



RESEARCH DONATION FREQUENTLY ASKED QUESTIONS (FAQ)

WHO IS NDRI?

The National Disease Research Interchange (NDRI) is a 501(c)(3) not-for-profit organization that provides project-driven human biospecimen service to academic and corporate scientists. NDRI was founded in 1980 by Lee Ducat, the mother of a diabetic child and a founder of the Juvenile Diabetes Research Foundation (JDRF), who was frustrated by the lack of information about her son's condition and hoped for a cure. Today, with funding from the National Institutes of Health (NIH), as well as other foundations and corporate partners, we provide all types of normal and diseased tissues to researchers studying a wide range of common and rare diseases and disorders.

HOW DO I DONATE TISSUES FOR RESEARCH?

If you would like to donate organs and tissues for research, you have several options. Our recovery partners can collect biomaterials through:

- Autopsy
- Surgery
- Transplant

After we receive your contact form, we will contact you to discuss participation in NDRI's Private Donor Program and the forms needed to register. You will be asked to fill out a consent and/or authorization form for research donation and medical and social history questionnaires to collect contact and medical history information.

It is important that you or someone you have appointed inform NDRI of current medical conditions or changes in the original information provided. This would include significant conditions such as chemotherapy/radiation treatments, eye diseases, surgeries, medication, or changes in medical status (e.g., insulin requirement for diabetes).

NDRI conforms to all applicable government regulations and local laws regarding informed consent, donor privacy, and tissue recovery.



IF I DONATE TISSUE FOR RESEARCH, CAN I STILL BE A TRANSPLANT DONOR?

Yes. The gift of life through organ and tissue transplant donation is one of the most precious gifts anyone can give. NDRI works closely with eye, organ, and tissue procurement organizations to ensure that all organs for transplantation are recovered first, followed by non-transplanted donated tissues, which are used for research.

In cases when tissues and organs cannot be used for transplantation, your donation can give hope and promise to medical research.

Contact your local transplant program to learn how you can become an organ or tissue transplant donor.

HOW ARE DONATIONS FOR RESEARCH DIFFERENT THAN TRANSPLANT?

Requirements for research are different than requirements for organ transplant, which requires healthy donors in certain age groups. It is important to understand that:

- Anyone at any age may be a research donor candidate.
- A history of disease does not rule out donation for medical research. Scientists frequently need diseased tissue to study treatments. In fact, NDRI participates in several disease-specific research programs. And patients may choose to donate disease organs removed during transplant.

WHY ARE ORGAN AND TISSUES IMPORTANT FOR MEDICAL RESEARCH?

You, or someone close to you, may have a debilitating or even life-threatening disease, for which there is currently no cure. Medical researchers have made great strides using both normal and diseased human tissue to advance diagnoses, therapies, and cures. Not surprisingly, human tissue gives researchers better information than animal tissues in studies of human disease. As scientists get closer to finding cures for many human diseases, donation to benefit research is critical. When you donate organs and tissues upon death or during surgery or transplant, you can help save lives by providing the materials that researchers need to find better treatments for and to cure diseases.



WHAT HAPPENS TO THE ORGANS AND TISSUES I DONATE?

NDRI receives thousands of requests for all types of tissue. We process donated tissues and send them to NDRI approved researchers. Your gift may benefit dozens of different research studies. If you prefer, you may specify what type of research you would like your donation to aid (e.g., diabetes, Lou Gehrig's disease (ALS), HIV/AIDS, etc.), 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. Our program is confidential, and your information remains anonymous.

WILL MY RELIGION SUPPORT ORGAN AND TISSUE DONATION?

As with transplant and surgical donation, 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 to discuss.

SHOULD I CARRY A DONOR CARD?

When NDRI receives your completed consent/authorization form(s) and medical/social history questionnaire, an NDRI donor registration card will be sent out to the address that you provided.

IS THERE A COST TO DONATE MY TISSUE?

There is no cost to the donor for donating tissue to research. However, the donor/donor family is responsible for any cost associated with their surgery or funeral/cremation arrangements. NDRI does not provide any financial incentives to donate organs and tissues for research.

WHERE DOES THE RECOVERY OF ORGANS AND TISSUES FOR RESEARCH OCCUR?

Organ and tissue recovery can occur, depending on local laws and with appropriate permissions, at your local hospital, funeral home, or other designated institution. It is helpful to have permission from the hospital, the funeral director, etc., ahead of time to perform the research recovery at their institutions. Please make NDRI aware of any imminent changes to the donor's health status, therefore all parties would be notified, and a donation plan can be finalized.



NDRI
Empowering Research and Discovery

National Disease Research Interchange Private Donor Program

POST-MORTEM DONATION FAQ

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 your gift is especially important to research use.

HOW MUCH TIME DOES NDRI NEED FOR NOTIFICATION OF DEATH?

It is important for NDRI to receive notification as soon as possible. Medical research involves study of living cells and tissues, which have a limited recovery window after death. Organs and tissues for research are typically recovered within 4 to 24 hours after death. It is important that the people close to you or caring for you are aware of your wishes, and that they notify NDRI as soon as possible. Please contact NDRI if there are any significant changes in health.

HOW ARE ORGANS AND TISSUES RECOVERED?

As soon as possible, your next-of-kin or healthcare team should contact our 24-hour number: (800) 222-NDRI (6374). In the event of post-mortem donation, NDRI will work with your family members, funeral director, or healthcare team to activate your personalized donation plan.

CAN I STILL HAVE A VIEWING IF I DONATE ORGANS AND TISSUES TO RESEARCH?

Yes. You can indicate your desired funeral arrangements, whether you plan to have an open or closed casket viewing or direct cremation, on your authorization form. Highly skilled recovery professionals perform the recovery of organs and tissues for research without affecting your wishes.

WHAT HAPPENS TO MY BODY ONCE I DONATE TO RESEARCH?

NDRI arranges the recovery of organs and tissues for research. Unlike some medical institutions and donation programs that use complete cadavers for instructional purposes, NDRI is NOT a whole-body donation program. NDRI does not perform memorial or burial services. Your family is still financially responsible for these arrangements and expenses.



NDRI
Empowering Research and Discovery

National Disease Research Interchange Private Donor Program

SURGICAL DONATION FAQ

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 will not be responsible for providing instruction to the surgical/pathology team or shipping the donated tissue to NDRI.

WHAT INFORMATION MUST I PROVIDE WHEN CALLING WITH A PENDING SURGERY?

When calling with a pending or scheduled surgery, please have the following information available so that NDRI can work with your surgical team to create your donation plan to ensure your donation can occur.

- Where your procedure will take place
- The scheduled date of surgery, if scheduled
- Contact information for the hospital and physician/surgeon
- If applicable, transplant listing date and center