
Facts about Organ and Tissue Donation for Research

Requirements for research are different than requirements for transplant, and it is important to understand that anyone at any age may be a research donor candidate. A history of disease does not preclude donation for medical research. Scientists frequently need affected tissue in order to investigate treatments.

Medical research

You or someone close to you may have a debilitating or even life-robbing disease for which there is currently no cure. Great strides have been made in medical research using both normal and diseased human tissue to advance diagnoses, therapies, and cures. Human tissue has proven to be much more relevant than animal models in studying human disease. As scientists get closer to finding cures for many human diseases, donation to benefit research is critical. Through anatomical donation upon death, or the donation of tissues removed during surgery or transplant, you can help save lives by providing the materials needed by researchers to ultimately treat and/or cure diseases.

What is the National Disease Research Interchange?

The National Disease Research Interchange (NDRI) is a non-profit organization founded in 1980 in the US to provide approved biomedical researchers with access to human tissue. NDRI was founded as the National Diabetes Research Interchange by Lee Ducat, the mother of a diabetic child and a founder of the Juvenile Diabetes Foundation, who was frustrated by the lack of information and had hope for a cure for her son's condition. Today NDRI, with funding from the National Institutes of Health, provides all types of normal and diseased tissues to researchers studying a wide range of common and rare diseases and disorders.

What happens to the tissues I donate?

NDRI has thousands of requests for all types of tissue. Tissues will be processed and sent to approved researchers in the NDRI network. Your gift may benefit dozens of different research studies. If you prefer, you may specify what type of research (e.g., diabetes, Alzheimer's, etc.) you would like your donation to aide, and we will give these studies priority. Your family may request information on the types of studies benefiting from your gift, but will not be able to obtain diagnostic information. Your identity and your family's identity will remain anonymous.

What do I have to do to donate for research?

If you would like to donate towards research, you have several options. Biomaterials can be collected through autopsy, surgery, transplant, or blood donations. NDRI conforms to all provisions of the laws in your country. To indicate the desire to donate for research, you or your next-of-kin should sign and have witnessed two copies of the enclosed Consent Form. You or your family member should retain one copy, and the other should be mailed to NDRI. In order for NDRI to maintain up-to-date records, we ask that you complete the enclosed medical questionnaire. It is important that you or someone you have appointed inform NDRI of current medical conditions or changes in the original information relayed. This would include significant conditions such as chemotherapy/radiation treatments, eye diseases, surgeries, medications, or change in medical status (e.g., insulin requirement for diabetes).

Does donating tissue for research compromise my ability to be a transplant donor?

No. The gift of life through organ and tissue transplant donation is one of the most precious gifts that someone can give. There are, however, instances when tissues and organs cannot be used for transplantation, but your donation can give hope and promise to medical research. NDRI works closely with eye, organ, and tissue procurement organizations to ensure that all organs needed for transplantation are retrieved first, and then non-transplanted donated tissues are utilized for research. Contact your local transplant program to learn how you can become an organ or tissue transplant donor.

Will my religion support organ and tissue donation?

As with transplant and surgical donations, many faiths openly encourage it, seeing this as a final act of giving and as an expression of hope. For further guidance, contact your religious leader.

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.

Living Donations

Living donations includes any biomaterial removed during a transplant or surgery, or donating blood.

How can I donate blood?

Blood donations can be drawn during a surgery or transplant. If you are not scheduled to have surgery, you may request a blood kit to donate blood. Once you have completed the consent form to donate blood, a coordinator will mail you a blood kit that you can take with you to your next blood draw. Take this kit to the appointment to have the nurse or phlebotomist draw your blood. The nurse will mail then the kit for you.

Do I need to have surgery at a certain facility or by a certain surgeon?

No. The staff at NDRI will coordinate and work with your surgeon and hospital to receive your donation. You are not responsible for providing instructions or shipping the donated tissue.

Do I need to notify my doctor?

Yes. NDRI asks that you notify your doctor and family of your desire to donate. Please let your physician know that a coordinator from NDRI will be contacting them about your surgery and desire to donate. Procurements are more welcomed by physicians when the patients notify them of their interest to donate to research.

What information must I provide when calling with a pending surgery?

When calling with a pending or scheduled surgery, let the coordinator know where, when, and by whom the surgery will be performed. Contact information for the hospital and physician/surgeon will also be needed.

Is there a cost to donate my tissue?

There is no cost to the donor for donating tissue during surgery or transplant procedures. The donor is responsible for any cost associated with their surgery. NDRI will not pay for you to have surgery. There may be a nominal fee from your doctor if you would like to have blood drawn to donate blood. This may not be the case if you are scheduled to have blood drawn for other purposes.

Anatomical Gift Donations

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

Please make your next-of-kin, doctors, caregivers, 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.

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.

How are tissues and organs recovered?

As soon as death occurs or is imminent, someone should contact an NDRI representative. **Our 24-hour number is 800 222 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.

Is the body transported to NDRI?

No. Recovery of tissues and organs is performed 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.

Does NDRI dispose of the remains of the body?

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.

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.

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.

*Thank you for your generosity and dedication
to serving medical research*