions, and behaviors related to the organ donation/transplantation process. This classroombased intervention is to be administered separately in 12 Seattle area high schools selected for their racial/ethnic and income diversity. The TransTheoretical Model, or Stages of Change framework, will be applied through a 33-item questionnaire self-administered to students in randomly selected classes within each school. Indicators of behavioral change will be tracked and measured at pre- and post-tests periods in the treatment and control groups.

**Grantee:** Upstate New York Transplant Services and State University of New York, Buffalo, NY

**Project Title:** Model Intervention to Increase African American Living Related and Non-Related Organ Donation

This project seeks to increase the rate of African American living related and non-related organ donation by training ESRD staff to educate patients and donors about living donation and improve their attitudes toward donation and by offering an education and support program for patients.

 Grantee: Upstate New York Transplant Services and State University of New York, Buffalo, NY
 Project Title: Pre-Planning Education: The Role of Funeral Directors as Partners in Increasing Organ and Tissue Donation This project seeks to increase organ and tissue donation by educating and developing better relationships with funeral home personnel and providing educational materials to funeral homes for distribution to clients involved in the pre-planning process.

#### **Fiscal Year 2001 Grantees**

 Grantee: Carolina Donor Services, Durham, NC, and University of Rhode Island, Kingston, RI
 Project Title: Individual and Campus-Wide Interventions to Increase Donation Intentions Among African-American College Students

This project will evaluate the efficacy of a theory-based innovative individualized intervention for increasing organ and tissue donation intention rates among African-American college students. It will build upon the success of an ongoing campus-wide intervention to increase donation intentions by adding proactive individually tailored interventions to further increase donation intentions.

Grantee:	Cleveland Clinic Foundation, Cleveland, OH, and Pennsylvania State University,
	University Park, PA
<b>Project Title:</b>	Utilizing the Structure and Resources of a Multi-Hospital Health System to
	Improve Organ Donation Rates

This project will test the effects of a program of awareness, education, and training for hospital personnel on rates of organ donation referral and actual donors in a multi-hospital system.

**Grantee:** Intermountain Organ Recovery System and University of Utah, Salt Lake City, UT

**Project Title:** Improving Organ and Tissue Donation through a Comprehensive Donor Registry and Statewide Community Outreach Campaign

This project will study the utility of a new, comprehensive, centralized statewide organ and tissue donor registry system and its impact on declarations of intent, consent rates, and organ and tissue donation. The project also will use the registry to evaluate both interest in, and actual, unrelated living donation rates within a multi-hospital system.

**Grantee:** LifeNet Organ Procurement Organization, Virginia Beach, and Medical College of Virginia Hospitals & Physicians of the Virginia Commonwealth University Health System, Richmond, VA

**Project Title:** Replication of Family Communication Protocol to Increase Organ and Tissue Donation

This project attempts to increase organ donation and the availability of transplantable organs through replication of a Family Communication Coordinator (FCC) Protocol in a general hospital. The hypothesis is that the FCC program will increase organ and tissue donation through better care of families faced with the possibility of donation.

**Grantee:** National Kidney Foundation of Illinois and University of Chicago, Chicago, IL **Project Title:** "Corporate Contributions For Life:" Supporting Organ/Tissue Donation Awareness in the Workplace

This project will test a model program to increase awareness of organ and tissue donation and transplantation in the workplace. Each project year, five major Chicago-area corporations of at least nine branches each will participate in study. Corporations will be randomly assigned to participate in one of two intervention modes or a control group.

 Grantee: North Mississippi Health Services, Tupelo, and Mississippi State University, Starkville, MS
 Project Title: Intervention Evaluation for Organ Donation in Two Mississippi Communities

This project will evaluate a series of multimodal interventions to improve attitudes toward and commitment to organ donation in two Mississippi counties with very low donation rates and relatively low support for donation.

Grantee: North Shore Long Island Jewish Health System, Great Neck, and Long Island University, Brookville, NY
 Project Title: A Systematic Model for the Improvement of Communication with Family Members about Death and Imminent Death in a Non-Transplant Hospital

This project will evaluate the impact of a timed family communication and support intervention on rates of consent for organ donation in five non-transplant hospitals on Long Island. The intervention consists of utilizing a team of specially trained on-call family communicators to provide information and social support to the family members of patients who are facing imminent brain death.

