

FAMILY SUPPORT: BEFORE, DURING AND AFTER DONATION



Center for Organ Recovery & Education

*A Pledge for Life*





*“It’s not how much we give  
but how much love we put into giving.”*

*— Mother Teresa* 

### **Your loved one's gift**

Your loved one has given such a precious gift of life, and CORE is dedicated to assisting you in the difficult days ahead. We cannot imagine your personal pain, but we are here to help you in any way we can. Your Donor Family Liaison will be in touch, and feel free to contact us if you have any questions or concerns.

As a donor family, you will continue to receive information for the first year following the death of your loved one. This literature on grief and bereavement is designed specifically for our donor families and includes information about grief support throughout our service area.



## When a loved one dies

Your loved one made a generous decision to give the gift of life through organ and tissue donation by registering as a donor through the Department of Motor Vehicles or the state donor registry. This decision meant agreeing to donate organs, tissue and corneas to patients in need of transplants when death occurred. It's a decision we are honored to help fulfill.

Because donation truly is a gift, CORE assumes the cost of the donation process. Our organization takes responsibility for hospital charges incurred after the time of death as noted by the physician. There is no cost to your family for your loved one's gift of donation. If you receive a hospital or funeral bill that you feel should be included in the donation process, please contact us as soon as possible at **800-DONORS-7 (800-366-6777)**. A CORE representative will review the bill and work with the hospital to ensure that you or your insurance company is not billed incorrectly.

When the donation process is complete, the CORE staff will contact the funeral home you have chosen so funeral preparations can begin. Donation should not interfere with your funeral arrangements. Some families wish to have their loved one's gift recognized as a part of their funeral arrangements. Phrases stating that your loved one "gave in death as he/she gave in life by being an organ, tissue, or eye donor" may be included in your loved one's obituary. Also you can request to have the CORE donor emblem included in your loved one's obituary.

CORE cannot assist your family with the cost of the funeral service; however if you receive a bill from the funeral home that is related to the donation process, please let us know.

After the funeral, many family members are overwhelmed by the numerous details which have to be completed to settle their loved one's affairs. Please allow your friends and family to assist you with these tasks. Organizations that need to be contacted may include your loved one's employer, the Social Security Office, your loved one's life insurance company, the Veterans' Administration Office (if your loved one was a veteran), the Internal Revenue Service and your loved one's bank. Some families find the assistance of an attorney helpful during this time. A death certificate may be needed by the agencies mentioned above. The funeral home can provide copies at your request.

Be sure to keep a copy with your tax preparation files.

## Donation

As a donor family member, you are part of a precious group of people whose loved ones continue to provide life and healing to others. Many find solace and joy from donation, because their loved ones not only helped others, but also live on in those who were given a second chance for life. It helps to know that something good came from a tragic event, and that it was something your loved one would have wanted.

The donation can also provide meaning when seen as a way to seek personal, emotional and spiritual growth, and to re-examine life perspectives. Some find valuable insights into simplification of life and future growth possibilities.

*“I originally said no to donation because I was so angry at my husband for dying and at the hospital for not saving him. But the hospital staff was very patient with me and let me work through my anger.”*

*— Wife of a 59-year-old tissue donor* 



## How is death determined?

Organ and tissue donation are only options after death has occurred. There are two ways to determine death – either a person’s heart stops beating (cardiac death) or the person’s brain stops functioning due to the absence of blood flow (brain death).

Most of us are familiar with death occurring when a person’s heart stops. Brain death can be more difficult to understand. Many times a person who has suffered brain death merely looks asleep. You may almost expect that at any minute your loved one will open his/her eyes.

This expectation is normal. When the brain ceases to function, the person dies and is permanently unable to think, breathe, see, hear or feel. He/she is no longer the person you once knew. Without oxygen and blood flow to the brain, the heart stops beating and all vital organs – heart, lungs, liver, kidneys, pancreas and intestines – are unable to function. Medical equipment, such as a ventilator, can keep the heart and all other vital organs functioning after the brain has died. Without the ventilator, the person would not be able to breathe on his/her own and the heart would stop beating within minutes.

A severe head injury or brain hemorrhage (bleeding) usually causes brain death. The determination of brain death is made only after a thorough evaluation in which numerous clinical tests are done. Brain death must be determined by a physician. The physicians determining brain death are in no way connected with the transplant team, nor can they, by law, perform the organ recovery or transplantation.

## How does the organ and tissue donation process work?


The information you or a trusted family member provided us about your loved one’s medical and social history was combined with extensive medical testing, a physical examination and multiple laboratory tests to determine which of your loved one’s organs or tissue were able to be recovered and gifted to others. The testing included screenings routinely performed on all donors to avoid the spread of infectious disease to recipients.

