

REPORT 2 OF THE COUNCIL ON SCIENCE AND PUBLIC HEALTH (I-17)
Targeted Education to Increase Organ Donation
Policy D-370.984
(Reference Committee K)

EXECUTIVE SUMMARY

Background. This report responds to Policy D-370.984 by reviewing current organ donation statistics, attitudes about donation, the disproportion between those needing a transplant and the organs available, factors influencing the decision to designate oneself as a donor, and educational interventions targeted to segments of the population with historically low rates of organ donation.

Methods. Literature searches were conducted in the PubMed database for English-language articles published between 2007 and 2017 using the search term “organ donation,” with the terms “minority,” “religion,” “education,” and “barriers.” A Google search was conducted using the same search terms. Additional articles were identified by manual review of the references cited in identified publications. The Health Resources and Services Administration (HRSA) Organ Donation and Transplantation and Organ Procurement and Transplantation Network websites, and the United Network for Organ Sharing website also were consulted.

Results. More than 33,000 transplants were performed in 2016, with kidney and liver transplants making up the majority. Most adults in the United States report supporting organ donation, yet only about half are registered as organ donors. Small but significant differences in support for organ donation and registration as an organ donor exist among certain racial and ethnic groups. Factors influencing support for organ donation are relational ties, religious and cultural beliefs, family influence, beliefs about body integrity after death, prior experience with the health care system, and knowledge about organ donation. Several educational programs addressing these factors and targeted to populations with low organ donation rates have been conducted in community and church settings, and have been variably successful in improving knowledge and positive perceptions about organ donation and intent to donate.

Conclusion. Although the number of organ donors and transplants has grown over the last two decades, the need for donated organs still far exceeds the number available for transplantation. This disparity is especially true for certain racial and ethnic minorities that make up a larger proportion of the transplant waiting list compared to their relative proportion among organ donors. Educational programs that address identified factors influencing attitudes toward organ donation and targeted to populations with historically low organ donation rates have been developed to improve donation. Those that have been successful should be continued and expanded to improve organ donation rates among populations most in need. In addition to targeted educational programs, successful non-targeted educational programs and other approaches should be continued as well.

REPORT OF THE COUNCIL ON SCIENCE AND PUBLIC HEALTH

CSAPH Report 2-I-17

Subject: Targeted Education to Increase Organ Donation
(Policy D-370.984)

Presented by: Robert Gilchick, MD, MPH, Chair

Referred to: Reference Committee K
(L. Samuel Wann, MD, Chair)

1 INTRODUCTION

2
3 Policy D-370.984, “Targeted Education to Increase Organ Donation,” asked:

4
5 That our American Medical Association study potential educational efforts on the issue of
6 organ donation tailored to demographic groups with low organ donation rates.

7
8 This report responds to Policy D-370.984 by reviewing current organ donation statistics, attitudes
9 about donation, disproportion between those needing a transplant and the organs available, factors
10 influencing the decision to designate oneself as a donor, and educational interventions targeted to
11 segments of the population with historically low rates of organ donation. Other factors affecting
12 organ donation rates, including mandated choice and presumed consent for donation of cadaver
13 organs, as well as novel models for living donation, have been discussed in Board of Trustees
14 Reports 13-A-15 and 15-A-12.^{1,2}

15 16 METHODS

17
18 Literature searches were conducted in the PubMed database for English-language articles published
19 between 2007 and 2017 using the search term “organ donation,” with the terms “minority,”
20 “religion,” “education,” and “barriers.” A Google search was conducted using the same search
21 terms. Additional articles were identified by manual review of the references cited in identified
22 publications. The Health Resources and Services Administration Organ Donation and
23 Transplantation and Organ Procurement and Transplantation Network websites and the United
24 Network for Organ Sharing website also were consulted.

