



**“SHARE  
YOUR LIFE.  
SHARE  
YOUR  
DECISION.”**

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How the Campaign to Increase  
Organ Donations Provides a Model  
for Public Health Awareness Efforts



Coalition for  
Clinical Trials  
Awareness

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# INTRODUCTION

Public health awareness campaigns in the United States have been highly successful at educating, increasing awareness, and mobilizing the general public to act in ways that benefit their fellow citizens and society as a whole.

One of the first public awareness initiatives stemmed from the National Foundation for Infantile Paralysis, now the March of Dimes foundation. In 1938 President Franklin D. Roosevelt launched a public awareness campaign with the help of radio broadcasts that asked Americans to send their pocket change through “a march of dimes to reach all the way to the White House.”<sup>1</sup> This campaign soared, raising more than \$18.9 million in 1945 for polio research, patient support, and public awareness of the disease.<sup>1</sup>

The campaign laid the foundation for dozens of subsequent federally supported public health

awareness campaigns. Those include today’s The Heart Truth, Go4Life, Screen for Life, and Know Stroke campaigns. But one of the largest, best known and arguably most successful public awareness initiatives has advanced the need for organ donations.

The federally supported organ donation effort sparked conversations about donating “the gift of life” in homes and workplaces across the country. Awareness efforts on organ donation continue today, and the federal government’s model remains applicable for 21st Century public health challenges.

Thus, as limited health care dollars force today’s policymakers to pinpoint the highest public health priorities and most effective approaches, policymakers might reflect on the highly successful organ donation initiative. It is both inspiration and archetype for meeting today’s high-priority public health needs.



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# ORGAN TRANSPLANTATION DONATION: A NATIONAL CHALLENGE



Increasing organ donations **required public health officials to educate the American public**—not just on the need for organ donors but also on the immense value that donation provided for patients.

Decades of medical advancements made transplanting organs and suppressing the immune system to decrease the risk of organ rejection possible. Thus, organ transplantation offered fresh hope for patients beginning in the 1980s. Yet as organ transplantations became more successful, America faced a new problem: finding enough donors to help patients in need.

Although public awareness of the need for organ donations existed, it did not necessarily spur Americans to action. According to one study, the overwhelming majority of Americans supported organ donation.<sup>2</sup> However, a second

study found that 84% of people surveyed who knew about organ donation were aware of the donor card, but only 20% of them were actual registered donors.<sup>3,4</sup>

Thus, increasing organ donations required public health officials to educate the American public—not just on the need for organ donors but also on the immense value that donation provided for patients. It also required eliminating certain barriers, specifically: misinformation about applicable religious beliefs, lack of procedural transparency, and logistical and economic factors.

## Barriers to Organ Donation

Barrier	Description
Religious Beliefs	<ul style="list-style-type: none"><li>• All major religions support organ donation. Yet many people cite religious beliefs as the basis for their hesitancy or refusal to become an organ donor.<sup>5</sup></li><li>• One study found that the majority of people have an incorrect perception of what their religion says about organ donation.<sup>6,8</sup></li></ul>
Lack of Procedural Knowledge and Transparency	<ul style="list-style-type: none"><li>• Some healthcare providers lacked knowledge of organ procurement procedures, and some donation program representatives lacked transparency; both instilled mistrust in potential donors.</li><li>• This barrier was further exacerbated by confusion about the definition of brain death.</li><li>• Donors and their families could fear that organ procurement goals would interfere with attempts to save the donor's life.</li></ul>
Logistical and Economic Challenges	<ul style="list-style-type: none"><li>• For living donors (eg., kidney donation), logistical and economic variables also present challenges.</li><li>• Taking time off of work and arranging child or elder care during the recovery process present logistical challenges. In addition, living donors incur between \$5,000 and \$20,000 in non-medical costs, including transportation, lodging, childcare, and lost wages.<sup>9</sup></li><li>• These expenses can burden families and discourage individuals from becoming organ donors.<sup>9</sup></li></ul>

# “SHARE YOUR LIFE. SHARE YOUR DECISION.”

## CAMPAIGN

Helping potential donors to overcome these barriers, and raising public awareness in general, fell to individual organizations such as the National Kidney Foundation and the American Medical Association in the early days of organ transplantation. But despite these organizations’ noble attempts, the number of organ donors remained low until the Coalition on Donation, the Advertising Council, Inc. (“Ad Council”), Congress, and the U.S. Department of Health and Human Services (HHS) combined their efforts to bolster public awareness and increase the number of organ donors.