Grantee: Organ Procurement Agency of Michigan and University of Michigan, Ann Arbor, MI

**Project Title:** Measuring the Effectiveness of a Culturally Sensitive Approach to Improving Attitudes Toward Organ Donation in the Arab-American/Chaldean Community In response to the paucity of donation research on Middle Eastern ethnic groups in the United States, this project will launch and evaluate the effects of a comprehensive community awareness campaign on organ donation rates among targeted Arab-American and Chaldean communities.

**Grantee:** Trustees of the University of Pennsylvania, Gift of Life Donor Program, and LifeSource Institute for Transplant Research, Education, Ethics, & Policy, Philadelphia, PA

Project Title: A Study of the Presumptive Approach to Consent for Organ Donation

The purpose of this project is to increase the consent and donation rate for organ and tissue transplantation by altering the approach to donor families during the consent discussion. Transplant coordinators will approach donor families, regardless of the presence of a driver's license or other form of donor designation, using a "Presumptive Approach to Consent."

Grantee:	University of Miami Organ Procurement Organization, Coral Gables, and
	University of Miami, Miami, FL
<b>Project Title:</b>	A Model Intervention for Increasing Intent to Donate in Primary Care Centers
	and Churches in Miami-Dade County, Florida

The purpose of this model intervention is to increase the number of minority organ and tissue donors by increasing intent to donate coupled with family notification of intent to donate among Blacks, Haitians, and Hispanics living in Miami-Dade County, Florida. A secondary purpose is to document project processes and outcomes to enable replication in other multi-ethnic communities.

Grantee: University of Wisconsin Hospital and Clinics Organ Procurement Organization and Knupp & Watson, Madison, WI
 Project Title: A Model for the Implementation of Donation after Cardiac Death (DCD) Protocols

This project seeks to produce a verifiable and demonstrable increase in organ donations through implementation and testing of a protocol for donation after cardiac death. This model will include the modification of existing specialized designated requester training modules to include information related specifically to DCD.

 Grantee: Upstate New York Transplant Services and State University of New York, Buffalo, NY
 Project Title: "Legacy for Life:" Lawyer's Role in Organ and Tissue Donation Education This project will implement a program to educate the legal community about organ/tissue donation and prepare and encourage attorneys to educate their clients about the critical need for donation. Client declarations of intent to donate coupled with family notification will serve as outcome measures. This intervention also seeks to enhance the level of communication between the legal community and health care providers with the organ procurement organization to increase the likelihood that an individual's wish to donate is fulfilled.

#### Fiscal Year 2000 Grantees

Grantee: Alabama Organ Center and University of Alabama, Birmingham, AL
Project Title: A Model Intervention for Increasing African-Americans' Intent to Donate in Two Counties in Alabama

The use of church health advocates to promote donation will be tested in two Alabama counties. Project components include provision of educational materials, incorporation of the clergy person as an agent of change and promotion of the state donor registry.

Grantee: Asian Transplant Awareness in Southern California, Orange, and Southern California Organ Procurement Center, Los Angeles, CA
 Project Title: A Grass Roots Effort to Increase Organ Donation Among Asians in Southern California

This project focuses on Chinese and Vietnamese Asian populations, testing the involvement of trained requestors who discuss donation in the native tongue of families of potential donors. It also will evaluate the target groups' attitude toward donation as affected by a media campaign and an existing targeted approach for increasing organ donation in Asian communities.

Grantee:New York Organ Donor Network and Columbia University, New York City, NYProject Title:Project to Support Donation: Changing the Culture of Organ and Tissue<br/>Donation

A team of crisis support specialists will provide crisis intervention services to suddenly bereaved and grieving family members of potential organ donors. A subset of the team will be hospitalbased full-time. The project team will be evaluated for its effectiveness in supporting families and increasing rates of consent.

Grantee: Southern California Organ Procurement Center, Los Angeles, and Strategy Research Corporation, Laguna Hills, CA Project Title: *Hispanic Media Campaign*  The purpose of the project is to evaluate the success and cost-effectiveness of a targeted culturally sensitive media campaign to increase organ and tissue donation in the Hispanic community. Input from community leaders will help to shape the message to be delivered through a variety of media.