25 26 ORGAN DONATION STATISTICS AND ATTITUDES

27
28 Donated organs and tissues for transplantation are most often obtained from deceased donors,
29 referred to as deceased organ donation. Deceased organ donors can donate kidneys, liver, lungs,
30 heart, pancreas, and intestines.³ In addition to these organs, tissues such as heart valves, skin, bone,
31 and tendons; corneas; and face and hands can be donated after death.³ Approximately 90% of organ
32 donations are from deceased donors; the remaining donations are from living donors.⁴ Organs
33 donated by living donors include one of two kidneys, one of two lobes of the liver, a lung or part of

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1 the lung, part of the pancreas, and part of the intestines. Tissues donated by living donors include
 2 skin, bone, bone marrow cells and umbilical cord blood cells, amnion (donated after childbirth),
 3 and blood.⁵ More than 33,000 transplants were performed in 2016.⁶ Kidney and liver transplants
 4 made up the vast majority of organs transplanted (approximately 58 and 23 percent, respectively).
 5 Less common transplants were heart (9 percent), lung (7 percent), kidney and pancreas (2 percent),
 6 pancreas (0.7 percent), intestine (0.5 percent), and heart and lung (0.05 percent).⁴

7
 8 Organ and tissue donation in the United States is voluntary. Individuals wishing to donate their
 9 organs after death “opt in” by documenting their desire. Deceased organ donation registration is a
 10 state process; individuals can sign up online with the state registry or through a state’s Department
 11 of Motor Vehicles. When the person’s preferences are not documented or known, the next of kin
 12 may decide to allow organs to be harvested for transplantation after death.³ More than 130 million
 13 adults in the United States (approximately 54% of the population) are registered as organ and tissue
 14 donors.⁴

15
 16 Living organ donation is not administered through state or other government programs. Rather, it
 17 most often occurs in the form of directed donation, in which the donor names a specific person to
 18 receive the organ or tissue, usually a biological relative or a biologically unrelated person with a
 19 personal or social connection (spouse, significant other, friend, or acquaintance).⁷ In non-directed
 20 donation, the living organ donor does not name a recipient. Those wishing to be non-directed
 21 donors can do so by contacting a designated Organ Procurement and Transplant Network (OPTN)
 22 transplant center, or by contacting the United Network for Organ Sharing (UNOS).⁷

23
 24 A 2012 survey of a nationally representative sample of US adults, administered by the Health
 25 Resources and Services Administration (HRSA), examined organ donation attitudes and behaviors.
 26 More than 95 percent of respondents supported or strongly supported the donation of organs for
 27 transplantation.⁸ Small but significant differences in support exist among racial and ethnic groups.
 28 Approximately 95 percent of those categorizing themselves as White, Asian/Pacific Islander, or
 29 Hispanic support or strongly support donation, while approximately 92 percent of Native
 30 Americans and 87 percent of African Americans support or strongly support donation.⁸ Despite
 31 strong support for organ donation, the survey indicated that fewer people took steps to register as
 32 organ donors; only 60 percent of respondents with a driver’s license reported that they had granted
 33 permission for organ donation on their driver’s license.⁸ Racial and ethnic differences were
 34 apparent on this measure as well; 65 percent of White, 56 percent of Asian/Pacific Islander, 47
 35 percent of Native American, 44 percent of Hispanic, and 39 percent of African-American
 36 respondents with a driver’s license reported that they had granted permission for organ donation on
 37 their license.⁸

38
 39 **ORGAN DONATION NEEDS**

40
 41 Although the number of both donors and transplants has been growing slowly over the last two
 42 decades, the need for donated organs far exceeds the number available for transplantation. Nearly
 43 120,000 people are on the national transplant waiting list, with the vast majority (81 percent)
 44 waiting for a kidney.⁴ Only about three in 1,000 registered donors actually become donors after
 45 death. This is due to a number of criteria that must be met for a donor organ to be appropriate for
 46 an intended recipient (the “matching” process). These include blood and human leukocyte antigen
 47 (HLA) type, body size, severity of the recipient’s medical condition, severity of donor’s pre-death
 48 medical condition, length of time on the waiting list, distance between the donor’s and recipient’s
 49 hospitals, and the availability of the recipient.⁹