The National Coalition on Donation, now Donate Life America, was established by the transplant community in 1992 as a non-profit alliance of various organizations, coalitions, and local affiliates that was funded by public donations, corporations, and affiliated organizations. The coalition’s hallmark inaugural initiative was to encourage registered organ donors to share their decision with their families, recognizing that families are often the gatekeepers of their loved ones’ organs.



“This is a message that **all Americans** need to hear and understand.”

HHS SECRETARY DONNA SHALALA

This effort was based on a Gallup poll that indicated that almost all Americans would consent to donate their loved ones’ organs if they knew of their decision beforehand.<sup>10</sup> However, only 50% of these people would consent if they did not know their family member’s wishes.<sup>10</sup> Further, only about half of Americans who wanted to donate had told their families.<sup>10</sup>

This research demonstrated that simply signing an organ donor card was not enough. To ensure that donors’ wishes were honored, they needed to share their decision with their family members so the donation could go through at the time when it mattered most.

In July 1994, the Coalition on Donation and the Ad Council confronted this challenge head-on by launching the “Organ and Tissue Donation: Share your life. Share your decision.” campaign. The campaign sought to share a single, common, and visible message to raise public awareness of organ donation, encourage people to sign organ donor cards, and spark positive conversations about organ donation among families. The goal was to bring organ donation into mainstream conversations so that individuals felt comfortable discussing their decision to be an organ donor while they were still in good health.

Recognizing organ donation as an important public policy issue affecting a large segment of the population, the federal government offered support by partnering with the Coalition on Donation and the Ad Council in the “Share your life. Share your decision” campaign. In 1997, Vice President Al Gore and HHS Secretary Donna Shalala launched the National Organ and Tissue Donation Initiative, which adopted “Share Your Life. Share Your Decision” as its slogan. Over the next several years, Congress, HHS, the Coalition on Donation, and the Ad Council employed various strategies to promote this shared message.



# MEDIA & PUBLIC OUTREACH



The “Share your life. Share your decision.” campaign utilized various media strategies, including **television, radio, and print advertisements to increase public awareness** and spark conversations regarding organ donation.



