

Tissue Banking- Bereavement Information Sheet

VHL Family Alliance and NDRI understand that donation can occur at a particularly difficult time for loved ones and we appreciate you thinking of donation at this time. The staff at NDRI is sensitive to the needs of donor families during the donation process. If you or your loved ones have questions about NDRI or the donation process, please do not hesitate to call at **800-222-6374**.

Does the donor family incur any expense for the donation?

There is no financial cost to the family for donation to research. The donor family is responsible for regular funeral/mortuary or cremation expenses, or an official autopsy if requested to determine cause of death.

Will the body be suitable for viewing and/or available for a timely funeral after donation?

Yes. You may specify unlimited or limited donation. If you choose a limited donation, it does not rule out the possibility of a regular, timely funeral service. A traditional, open-casket funeral service can still take place, even though many organs and tissues have been donated. Highly skilled professionals perform the recovery procedures, and the appearance of the donor is unchanged. Unlimited donations are usually offered when a cremation is desired.

How will someone know, upon my death, that I want to be a donor?

Please make your loved ones, doctors, caregivers (e.g., nursing home staff), and attorney aware of your registration with NDRI. At least one person should be designated as a contact for NDRI. This person will be responsible for notifying NDRI as soon as possible after death, so that timely arrangements can be made. NDRI will make every effort to enlist the aid of a trained medical professional to perform the recovery after death. It is helpful to finalize these arrangements in advance if possible, since rapid recovery of this precious gift is very important.

Should I carry a donor card?

NDRI currently does not use donor cards. We are in the process of evaluating such a system, as more people wish to donate. However, through experience, NDRI has found that informing your family, friends, doctors, attorney, and health providers of your intentions is the best way to ensure your donation. Please give them our name and number.

How are tissues and organs recovered?

As soon as death occurs or is imminent, or a surgery is scheduled, someone should contact an NDRI representative. **Our 24-hour number is 888-222-NDRI (6374)**. In the event of death, NDRI will work with your family members, funeral director, hospital or nursing home staff to arrange for the transfer of the body, if applicable, and the tissue recovery at an appropriate location.

How much time does the contact have to notify NDRI?

It is very helpful for NDRI to receive notification as soon as possible. Medical research involves study of living cells and tissues, which have a limited viability after death. Some fragile tissues, like eyes or heart, need to be recovered within a few hours after death; brain tissue, bone, and other more durable tissues are sometimes viable up to 12-24 hours after death. It is important that the persons close to you or caring for you are aware of your wishes, and that they notify the designated NDRI contact as soon as possible.

Is the body transported to NDRI?

No. Recovery of tissues and organs is preformed at your local hospital, funeral home, or other designated institute. It is helpful in the coordination of the donation to have permission from the hospital pathology department, the funeral director, etc. ahead of time. This arrangement will be made by NDRI once they have been notified.

Does NDRI dispose of the remains of the body if unlimited donation is made?

No. NDRI arranges the recovery of tissues and organs for research, unlike medical institutions that use complete cadavers for instructional purposes. NDRI is not able to perform cremation, memorial, or burial services. Your family is still responsible for these arrangements and expenses.

What do I have to do to register with NDRI to become a donor?

Follow these simple steps:

1. Request a sign-up kit by contacting NDRI at 800-222-6374 ext. 251 or email raredisease@ndriresource.org. **Click here to request your sign-up kit.**
2. The kit will include materials for you to give a urine or saliva sample and/or supplies to have a blood sample taken by your physician. To indicate the desire to donate for research, you or your next of kin and a witness should sign two copies of the enclosed consent forms. You or your family member should retain one copy, and the other should be mailed to NDRI. You will also need to fill out and mail to NDRI the medical questionnaire. All information will be kept in the strictest confidence.
3. Return the completed sign-up kit to:

Special Initiatives Coordinator
National Disease Research Interchange
1628 JFK Blvd.
8 Penn Center, Suite 800
Philadelphia, PA 19103
Fax #: 215-557-7154

What do I do if I have suddenly become very ill and have not pre-registered with NDRI, but would like to donate tissue after my death?

You or your next of kin and a witness should fill in two copies of the 'Consent for Donation of Anatomical Gifts' form. **Click here to access the form** or call NDRI at their 24 hour number **800-222-6374**. After completing the form you should call NDRI at the number just listed so that they are aware of the situation. The consent form can be faxed to NDRI at 215-557-7154.

What do loved ones do if a family member has just died and never signed a consent form, but they want to donate tissue to the bank?

The next of kin and a witness should fill in two copies of the 'Consent for Donation of Anatomical Gifts' form as soon as possible and contact NDRI on their 24 hour number **800-222-6374**. **Click here to access the form** or call NDRI at the number just listed.