1 The proportion of racial and ethnic minority patients on the waiting list is higher than the
2 corresponding proportion of racial and ethnic minorities who are donors.⁴ For example, African
3 Americans make up nearly 30 percent of patients on the waiting list, but only approximately 16
4 percent of donors are African American.⁴ Hispanics and Asians make up nearly 20 and 8 percent,
5 respectively, of patients on the waiting list, but only approximately 14 and 3 percent of donors are
6 Hispanics and Asians, respectively.⁴ This disparate representation on the transplant waiting list
7 exists partially because minority groups, specifically African Americans, are disproportionately
8 impacted by chronic conditions such as diabetes, heart disease, and hypertension, which often are
9 managed with transplants.^{10,11,12} Additionally, African Americans have more HLA polymorphisms
10 and enhanced alloreactivity, making the chance of finding a matching donor, especially among a
11 pool of donors that includes proportionally fewer African Americans, particularly difficult.^{10,12,13}
12

13 FACTORS INFLUENCING ORGAN DONATION

14
15 Irving et al.¹⁴ conducted a systematic review of studies that characterized factors influencing
16 attitudes toward deceased and living organ donation, and categorized the factors into several broad
17 themes:
18

- 19 • Relational ties: The needs of family members or friends appear to be more influential in the
20 decision to become a donor than those of strangers. Many study participants were willing
21 to donate an organ to a family member or friend even if they were not willing to donate to
22 someone they did not know.
23
- 24 • Religious beliefs: While some believe that organ donation aligns with the altruistic tenets
25 of their religion, others believe that donation is not consistent with their religion. For
26 example, some Islamic study participants interpret the Qur'an and traditional Islamic
27 literature as forbidding organ donation. Others believe that transplantation, and therefore
28 the facilitation of transplantation through organ donation, is "playing God." The most
29 common religious objection to organ donation was the need to maintain body wholeness to
30 enter the next life.
31
- 32 • Cultural beliefs: Cultural beliefs concerning health care and death and dying, often based
33 on superstition, are associated with lack of support for organ donation. For example, study
34 participants cited the belief among some cultures that discussing death could lead to one's
35 own death. Others believe that death is a private matter, that ancestral approval is needed
36 before organ donation, and that grieving rituals are disrupted by organ donation.
37
- 38 • Family influence: Family members' beliefs about organ donation often influence
39 individual beliefs. Study participants with one or both parents who object to organ
40 donation expressed reluctance to be donors themselves, and some participants believed that
41 they should seek permission from family members if they wanted to be donors. Other
42 participants believed that by designating themselves as organ donors, they were sparing
43 their family members difficult decisions after their death.
44
- 45 • Body integrity: Apart from religion, body integrity after death appears to influence support
46 for donation. Participants worried that family members would be traumatized about the
47 thought of their bodies being "cut up," and that organ donation would preclude an open
48 coffin at their funeral.
49

- 1 • Interaction with the health care system: A distrust of the organ donation system and
2 process, often based on negative experiences with the health care system, reduce support
3 for organ donation. Participants questioned the concept of “brain death,” and were
4 suspicious of health care providers making such a designation. Some believed that organ
5 donors would not receive proper care since health care personnel would only be interested
6 in harvesting their organs, or that donor bodies would not be treated with dignity and
7 respect. Opinions based on previous experience or interactions with the health care system
8 were more prevalent among study participants belonging to minority groups that have
9 historically experienced a sense of marginalization from the health care system.
10
- 11 • Knowledge about the organ donation process: A lack of knowledge about the organ
12 donation process is a barrier to donation. Study participants expressed the need for more
13 information before they could commit to donation, and a lack of awareness about where
14 such information could be obtained.
15

16 Across a number of studies assessing characteristics of those willing to donate, individuals who are
17 younger, are female, have higher educational levels and/or socioeconomic status, and have higher
18 knowledge about organ donation are generally more likely to have positive attitudes toward
19 donation and are more willing to donate.¹⁵ The HRSA organ donation attitudes and behaviors
20 survey found that the following attitudes were predictors of designating oneself as an organ donor:
21 placing low importance on body wholeness after death, family support for organ donation, being
22 receptive to receiving a transplant as a life-saving measure, an understanding that many people die
23 while on the transplant waiting list, and not believing the notion that physicians would be less
24 likely to save the life of a person who is a donor.⁸
25