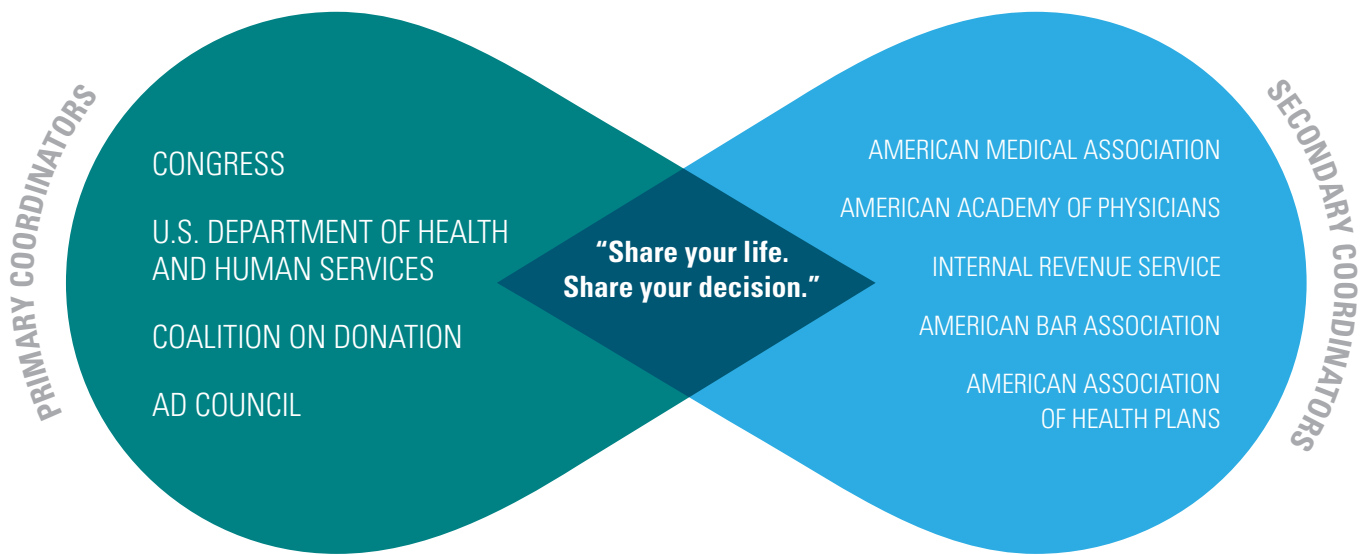
The “Share your life. Share your decision.” campaign put this information into action, utilizing various media strategies, including television, radio, and print advertisements to increase public awareness and spark conversations regarding organ donation. In an effort to drastically increase the number of organ donors, the campaign applied an aggressive approach; it directly addressed the issue of organ donation, sometimes using shock value to convey its message. Comprehensive, federally-sponsored research informed campaign efforts. In 1998, HHS hosted a national conference to identify the most effective strategies to increase the number of organ donors. Building upon that effort, HHS allocated \$5 million in grants through its Health Resources and Services Administration in 1999 for researching and evaluating public awareness strategies.<sup>11</sup> One television advertisement, for example, featured a person falling into a frozen lake, with the viewer in the place of the rescuer. The voiceover explains “To be a donor, even if you’ve signed something, you must tell your family now, so they can carry out your decision later. Otherwise, it’s like throwing a 12-foot rope to someone who’s 15 feet away.”

Additional media tactics included celebrity endorsements. One of the most popular and well-known advertisements for the initiative was the Michael Jordan campaign. This effort, which targeted children and sports fans, distributed more than 12 million organ donor cards and more than a million posters featuring Michael Jordan’s image.<sup>12</sup>



The U.S. Postal Service also supported organ donation awareness by issuing the Organ and Tissue donation commemorative stamp in 1998. The stamp featured two intertwined people with hands on each other’s hearts. This stamp sought to highlight organ donation as a gift of life and to increase the number of organ donors by raising awareness.

# PARTNERSHIPS



Recognizing the value of partnerships, the federal government teamed up with over a dozen public, private, and volunteer organizations in addition to the Coalition on Donation and Ad Council to promote the “Share your life. Share your decision.” campaign. In addition to various medical and legal organizations, many faith, minority, business, government, and media organizations also offered their support in encouraging organ donors to discuss their decision with their families.

For example, in response to a 1991 study that revealed that people expected to find organ donor cards and materials at health care facilities, but such facilities did not necessarily have these materials on hand, the American Medical Association and the American Academy of Physicians worked to provide physicians with donation materials and encouraged physicians to talk about organ donation with their patients.<sup>13</sup>

In addition, the Internal Revenue Service partnered with HHS to distribute organ donor cards and information to the public with income tax refunds. With the Health Insurance Portability and Accountability Act of 1996, Congress directed the Secretary of the Treasury “to the extent practicable, to include certain organ and tissue donation information with income tax refund payments.”<sup>14</sup>

The American Bar Association offered further support for the campaign by encouraging its members to discuss clients’ organ donation wishes during the preparation of wills and estates. In addition, the American Association of Health Plans encouraged insurance providers to provide organ donation materials to members. Finally, media organizations played a large role in this campaign, donating over \$33 million in television, radio, and print advertisements in the first year of the campaign and over \$47 million in advertisements in the second year.<sup>15</sup>



With the passage of the **Health Insurance Portability and Accountability Act of 1996**, Congress allowed information about organ and tissue donation to accompany federal tax refund payments.

