

## *Bill of Rights for Donor Families*

This document is intended to represent the rights and legitimate expectations of families of loved ones who may die and 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 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.

### **Donor 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 healthcare 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 the (impending) death of their loved one, with appropriate reference to the concept of cardiac and/or brain death and the basis upon which it has been or will be determined that that concept applies to their loved one.
4. To 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 have an opportunity to make organ and/or tissue donation decisions on behalf of themselves and of their loved one who has died. This opportunity is to be included in the normal continuum of care by the healthcare provider after death has been determined and the family has had sufficient time to acknowledge that death has occurred.
7. 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/or tissue donation, and the implications of organ and/or tissue donation for later events, such as funeral arrangements, viewing of the body, and related practices.
8. To be provided with time, privacy, freedom from coercion, confidentiality, and (if desired) the services of an appropriate support person (e.g., clergy person) 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 and to enable family members to make an informed and free decision about donation.
9. To have their decisions about organ and/or tissue donation accepted and respected.
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., a lock of hair).
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 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.
13. To receive timely information regarding how any donated organs and/or tissues were used, and, if desired, to be given an opportunity to exchange anonymous 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.

14. 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 erroneously be addressed to the family.
15. 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/or 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. 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. Also, these explanations may need to be repeated or supplemented in more than one interchange.

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