26 Some factors influencing support for organ donation are more pronounced in certain racial or
27 ethnic groups than in others. For example, interviews with African Americans found the following
28 as predominant barriers: religious beliefs and misperceptions, distrust of the medical establishment,
29 fear of premature declaration of death if a donor card has been signed, and a preference among
30 African American donors for assurance that the organs will be given preferentially to African
31 American recipients.¹⁶ In Native Americans, the importance of traditional religious beliefs,
32 including the need to be buried with an intact body, is a barrier to deceased organ donation.^{17,18,19}
33 Among Hispanics, greater concern over body disfigurement and greater doubt that physicians do
34 all they can to preserve life before pursuing organ donation exist compared to non-Hispanic
35 whites.^{20,21,22}
36

37 It is unclear that religion itself is a consistent barrier to organ donation.^{10,20} The role of religion in
38 support for organ donation is often confounded by community and cultural norms.²⁰ In
39 international studies, Buddhists have reported objection to deceased organ donation based on the
40 religious belief that a person’s spirit remains in the body as long as the heart is still beating, even
41 though brain death has occurred.^{20,23} This is despite a central Buddhist tenet that honors persons
42 who donate their organs to save a life. Studies of Muslims have indicated that religious beliefs are a
43 barrier to organ donation, and in the United States, Muslims who demonstrate negative aspects of
44 religious coping (a psychological state in which individuals express an insecure relationship with
45 God and an ominous view of the world) are more likely to hold negative attitudes toward organ
46 donation.²⁴ However, other measures of Muslim religiosity are not correlated with organ donation
47 attitude, and many Muslims in the United States believe that donation is justified.²⁴ Among
48 Christians, non-Catholic Christians are more likely to report willingness to be organ donors than
49 are Catholic Christians.²⁰
50

51 TARGETED EDUCATIONAL INTERVENTIONS TO INCREASE DONATION

1
2 Given the significant need to increase the number of organs available for donation, educational
3 interventions are needed to improve willingness to donate. Ideal interventions include those that
4 address perceptions that influence the decision to donate and target populations most likely to hold
5 such perceptions.¹⁴ A systematic review of interventions to improve organ donor registration
6 among minorities found that educational interventions alone or combined with mass media
7 approaches (as opposed to mass media alone) were most effective.²⁵ Those that included strong
8 interpersonal components, were delivered by members of the local community in familiar
9 environments, and included immediate opportunities to register were important for improving
10 outcomes.²⁵ Others have emphasized culturally appropriate strategies to engage minority groups,
11 and comprehensive information about organ donation that can be easily obtained.¹⁴ A recent study
12 examining factors that may facilitate the willingness of African Americans to become organ donors
13 determined that improving knowledge about organ donation, particularly with regard to donor
14 involvement and donation-related risks, may be successful in increasing organ donation.²⁶

15
16 Examples of national, church-based, and community-based targeted educational interventions are
17 summarized below. It is important to note that although some interventions appear to have been
18 successful in improving knowledge and attitudes about organ donation, discussion of organ
19 donation with family members, and changing organ donor status, it is generally difficult to measure
20 intervention success because of concurrent programs that directly or indirectly affect organ
21 donation.²⁷ For example, policies aimed at motorcycle helmet use, health system transformation,
22 public health spending, smoking rates, and chronic disease affect the health of the donor pool,
23 which in turn could affect the number of organs available for donation.²⁷

24 25 *Nationally Targeted Interventions*

26
27 The National Minority Organ Tissue Transplant Education Program (MOTTEP) was created in
28 1991 with a mission to decrease the number of ethnic minority Americans on transplant waiting
29 lists.^{17,28,29,30} Fifteen national sites were funded to carry out community-based programs that
30 centered on approaches including community participation and direction to target specific
31 community differences; face-to-face presentations, especially to smaller audiences to foster
32 discussion; collaboration and partnerships with religious, social, and civic organizations; media
33 promotion of MOTTEP's message; dissemination of culturally sensitive and informative brochures,
34 videos, public service announcements, and other information; and comprehensive evaluation to
35 gauge effectiveness of the program.^{17,29,31} The number of organs recovered for transplantation from
36 African Americans increased more than 3-fold between 1991 and 2016, with some suggesting the
37 success is partially due to MOTTEP efforts.^{29,31,32}