# EFFECTIVENESS



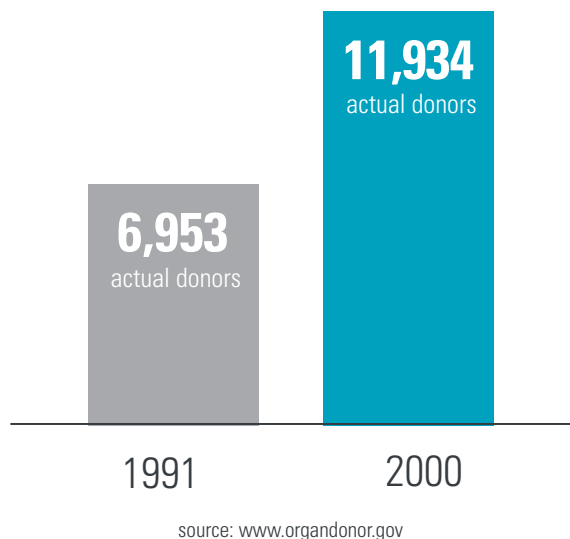
Thanks in large part to efforts by Congress, HHS and the Coalition on Donation, today **more than 47% of Americans** are registered as organ donors.

Thanks to the combined efforts of the federal government, Coalition on Donation, Ad Council, and countless other organizations, the number of registered organ donors increased by 5.6% in the first year of the campaign.<sup>16</sup> This change was the first significant increase in the number of organ donors in three years.<sup>16</sup> A potential reason for this increase was the effectiveness of the media advertisements. According to one study, 59% of respondents were exposed to the “Share your life. Share your decision” television or radio commercials.<sup>17</sup>

This campaign also played a significant role in mobilizing the public to act. In a four-year study that tracked the success of the “Share your life. Share your decision” campaign, researchers found that the proportion of individuals who signed an organ donor card increased significantly.<sup>17</sup> In just two years, the proportion of registered organ donors increased by 22 percent.<sup>18</sup> This suggests that the campaign had a significant impact on mobilizing individuals who positively viewed organ donation to act on their beliefs and register as donors.

Today, more than 120 million Americans (approximately 47% of the total U.S. population) are registered as donors.<sup>19</sup> Efforts to register more donors continue, but these statistics represent a monumental victory for the organ donation campaign that is in large part due to the “Share your life. Share your decision” initiative. Beyond these numbers, though, this campaign empowered non-profit organizations and provided them with the funding, infrastructure, and momentum to promote organ donation.

## Increase in Organ Donors Over Time



The partnership between the Coalition on Donation, the Ad Council, Congress, and HHS illustrates the value of public and private organizations working together to disseminate a single comprehensive message to achieve shared public health goals.



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# IMPLICATIONS FOR 21<sup>ST</sup> CENTURY PUBLIC HEALTH PRIORITIES

One initiative that could likewise benefit from a federally funded public awareness campaign is clinical trials awareness. Like organ donation, participation in clinical trials is an altruistic act that benefits society without the promise of individual benefit. Because clinical trials are an essential component of medical discovery and the approval of new therapies, awareness of the societal benefits of clinical trials and participation is an important public policy issue that affects all Americans and is crucial to ensuring patient access to new medical therapies.

Despite the importance of clinical trials, however, only 10% of Americans have enrolled in a trial. Eleven percent of clinical trial sites fail to enroll a single patient.<sup>20-21</sup> These statistics result from lack of public awareness and understanding of clinical trials. In a study of 1,000 healthy adults, 40% of survey participants did not understand clinical trials, though 32% indicated that they would be very willing to participate in a cancer clinical trial if asked to do so.<sup>22</sup>