If your loved one was an organ donor, one of our coordinators worked with the United Network for Organ Sharing (UNOS) to match your loved one’s organs with recipients. After the organs were accepted, transplant teams from each facility traveled to the hospital where your loved one died for organ recovery surgery. The utmost respect was given to your loved one and his/her precious gift of donation. Once recovery was complete, the organs were transported to the recipients’ transplant centers for transplantation surgery.

If your loved one was a tissue donor, tissue was recovered by one of our highly trained tissue coordinators. After recovery, the gifts of tissue were sent to our tissue partners to be prepared for transplant. This process may take several months. The generous gifts of tissue may be shared with recipients for up to five years following the donation.

## Did my loved one experience pain?

No. Once a person has died, the nerve pathways that conduct the feelings of pain no longer work. Therefore, no pain is experienced.

*“We all face stormy times in our lives, storms that can seem impossible to bear. However once the storm is over, we wonder to ourselves how we got through them and managed to survive. One thing is for certain, those storms we go through will change our lives and occasionally we will not be the same people who walked into them.”* 

## Tissue donation

Your loved one's tissue donation is an incredible gift that restores life and hope to grateful recipients. Each year millions of people benefit through the restored health and quality of life that donated tissue provides. When consent is given for tissue donation, trained tissue recovery specialists come to the hospital. Your loved one is treated with the utmost respect and special care is taken to preserve his or her appearance.



## How does donated tissue help others?

**Corneas** – Disease, infection or trauma to the thin clear covering of the eye, the cornea, can cause blindness. Sight can often be restored through transplantation of donated corneas.

**Heart valves, descending thoracic aorta, aortic arch and pericardium** – Donated heart vessels and valves can mean the difference between life and death to recipients. The largest vessels of the heart leading to and from the lungs may be transplanted to a patient whose vessels have been damaged by trauma or disease. Cells from the vessels may also be extracted so a fully functioning new vessel can be grown for use in surgery. The pericardium is the sac surrounding the heart and is often used as a patch or covering to help in cardiac, bladder, brain or oral surgeries.

**Skin** – Donated skin can be used as a temporary covering for severe burns. The donated skin functions as the burn patient's own skin for a short time, reducing pain and decreasing the risk of infection. It can also be used to replace the inner layer of a patient's skin, significantly reducing scarring and restoring mobility. Skin grafts can also be used to fill soft tissue defects due to cancer or trauma, to restore bladder control, in periodontal surgery to correct gingival defects, and to facilitate abdominal wall repair for hernias or other injuries.

**Bone grafts and associated connective tissues** – Thousands of people require surgery to repair spinal injuries, to reconstruct jaws after cancer or severe gum disease, or to replace limbs after trauma. Disease and trauma, sometimes from sports injuries, cause damage to certain joints in the body, such as the knee or the shoulder. Donated ligaments and tendons are used to rebuild these joints and restore mobility to hundreds of patients. Other connective tissues can be used as a strengthening measure in tissue areas throughout the body that have weakened due to illness, age or disease process. Bone grafts can also be used to help patients with bone cancer and ribs are used in a variety of orthopedic surgeries to replace or restore function, mobility and structural support. Smaller sections of bone are used to strengthen areas of a deformed spine or to fill areas where bone has been lost or damaged. Rib cartilage is used for ear and nose reconstruction.

**Veins and arteries** – Many people lose circulation in their legs, or even in their hearts, due to disease or trauma. Donated veins and arteries are used to restore circulation in heart bypass surgery and to avoid limb amputation. Aortoiliac arteries are used in vascular reconstructive surgery treating aneurysms and/or synthetic graft infection.

## How will you learn how your loved one's tissue is used?

If your loved one was a tissue donor, he/she may have the opportunity to restore the health of 50 or more people. Information about the recipients of your loved one's corneas recipients is usually available within several weeks. Because other tissue grafts may be transplanted into recipients for up to five years, we may not know the impact of your loved one's gift of donation for some time.



## Recipients of the gift

### **Who received my loved one's gifts?**

At six weeks you will receive a letter from CORE with information from us explaining which of your loved one's organs or tissue were recovered as well as general information about the organ recipients who benefited from your loved one's gifts. To respect the confidentiality of your family and your loved one, names and other identifying information are not revealed.

Because your loved one's gifts of tissue may be shared with others for up to five years, we may not have tissue recipient information to share with you for some time. Please be assured that your loved one's generosity will always be remembered by the recipients who so gratefully benefited from their gifts.

If you desire further updates on the recipient(s), you may contact CORE at **800-DONORS-7 (800-366-6777)** and request this information.

