



Gift of Hope Organ & Tissue Donor Network Guidelines for Informed Consent for Organ and Tissue Donation

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Tissue (defined as bone, connective tissue surrounding bone, vessels, heart valves, skin and eyes/corneas) and organ transplants have become an important and growing part of modern medical practice. Advances in medical science have made it possible for millions of Americans to receive these lifesaving and life-enhancing gifts.

None of this would be possible, however, were it not for the thousands of donors and donor families who give their organs and tissues in a selfless act of generosity.

In an effort to ensure that families are provided with sufficient/appropriate information about the donation and transplantation process, so that their decision to donate is an informed consent, Gift of Hope Organ & Tissue Donor Network has developed this position paper on Guidelines for Informed Consent.

At the most basic level, the following principles must guide the consent process:

- Information concerning the donation should be presented in language and terms that are easily understood by the consenting person.
- The consent should be obtained under circumstances that provide next-of-kin with an opportunity to ask questions and receive informative responses.
- A copy of the signed consent form should be shared with the next-of-kin, and information should be provided regarding ways to reach Gift of Hope following donation.
- The person seeking the consent should be trained to appropriately answer any questions about the donation process that the consenting person may have.
- Coercion should not be exerted in any manner, nor monetary inducement offered to obtain consent for donation.

The following list of “Guidelines of Informed Consent” is intended to highlight the information considered desirable to informed decision-making by a family member or other legally authorized person who is being approached for consent to organ and/or tissue donation. This information, whether communicated verbally or included on consent forms, is not intended to preempt any applicable federal, state, or local laws or regulations. It is intended to *guide* Gift of Hope designated requesters in making donation requests.

Guidelines for the Consent Discussion

- Confirm the potential donor's next-of-kin relationship and right to authorize donation.
- Confirm the next-of-kin's understanding of the potential donor's condition.
- Describe the donation options available and the purposes/benefits of each, including saving and enhancing the lives of others, as well as research and education uses.
- Identify organs and/or tissues (including cells) that are being requested for donation in language that the next-of-kin can understand (with subsequent information provided on gifts recovered).
- Describe, in general, the recovery process, including but not limited to timing, necessary surgical procedures, relocation of donor if applicable, and contact information.
- Request for consent for removal of body to another location, if applicable.
- Explain that laboratory tests, including HIV testing, will be completed to determine the medical suitability of the donor, and to aid in ruling out the possibility of transmissible diseases.
- Explain that *every* family will be asked a lengthy series of questions that are extremely sensitive regarding the patient's medical and behavioral history. Explain that the completion of a medical and behavioral history is required by the United States Public Health Service to assist in identifying potentially transmissible diseases because laboratory testing alone cannot completely address the need to prevent disease transmission.
- Explain that the spleen, lymph nodes, and blood may be removed, and cultures may be performed for the purpose of determining donor suitability and/or used to determine compatibility of donor and recipient.
- Explain the need for access to the donor's relevant medical records, and that those medical records may be released to other parties directly involved in the procurement, transplantation, processing and distribution of the organs or tissues.
- Explain that costs related to the evaluation, recovery, preservation, and placement of the organs and tissues will not be charged to the donor family. However, while the recipient does not pay for the organ or tissue, there will be an eventual charge to the recipient for the costs of services related to the donation process, including

but not limited to laboratory testing, surgical recovery, and preparation of organs and tissues for distribution.

- Explain that the donation process may have an impact on the appearance and feel of the body. Generally, however, donation does not impact the family's ability to have an open-casket viewing.
- Describe any involvement by the medical examiner and/or coroner, including an explanation that an autopsy may be performed.
- Explain that all organs and tissues recovered are intended for medically therapeutic purposes and/or medical research and education. Tissues and organs donated through Gift of Hope are not intended for use in cosmetic surgeries.
- Explain that while Gift of Hope strives to make organs and tissues available through not-for-profit organizations, in order to provide life-saving and life-enhancing organs and tissues to everyone, it is sometimes necessary to work with for-profit organizations.
- Explain that the actual processes of organ and tissue donation differ in nature. While both organs and tissues are donated, recovered and tested, tissues are subject to a complexity of procedures including inventorying, processing, storing, maintenance, and delivery. It must be understood that in this lengthy, complex process some or all entities involved can financially profit for their services.
- Inform that Gift of Hope makes every effort to return tissues for use in the local community; however, if no local or national needs exist, tissues may be transplanted abroad.
- Offer an option to the person executing the consent to designate the person or people to receive follow-up information, or to request that no follow-up information be provided.