38 39 *Church-Based Targeted Interventions*

40
41 Another educational program targeting African Americans, Project ACTS (About Choices in
42 Transplantation and Sharing), was a self-administered donation education intervention developed
43 with a focus on addressing religious barriers to donation and encouraging family discussion.³³ The
44 program consisted of materials distributed at churches that are taken home and reviewed
45 individually. The materials included a video hosted by a gospel choir with excerpts from individual
46 and family conversations about beliefs, attitudes, myths, misconceptions, and fears about organ
47 donation/transplantation; an educational pamphlet; a donor card; a National Donor Sabbath
48 pendant; and several additional items embossed with the project name and logo. Participants in the
49 program were 1.6 times more likely to have discussed, or be in discussion, with family members
50 about their organ donation wishes than those who had not participated in the program.³³ A revised
51 program, Project ACTS II, was designed to improve uptake by testing the intervention in individual

1 and group settings.³⁴ Participants in the revised program who viewed the video in a group setting
2 had a significantly greater increase in positive attitudes toward donation and beliefs than those who
3 were given the video to view at home.³⁴ It is thought that the group dynamic provided an
4 opportunity for active contemplation of donation-related beliefs, attitudes, and the act of
5 registration, and engaged people in a way that could not be attained by reviewing materials
6 individually.³⁴

7
8 A church-based intervention targeted to Hispanics entailed a 45-60 minute educational program,
9 created specifically for religious organizations, administered to participants in four Catholic
10 churches whose membership was predominantly Hispanic.³⁵ The program, led by a local organ
11 procurement organization and conducted in both English and Spanish, included factual information
12 about the need for organ and tissue transplantation, how the organ donation and allocation process
13 serves such a need, and discussion of religious misconceptions regarding organ donation. After the
14 intervention, significant increases in organ donation knowledge and positive perceptions regarding
15 organ donation were observed.³⁵ However, no change in intent to donate was observed.
16 Interestingly, both before and after the intervention, those whose families supported organ donation
17 were more likely to indicate intent to donate than those whose families did not support donation.
18 The study authors therefore suggest that education focused on family support is important in
19 improving intent to donate.³⁵

20
21 Other church-based education programs have not been successful. A peer-led program at
22 predominantly African American churches, in which a church member was trained to provide
23 educational sessions within the church, included the viewing of a video and discussions about
24 organ donation and the provision of brochures and flyers containing the web address of the donor
25 registry.³⁶ No statistically significant differences in organ donation attitudes or intent to donate
26 were observed following the intervention.³⁶ The study concluded that lack of pastoral support may
27 have influenced outcomes, and that participants misinterpreted the consent form to be involved in
28 the study as an affirmative indication that they wished to be organ donors.³⁶

30 *Community-Based Targeted Interventions*

31
32 A 2007-2012 community-based intervention targeting Hispanics resulted in an increase in consent
33 for organ donation.³⁷ Media messages were conveyed on television and radio, and culturally
34 sensitive educational programs were held at high schools, churches, and medical clinics in four
35 Southern California neighborhoods with a high percentage of Hispanic residents. Among those
36 targeted by the intervention, the consent rate for organ donation increased significantly from 56
37 percent before the intervention to 83 percent after the intervention.³⁷

38
39 A different approach has been to use peer-to-peer techniques to deliver health education messages.
40 This technique was employed in several Michigan hair salons, with hair stylists acting as lay health
41 advisors to improve organ donation among their African-American clients.³⁸ Stylists delivering the
42 intervention were asked to discuss organ donation at least twice with their clients. Following the
43 intervention, clients in the intervention group were 1.7 times more likely than those in the control
44 group (in which general health topics, but not organ donation specifically, were discussed) to report
45 positive donation status.³⁸

47 CURRENT AMA POLICY

48
49 The AMA has a number of policies related to improving organ donation. Regarding education,
50 AMA policy supports “state of the art” educational materials for the medical community and the
51 public that address the importance of organ donation and the need for organ donors (H-370.995, H-

