



## Organ donation education initiatives: A report of the Donor Management Task Force ☆☆☆☆



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### ABSTRACT

**Purpose:** It is essential that hospitals and health professionals establish systems to facilitate patients' organ donation wishes. Donation education has been neither standardized nor systematic, and resources related to donation processes have not been widely accessible. This report describes 2 free, publicly available educational resources about the organ donation process created to advance the mission of basic education and improve donation processes within hospitals and health care systems.

**Materials and methods:** Members of the Donor Management Task Force of the Organ Donation and Transplantation Alliance (the Alliance) and the Health Resources and Services Administration of the US Department of Health and Human Services convened annually in person and by teleconferencing during the year to develop 2 educational vehicles on organ donation.

**Results:** Two educational products were developed: the Organ Donation Toolbox, an online repository of documents and resources covering all aspects of the donation process, and the Educational Training Video that reviews the basic foundations of a successful hospital donation system.

**Conclusions:** There is a need for more research and education about the process of organ donation as it relates to the medical and psychosocial care of patients and families before the end of life. The educational products described can help fill this critical need.

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## 1. Introduction

At the end of the 20th century, the organ donation system in the United States was hindered by significant variability in performance and outcomes [1]. The transplantation waiting list was (and still is)

growing at a pace that exceeded the availability of donated organs [2]. In response to this crisis, the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services organized the first Organ Donation Breakthrough Collaborative in 2003 [3].

Most potential organ donors are concentrated in a relatively smaller proportion of the nation's hospitals (half of eligible donors in 206 hospitals) [4]. Representatives of 300 hospitals with the highest donor potential and the nation's 58 organ procurement organizations (OPOs) participated in a nationwide initiative to establish, share, and spread highly effective donation practices. From 2003 to 2009, major advancements in organ donation occurred: the national conversion rate (proportion of eligible donors who become actual donors) increased from 54% to 74%, and the rate and frequency of donation after circulatory determination of death (DCDD) increased from 4.2% to 11.5% [5]. During that same period, an increase in the overall number of US organ donors and an increased number of organs transplanted occurred [1]. Subsequently, HRSA and the Organ Donation and Transplantation Alliance (the Alliance) formed a working group to advance the mission of improving national organ donation practices and education. This Donor Management Task Force (DMTF) first convened in August 2010 in

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☆☆ All authors are members of the Donor Management Task Force and the Donor Management Leadership Council of the Organ Donation and Transplantation Alliance.

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Philadelphia. In 2015, the DMTF evolved into the Donor Management Leadership Council [6].

## 2. Donor Management Task Force

### 2.1. Goals and purpose

Experts advocate providing the option of donation as a routine part of medical care for patients at the end of life [7], a recommendation supported by the fact that more than 50% of adults in the United States are registered organ donors [8], and more than 75% of families authorize organ donation in the absence of such prior documentation (Organ Procurement and Transplantation Network data, January 2008–June 2010). The Task Force goals were to (1) advance scientific knowledge that influences organ donor management practices; (2) promote critical care and quality improvement practices that optimize organ viability and number of organs transplanted from each donor; (3) assure death by neurologic criteria is pronounced in a timely manner; (4) assure each donation occurs using the most appropriate donation pathway: donation after neurologic determination of death or DCDD.

### 2.2. Participants

The DMTF consisted of a diverse membership of representatives from the 11 regions of the national Organ Procurement and Transplantation Network. Participants from highly performing donation service areas (DSAs) included intensivists (medicine, surgery/trauma, pediatrics, and anesthesiology), neurologic and transplant specialists, and OPO representatives. At-large Task Force members represented national organizations such as the American Academy of Neurology, the American Association of Critical Care Nurses, the American Society of Transplantation, the Association of Organ Procurement Organizations, and the Society of Critical Care Medicine.