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In addition to the lack of awareness, Americans don't perceive clinical trials as being important. In a 2006 survey that asked a group of 900 people which group they thought made a greater contribution to society, 40% said organ donors, 29% said blood donors, 10% said people who raise money for charity by running in a race. Only 9% said people who participate in clinical trials.<sup>23</sup> This effort also struggles with

a lack of communication from those who have participated in clinical trials. Statistics show that 88% of clinical trial participants rarely or never talk about clinical research after the trial ends.<sup>24</sup>

The Institute of Medicine (IOM) has recognized the “increasing difficulty of recruiting and retaining an appropriate human subject population for specific clinical trials” as a serious problem.<sup>25</sup> In 2012, the IOM published a summary of its workshop entitled *Public Engagement and Clinical Trials*, in which participants identified barriers to clinical trial participation that can be overcome with a public awareness campaign. The barriers include physicians' and patients' lack of awareness of available clinical trials, lack of public awareness of the societal benefits of clinical trials, and the difficulty faced by physicians and patients to remain impartial towards treatment preference.

An opportunity therefore exists for a federal awareness campaign to facilitate medical discovery and improve patient access to therapies by increasing clinical trial participation. Given the similarities between organ donation and clinical trials, a campaign similar to the organ donation initiative would likely be effective in promoting clinical trials awareness and participation.





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### Similarities between Organ Donation and Clinical Trials as Large-scale Public Health Challenges

Factor	Organ Donation	Clinical Trials
Issue, Impact are National in Scope	✓	✓
Initial Level of Public Participation	< 20%	10%
Target Population Demographics People of all races, genders, and ages	✓	✓
Effect of Low Participation Public health suffers Medical research and discovery suffer	✓	✓ ✓
Benefit to Individuals and Society as a Whole	✓	✓
Barriers Religious Beliefs Family Perception Mistrust in procedures Logistical and economic factors Lack of public awareness Lack of maintaining treatment preference neutrality	✓ ✓ ✓ ✓ ✓	✓ ✓ ✓ ✓ ✓

# CONCLUSIONS

The “Share your life. Share your decision.” organ donation campaign demonstrates that government involvement and partnership with non-profit organizations in public health initiatives can be considerably effective. Although the efforts of individual organizations were important in establishing the need for organ donation and launching grassroots awareness efforts, the federal government’s assistance in the “Share your life. Share your decision.” campaign was required to make a significant, concerted, and meaningful impact on organ donation.

The multi-faceted strategic approach used in this campaign was particularly successful and provides an exemplary model for a public health awareness campaigns focused on increasing clinical trials participation.

## ABOUT THE AUTHOR

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## ABOUT CCTA

The Coalition for Clinical Trials Awareness is a nonprofit group of health care providers, patient advocates, medical researchers and industry and government stakeholders working together to increase public awareness about the importance of clinical trials participation.

To learn more, visit [www.CCTAwareness.org](http://www.CCTAwareness.org).

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# APPENDIX BACKGROUND ON ORGAN TRANSPLANTATION

The 1950s and 1960s were marked by exciting and transformative advancements in organ transplantation. For the first time in history, physicians successfully transplanted kidneys, lungs, livers, hearts and pancreases from deceased donors. Despite these advancements, organ rejection remained a significant risk that undermined the practicality and feasibility of transplants. However, in 1976, scientists discovered cyclosporine's ability to decrease the risk of organ rejection by suppressing the immune system. After it gained FDA approval in 1983, cyclosporine was directly responsible for increasing the long-term survival rate of transplant recipients and the overall success of organ transplantation.

With the ability to perform more successful transplants came the need for a centralized system and standardized procedures for organ procurement and allocation. Prior to the 1980s, individual hospitals and local organ procurement organizations managed all aspects of organ recovery and distribution. This lack of centralization and standardization made organ procurement and allocation subject to unfair bias and variable standards and criteria. In response to this issue, the National Organ Transplant Act of 1984 created the Organ Procurement and Transplantation Network (OPTN), which presides over the Unified Network of Organ Sharing (UNOS). UNOS is directly responsible for managing the national registry of potential donors and recipients and ensuring compliance with organ allocation policies.



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