

❖ **THIS DOCUMENT** is intended to represent the rights and legitimate expectations of families of loved ones who die and who are (or may be considered) potential organ and/or tissue donors. This document is also intended to serve as a guide for services that are (or should be) offered to such families.

❖ **THE TERM "FAMILY"** identifies legal next-of-kin but is also intended to embrace other individuals who may have a significant relationship with a potential or actual organ and/or tissue donor, whether through biological, matrimonial, legal or affectional ties.

❖ **THE TERM "DONOR FAMILY"** identifies family members who may be or have already been approached to give consent for organ and/or tissue donation from the body of a loved one after death has occurred.

❖ **THIS DOCUMENT** does not address the situation of living persons who are contemplating or have consented to organ and/or tissue donation during their lifetime.

❖ **ALL EXPLANATIONS** mentioned in this document should be provided by a knowledgeable and sensitive person in a private, face-to-face conversation whenever possible in a manner suited to the family's needs. These explanations may need to be repeated or supplemented more than one time, and have to meet state and/or federal requirements and regulations.

The *Bill of Rights for Donor Families* has been officially endorsed by the following organizations:

- * American Association of Critical-Care Nurses
- * Association of Organ Procurement Organizations
- * Division of Transplantation, Health Resources & Services Administration, U.S. Department of Health & Human Services
- * National Donor Family Council
- * National Kidney Foundation
- * North American Transplant Coordinators Organization

This document was prepared by Charles A. Corr, PhD, Lucy G. Nile, MA, and the members of the 1994 Executive Committee of the National Donor Family Council (NDFC) of the National Kidney Foundation. Revised by the 2002 Executive Committee of the NDFC.

The mission of the National Donor Family Council is to enhance the sensitivity and effectiveness of the organ and tissue recovery process, to provide opportunities for families to grieve and grow, and to utilize the unique perspective of these families to increase organ and tissue donation.



National Donor Family Council
National Kidney Foundation
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03-60-0613

Bill of Rights

For
Donor
Families

Families have the right:

1. To a full and careful explanation about what has happened to their loved one, his or her current status, and his or her prognosis.
2. To be full partners with the health care team in the decision-making process about the care and support given to their loved one and to themselves.
3. To a full and careful explanation about how the (impending) death of their loved one was or will be determined with appropriate reference to the concepts of cardiac and/or brain death.
4. To be given opportunities to be alone with their loved one during his or her care and after his or her death occurs. This should include offering the family an opportunity to see, touch, hold or participate in the care of their loved one, as appropriate.
5. To be cared for in a manner that is sensitive to the family's needs and capacities by specially-trained individuals.
6. To be informed if their loved one had previously indicated an intent to donate organs and/or tissues and their family's responsibility to honor that decision.
7. To be given the opportunity to make organ and tissue donation decisions on behalf of their loved one, where appropriate and in accordance with applicable laws. This opportunity should be included in the normal continuum of care by the health care provider after death has been determined and the family has had sufficient time to acknowledge that death has occurred.

8. To receive information in a manner that is suited to the family's needs and capacities about the need for organ and tissue donation, the conditions and processes of organ and tissue donation and the implications of organ and tissue donation for later events, such as funeral arrangements, viewing of the body and related practices.
9. To be provided with time, privacy, freedom from coercion, confidentiality and (if desired) the services of an appropriate support person (e.g., clergyperson) and other resources (e.g., a second medical opinion, advice from significant others or the services of an interpreter for those who speak another language) which are essential to optimal care for the family.
10. To have opportunities to spend time alone with their loved one before and/or after the process of removing donated organs and/or tissues, and to say their 'goodbyes' in a manner that is appropriate to the present and future needs of the family, and consistent with their cultural and religious identity (e.g., asking the family if they want handprints, footprints, a lock of hair, etc.).
11. To be assured that their loved one will be treated with respect throughout the process of removing donated organs and/or tissues.
12. To receive basic written information from Organ Procurement Organizations (OPOs) and tissue banks either at the time of consent or in the days immediately following that decision. At a minimum, this written material should include a copy of the signed consent form(s), information on how the organs and tissues may be used, and instructions on how to follow up with the OPO or tissue bank in case concerns arise.

13. To receive timely information that is suited to the family's needs and capacities about which organs and/or tissues were or were not removed, and why.
14. To receive timely information regarding how any donated organs and/or tissues were used, upon request and whenever possible. If desired, families should be given an opportunity to exchange communications with individual recipients and/or recipient family members. Upon request, donor families should also be given accurate updates on the condition of the recipients.
15. To be assured that the donor family will not be burdened with any expenses arising from organ and/or tissue donation, and to be given assistance in resolving any charges that might be erroneously addressed to the family.
16. To receive ongoing bereavement follow-up support for a reasonable period of time. Such support might take the form of: the name, address and telephone number of a knowledgeable and sensitive person with whom they can discuss the entire experience; an opportunity to evaluate their experience through a quality assurance survey; free copies of literature about organ and tissue donation; free copies of literature about bereavement, grief and mourning; opportunities for contact with another donor family; opportunities to take part in a donor or bereavement support group and/or the services of a skilled and sensitive support person.