## Grantee: Upstate New York Transplant Services and State University of New York, Buffalo, NYProject Title: "Talk It Up:" Students and Families Discussing Organ Donation

Through a teacher training program and a class-assigned family interview, the project provides high school students with the knowledge and incentive to promote family discussion and shared decision-making about organ donation. The approach includes a post-discussion "debriefing" session, as well as the use of a take-home study guide and a resource manual.

#### **Fiscal Year 1999 Grantees**

**Grantee:** Albany Medical College and Center for Donation and Transplant, Albany, NY **Project Title:** *Testing and Replication of a Model Volunteer Program* 

This project proposes to increase donation consent rates by evaluating and replicating a volunteer program that teaches mothers of organ donors to counsel potential donor families about the option of donation. The project will enable an assessment of the donor family member's role in, and impact on, the donation decision process.

Grantee:	California Transplant Donor Network, San Francisco, CA, and Market Study
	International, Houston, TX
<b>Project Title:</b>	Proposal to Increase Organ Donation Consent Rates Involving Targeted Minority
	Populations

This grant award will facilitate the development of cultural diversity and request training programs to garner donation support among African Americans and Asians in Northern California.

Grantee:	Donor Network of Arizona, Phoenix, and University of Arizona College of
	Medicine, Tucson, AZ
<b>Project Title:</b>	Comprehensive Approach to Raising Organ and Tissue Donation Consent in the
	Hispanic Population

This project proposes to increase donation consent rates among Hispanic families through a comprehensive approach – including community, media, and requester outreach – to increase donor awareness and family discussions.

## Grantee:Education Development Center and New England Organ Bank, Newton, MAProject Title:Increasing Organ Donation by Enhancing End-of-Life Care: A Family-Centered<br/>Quality Improvement Program

This project is based on empirical research indicating that families are more likely to consent to organ donation if they are satisfied with the care that their loved ones received at the end of life. The New England Organ Bank and the Education Development Center of Boston will collaborate with hospitals in Massachusetts, Rhode Island, and New Hampshire to enhance end-of-life care and improve the donation request process. The study aims to increase health professionals' comfort and skill discussing death and dying and to build hospitals' capacity to support families through the end-of-life period.

## Grantee:Emory University and LifeLink of Georgia, Atlanta, GAProject Title:The Renaissance State-Wide Initiative to Increase Organ Donation in the State of<br/>Georgia

The purpose of this project is to replicate a successful donation-enhancing program launched at Emory University Hospital in Atlanta known as the "Renaissance Project." This end-of-life care model will be expanded to four additional Georgia hospitals with the goal of enhancing family support practices and increasing the number of organ donors at each institution.

Grantee: Golden State Donor Services, Sacramento, CA, and Market Study International, Houston, TX

#### Project Title: Increasing Donation in the Hispanic Community Through Mass Media

This project aims to reverse the declining rate of donation consent among Hispanic families in the Sacramento area by implementing and evaluating an ethnically sensitive media campaign. This undertaking is especially critical in California due to the disproportionate rate at which Hispanics are placed on the transplant waiting list because of end-stage organ failure.

Grantee: Howard University and Minority Organ and Tissue Transplant Education Program (MOTTEP), Washington, DC
Project Title: "Say YES!" to Organ and Tissue Donation: Implementation and Evaluation of a Promising Youth Intervention This project seeks to increase the number of youth registering to become donors when obtaining a driver's license by encouraging family discussions and promoting an informed donation decision. This program will enhance existing school-age driver curriculum with materials to increase family discussion on organ and tissue donations, raise positive consent rates, and increase youth awareness of organ donation needs.

Grantee: Johns Hopkins University and Transplant Resource Center of Maryland, Baltimore, MD

Project Title: Interdisciplinary Experiential Training for End-of-Life Care and Organ Donation

This project will implement and evaluate a family-centered program focusing on end-of-life decision making and organ donation discussions with the goal of increasing the frequency of donation consent. The proposed program will utilize a multi-disciplinary approach involving such health care professionals as physicians, nurses, hospital clergy, and organ procurement coordinators who play consistent, important, and inter-dependent roles in caring for patients and families when organ donation is possible.

