

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. Indeed scientists frequently need affected tissue in order to investigate treatments.

Medical and Scientific 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 identifying genes and potentially 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, you can help save lives by providing a means to the end of these diseases.

What is the National Disease Research Interchange?

The National Disease Research Interchange (NDRI) is a non-profit organization founded in 1980 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.

Does donating 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 in transplant donation, most faiths encourage it, seeing this as a final act of giving and as an expression of hope.

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.

What do I have to do to donate for research?

NDRI conforms to all provisions of the Uniform Anatomical Gift Act. To indicate the desire to donate for research, you or your next of kin should sign and have witnessed two copies of the NDRI Research Consent Form (available by calling 800-222-6374). 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 a 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 status (e.g., insulin requirement for diabetes).

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.

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 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 aid, 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.

Thank you for your generosity and dedication to serving medical research

If you are interested in becoming a donor for research and have further questions or if you would like to make a financial contribution to support important medical research, please call NDRI at **1-800-222-NDRI (6374)**.