1 370.996), development of effective methods for meaningful exchange of information to educate the
2 public about donating organs (H-370.959), implementation of UNOS recommendations for organ
3 donation (H-370.983), and the provision of educational materials by states and local organ
4 procurement organizations to attendees of driver education and safety classes (H-370.984).
5 AMA policy also encourages research on methods for increasing the number of organ donors in the
6 United States, including studies that evaluate the effectiveness of mandated choice and presumed
7 consent models for increasing organ donation (H-370.959); studies evaluating the use of incentives,
8 including valuable considerations, to increase living and deceased organ donation rates (H-
9 370.958); and pilot studies on promotional efforts that stimulate each adult to respond "yes" or "no"
10 to the option of signing a donor card. Ethical Opinion 6.1.4, "Presumed Consent and Mandated
11 Choice for Organs from Deceased Donors," describes the ethical challenges of presumed consent
12 and mandated choice models and emphasizes the need for education about organ donation.

13 14 CONCLUSIONS

15
16 Although the numbers of organ donors and transplants have grown over the last two decades, the
17 need for donated organs still far exceeds the number available for transplantation. This disparity is
18 especially true for certain racial and ethnic minorities that make up a larger proportion of the
19 transplant waiting list compared to their relative proportion among organ donors. Educational
20 programs that address identified factors influencing attitudes toward organ donation and targeted to
21 populations with historically low organ donation rates have been developed to improve donation.
22 Some have been successful at improving knowledge about organ donation, comfort in discussing
23 organ donation wishes with family members, and intent to donate; however, it is difficult to
24 determine the impact of the programs on donation because they do not occur in isolation from other
25 factors that may influence organ donation rates.

26
27 Non-targeted educational approaches have had success as well. For example, an organ donation
28 registration campaign in California consisting of intense public awareness using public service
29 announcements; news conferences; and community outreach in federal buildings, universities, and
30 libraries; combined with an online organ donor registration process at the Department of Motor
31 Vehicles, improved consent for donation from 47.5 percent before the campaign to 51 percent after
32 the campaign.³⁹ And direct mail campaigns, in which information about organ donation and a
33 request to join the state organ donor registry are mailed to residents, have been successful in
34 prompting both young adults and older adults to join organ donation registries.^{40,41}

35
36 Additionally, other approaches to improving organ donation rates should be explored. A 2015
37 analysis examined a number of state policies on organ donation, including first-person consent
38 laws, donor registries, dedicated revenue streams for donor recruitment activities, population
39 education programs, paid leave for donation, and tax incentives, and found that only revenue
40 policies to promote organ donation had any effect on organ donation and transplantation.²⁷ These
41 revenues can be used on funding for outreach campaigns and educational programs that incorporate
42 elements that appear to be most successful in increasing intent to donate. Others have proposed that
43 financial incentives in the form of a contribution to a donor's retirement fund, an income tax credit,
44 a tuition voucher, or a posthumous funeral benefit would be far more effective at increasing the
45 donor pool than educational approaches.⁴²

46
47 The Council on Science and Public Health supports continued implementation of targeted
48 educational programs that have shown promise in increasing intent to donate, and encourages
49 further study of other approaches that may be successful.

50 51 RECOMMENDATIONS

1

2 The Council on Science and Public Health recommends that the following statements be adopted
3 and remainder of report filed.

4 1. That Policy H-370.959, "Methods to Increase the US Organ Donor Pool," be amended by
5 addition to read as follows:

6 In order to encourage increased levels of organ donation in the United States, our American
7 Medical Association: (1) supports studies that evaluate the effectiveness of mandated choice
8 and presumed consent models for increasing organ donation; (2) urges development of
9 effective methods for meaningful exchange of information to educate the public and support
10 well-informed consent about donating organs, including educational programs that address
11 identified factors influencing attitudes toward organ donation and targeted to populations with
12 historically low organ donation rates; and (3) encourages continued study of ways to enhance
13 the allocation of donated organs and tissues. (Modify Current HOD Policy)

14

15 2. That Policy D-370.984 be rescinded, having been accomplished through this report. (Rescind
16 HOD Policy)

Fiscal note: Less than \$1000

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