### **How are my loved one's organs matched with recipients?**

The United Network for Organ Sharing (UNOS) keeps a national list of everyone in the United States waiting for an organ transplant. Our organ coordinators who worked with your family communicated with UNOS to find the best matches between your loved one's organs and waiting recipients. The system is designed to fairly distribute organs based on medical urgency, genetic matching, waiting time and geography. Factors such as race, gender, income or celebrity status do not influence who receives organs and tissue.

### **Will I hear from my loved one's recipients?**

The decision to communicate is a personal one for both donor families and transplant patients. After the death of your loved one, you may correspond anonymously with the organ recipient(s), and CORE will forward your letters. When writing a letter, we encourage you to do what is most comfortable for you. If you choose to write a letter, please send it to one of our Donor Family Liaisons who will review your letter to ensure confidentiality and then forward it to the recipient. Please feel free to send a greeting card, a letter, or photographs. As a tissue donor family, because the gifts of tissue donation may not be shared for transplant for quite some time, we are unable to forward letters from tissue donor families to tissue recipients until a recipient has initiated contact.

Please understand that recipients also go through a period of grief because they realize that the gift they received came as the result of someone's death. It takes time for some recipients to feel comfortable writing to the donor family. CORE cannot guarantee the recipient will correspond with your family. Whether or not you receive communication from your loved one's recipients, please know that his or her gifts of donation are received with hope and gratitude. Following written correspondence between your family and the recipient(s), and a signed consent, CORE will release the identities of both parties if your family and the recipient(s) both desire. At that time, you may meet in person. CORE's Donor Family Liaisons are available to help facilitate your first meeting or phone call.

## Research donation

Through donations to advance medical research, your loved one has another opportunity to help others. Our organization will make every attempt to transplant your loved one's organs and/or tissues. However, because of current or preexisting medical conditions, the surgeons may not be able to transplant all the gifts that you have authorized. In this case, you may have given authorization to help others through medical research. Our organization works with a variety of researchers in Pennsylvania and throughout the U.S. In some cases, we can provide you with information about the diseases researchers are investigating and the goal of the study immediately. However, because life sciences research is ever-changing, some studies may take years to develop. In such cases, no specific follow-up information can be provided.

Remember that your loved one's donation to research is invaluable and will benefit medical research that leads to new therapies, procedures, and medicines that will improve health and save lives. Drugs to help lower cholesterol, lower blood pressure, or strengthen bones to prevent osteoporosis have helped many people live longer, healthier lives. Without research, these drugs would not exist.

If you desire additional information concerning your loved one's donation to medical research, please contact CORE at **800-DONORS-7 (800-366-6777)**. We will share all information available.

## Coroner cases

As part of the donation process, all potential organ donors are reported to either the county coroner's office or medical examiner's office by the hospital staff. The coroner may choose to come to the hospital and review the hospital's medical records to determine the cause of death. Situations in which the coroner may become involved include:

- Sudden death of a healthy child
- Death caused by known or suspected homicide or suicide
- Death that occurred within 24 hours of admission at a hospital
- Inability of the physician to state the cause of death after careful review of the medical records
- Death caused by an accident, such as a motor vehicle accident
- All deaths in which the patient was under anesthesia
- Death caused by drowning, fire, acute alcoholism, drug addiction, strangulation or malnutrition
- Death caused by an occupational disease or occupational accident

The investigation by the coroner's office may or may not involve an autopsy. The investigating coroner makes that decision.

An autopsy is performed to determine the medical cause of death and to gather evidence that might be needed in a court of law. An autopsy will not prevent your loved one from having a traditional viewing at the funeral. If an autopsy is deemed necessary, please inform your funeral director. Your funeral director will then communicate with the county coroner's office to make arrangements.

If you have questions or wish to obtain a copy of an autopsy report, please contact the coroner or medical examiner's office that handled the case.

### **Aftercare and Bereavement Support**

Our Donor Family Liaisons are here to support you as you go through this journey. As a donor family, you will continue to receive information for the first year following the death of your loved one. This literature on grief and bereavement is designed specifically for our donor families and includes information about support groups located throughout CORE's service area. If you do not wish to receive any of the above mentioned information or any additional bereavement material from our organization, please notify CORE's Donor Family Services at **800-366-6777**.

One of the additional ways we can support you is to share updated information regarding your loved one's donation. CORE can provide health updates about organ recipients as well as general transplant information about potential tissue recipients beginning nine months following the donation. For further information, please contact CORE's Donor Family Services.



**Center for Organ Recovery & Education (CORE)**  
**Attention: Donor Family Services**  
**204 Sigma Drive, RIDC Park**  
**Pittsburgh, PA 15238**  
**800-DONORS-7**  
**800-366-6777**



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