### 2.3. DMTF subcommittees

The DMTF was divided into 3 subcommittees, each tasked with addressing a critical component of the organ donation process. The Scientific Knowledge subcommittee focused on promoting donor management research. The DSA Best Practices subcommittee was tasked with developing processes using existing policies and practices or creation of new guidelines to improve the quality of care provided from hospital admission through the donation. The Declaration of Death subcommittee was charged with promoting timely declaration of death, bringing consistency to the practices of declaration of death by neurologic criteria, and developing strategies to preserve the possibility of donation by maintaining organ viability when the possibility of neurologic death was not certain or had not yet occurred.

### 2.4. Education initiatives and products

The DSA Best Practices subcommittee identified 2 critical areas of need: (1) a central repository of information for health care and OPO professionals involved in the donation process that could be easily accessed during the care of organ donors and (2) the paucity of basic education about organ donation in medical and nursing schools, residencies, and health care organizations [9–10] that focused on donation and the detailed processes involved in the care of potential organ donors from hospital admission up until recovery of organs for transplantation. To directly address these respective needs, 2 projects were developed and undertaken, the Organ Donation Toolbox and an educational training video.

The challenge creating these initiatives was organizing and presenting educational content in a field where limited scientific evidence is available to support strong recommendations. Two strategies were used to achieve this goal. First, best practices were accumulated from

experts with significant experience in the donation field and from highly performing centers that participated in the national collaborative meetings. The validity of using the identified practices was indirectly supported by the fact that conversion rates and DCDD frequency increased substantially as a result of the combined efforts of such experts and the work produced by the collaboratives. Second, the DMTF members used an indirect needs assessment by reviewing the requests for information derived from the HRSA/Donation-Transplantation Community of Practice listserv. Frequent requests through the listserv for dependable protocols and policies generated a collection of high-yield materials from around the country. The distribution of many “tried and true” processes, procedures, and protocols formed the foundation of the Toolbox. The DMTF members also solicited examples of best practices, reviewed published materials, and used personal experience to collate the resulting content. Committee members and Toolbox editors reviewed and vetted the materials in each folder, and group consensus was used to make final determinations for inclusion.

### 2.5. Organ Donation Toolbox

The Organ Donation Toolbox (<http://organdonationalliance.org/organ-donation-toolbox/>) began development in May 2011 and was officially unveiled at the 2012 National Learning Congress for Organ Donation and Transplantation. It includes documents describing best practices and other resources for hospitals, health care providers, and OPOs to use during the care of potential organ donors. Some key categories of the Toolbox are seen in Fig. 1. Each folder contains a wide variety of documents relevant to that section, including scientific publications, hospital policies and protocols, OPO publications, photos, and references for further reading. Readers are encouraged to explore the Web site to view or download content.

A critical element to assure ongoing relevance and reliability of the toolbox was development of a process for ongoing content review. Each toolbox subject folder was compiled by a health care professional(s) with expertise in that field. The editor reviews, edits, and updates the contents of each folder annually allowing the toolbox to become a dynamic evolving resource.

The Toolbox is currently administered and maintained by the Alliance. It continues to be used by a large number of health care professionals.

### 2.6. Educational training video

The educational training video was intended to introduce important aspects about organ donation to a multidisciplinary spectrum of health care professionals. The goal was to explain the donation process beyond its scientific aspects and highlight the psychosocial context in which patients and their families participate in donation. It was critical to emphasize that successful donation is the result of complex interpersonal and medical interventions occurring throughout a patient's hospital course, not just at the end of life, because missed opportunities to facilitate a patient's donation wishes are often the result of events starting with the earliest interactions between the health care team, patient, and family. To that end, the video highlights personal experiences of donor families, transplant recipients, and medical professionals that illustrate the best practices determined through the methodology previously described.

Content focused on 4 areas: (1) the need for organ donation, (2) the importance of honoring a patient's decision to donate, (3) the process of donation from hospital admission to organ recovery, and (4) how donation helps donor families. A video production company was contracted through the Alliance. Video segments were scripted, reviewed, and refined, and “Key Learning Points” were highlighted to emphasize critical content. A posttest was created, and approval for online CME and CEU credits was obtained. The final product “Saving and Healing Lives Through Organ and Tissue Donation: Continuing our Healthcare Mission,” is a 30-minute video released in October 2014 and posted on

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