#### Grantee: Kentucky Organ Donor Affiliates, Louisville, and University of Kentucky, Lexington, KY Project Title: Increasing Commitment to Organ and Tissue Donation Through a Work-Site Intervention

Kentucky Organ Donor Affiliates will collaborate with United Parcel Service to study the effect of a work-place donor education program. This program could potentially serve as a model for corporate education programs throughout the country.

**Grantee:** LifeGift Organ Donation Center, Houston, and University of Houston, Clear Lake, TX

Project Title: African-American Community Outreach Project

This program aims to increase family donation discussions and minority community support by implementing and evaluating an intensive education and training program targeting African American religious and spiritual leaders in Harris County, TX. The project will prepare clergy to develop and implement effective donation education and support programs for each of their congregations.

**Grantee:** LifeGift Organ Donation Center, Houston, and University of Houston, Clear Lake, TX

Project Title: Project to Increase Organ Recovery From Level 1 Trauma Centers

This project proposes to replicate a successful pilot program which significantly increased organ donation by placing "in house procurement coordinators" in two Level 1 Trauma Centers. The grantee will disseminate the concept to hospitals in Detroit, Seattle, and Houston demonstrating significant untapped donor potential.

# Grantee: Louisiana Organ Procurement Agency, Metairie, and Keating Magee & Associates, New Orleans, LA Project Title: The Kiosk Learning Center: A Community Outreach Approach to Increase Donor Consent Rates, Public Access, and Overall Awareness

This project will attempt to improve driver's license renewal efficiency and enhance donor education and registry sign-up by placing in public venues ATM-like kiosks that enable these functions.

Grantee: National Kidney Foundation, New York, NY, and ITG Enterprises, Columbia, MO Project Title: *Take Time to Talk: A Family Discussion Guide* 

The National Kidney Foundation will study the feasibility of incorporating a donation education program into funeral pre-planning activities. The goal of this program is to provide individuals the opportunity to conduct family discussions about donation at the time they are making other end-of-life arrangements.

Grantee: Oklahoma Organ Sharing Network, Oklahoma City, and University of Oklahoma, Norman, OKProject Title: *Project Team Life* 

This proposal seeks to increase commitment to donate by implementing and evaluating the impact of an organ and tissue donation and transplantation curriculum in elementary and secondary public schools in Oklahoma.

Grantee:	Organ Procurement Agency of Michigan, TransWeb, and University of Michigan,
	Ann Arbor, MI
<b>Project Title</b>	Measuring the Effectiveness of a Multimedia Internet-Based Approach to
	Increasing Donor Registry Participation

This project aims to expand a previously existing transplant education Internet site by creating a new path focusing on the donor family's view of organ donation. The project's intent is to encourage participants to join a donor registry and provide specially designed electronic greeting cards to notify family members of the registrant's desire to donate.

# Grantee: Regional Organ Bank of Illinois and University of Illinois, Chicago, IL Project Title: Impact of Educational Interventions Regarding Organ Donation on Declaration of Intention to Donate and on Family Discussion in the African American Community

This project seeks to increase the number of African-Americans who are willing to join the Illinois organ donor registry and talk to their families about their decision by assessing the effectiveness of two separate strategies to encourage registry participation and by conducting and evaluating an ethnically sensitive media campaign.

Grantee:	South-Eastern Organ Procurement Foundation, Richmond, VA, and the
	University of Rhode Island, Providence, RI
<b>Project Title:</b>	Stage-Based Curriculum Training for Procurement Coordinators to Increase
	Family Consent for Organ and Tissue Donation

The aim of this project is to improve family donation consent rates by training procurement coordinators to match their donation requests to reflect the family's readiness to donate. This project, involving staff from 16 of the Nation's 61 organ procurement organizations, represents the first multi-center study of requester training program effectiveness.

### **Grantee:** Upstate New York Transplant Services and State University of New York, Buffalo, NY

### **Project Title:** Decision for Life: An Intervention to Increase Organ Donation in the African American Community

This program seeks to increase the number of African Americans in the Buffalo urban community who have signed donor cards and discussed donation with their families. It will train African American community educators to implement public education programs and increase medical student and resident awareness of the importance of approaching potential donor families in a culturally sensitive manner.