

## Your loved one's gifts make a difference.

Thank you for donating the tissues of your loved one at a most difficult time. The information in this booklet is provided by the National Donor Family Council (NDFC). The Council works to enhance the sensitivity and effectiveness of the organ and tissue recovery process, to provide opportunities for families to grieve and grow and to use the unique perspective and experiences of donor families to increase organ and tissue donation. This booklet has been written by donor families and professionals who volunteer to help the council do its work. We hope that it will help to explain the process of tissue and eye donation and clarify how your loved one's generous gifts helped people in need of eye, bone or other tissue transplants. We have included a glossary at the end of the booklet for your information and reference.

## What is considered a tissue?

Eyes, bone, skin, ligaments, tendons, and veins are considered tissues. Heart valves, pericardium and fascia lata, as well as the cornea and sclera of the eye, are also tissues. Definitions for more specific tissues can be found in the glossary.

## Why is tissue needed?

Medical uses for donated tissue have increased over the past several years. Success in the transplantation of bone and other tissues has also greatly increased. Tissue transplants can dramatically change and improve the quality of life for many individuals and may even save lives.

**Did you know that there are more than one million tissue transplants performed in the United States each year?**

- Tissue is needed to replace bone, tendons and ligaments lost because of cancer, sudden and severe injuries, degenerative joint disease, arthritis and other conditions.

- In many cases, bone transplants can prevent the need for amputation or multiple surgical sites during spinal fusion. Bone can help rebuild the facial structure such as the jaw. It can also be used in dental and periodontal surgeries.
- Skin is urgently needed for patients with severe burns and can mean the difference between life and death. Skin can also be used for various reconstructive surgical procedures.
- Heart valves replace those damaged by disease or deformities and offer the chance of an active life for many children and adults.
- Inner ears can help restore hearing for certain types of deafness.
- Eye tissue restores sight.

## What are other medical uses of tissue?

Tissues can also be donated for medical research and education. If your family consented to donate for research, the tissue was placed with scientists and physicians, depending on their needs. Research gifts are vital to help medical professionals work toward finding effective treatments for various tissue diseases.

## Why is the medical and social history of my loved one so important?

All tissue and eye banks and other recovery agencies must evaluate donated tissues to ensure that the tissues are safe for transplantation. As part of that evaluation, the Food and Drug Administration (FDA) requires that a series of questions be asked about every potential donor's medical history and social behaviors. These questions were very similar to questions that are asked when you donate blood. We know that the questions were very personal, but they were necessary to ensure that tissues from your loved one could be safely transplanted into waiting recipients.

## How were my loved one's tissues removed?

Your loved one was treated in a respectful manner. The tissues that you consented to donate (bones, skin, heart valves, veins, corneas and other tissues) were carefully removed in a clean, surgical procedure with the utmost respect. The tissues were then evaluated and prepared for use.

## When will the tissues actually be transplanted?

Some of the tissue, such as the corneas, will be transplanted within five to seven days of the donation. Tissues such as bone have many uses and can be stored for many years until needed for transplant. Please remember that every effort is made to transplant donated tissues. However, sometimes it is determined that tissues cannot be used. There may be several reasons why donated tissues are not used, most often related to possible risks to recipients' health and well-being.

## How can I obtain information about the recipients?

You should receive acknowledgment of your gift from the recovery agency, which will provide you with general information available at that time about what tissue was recovered. It is important to remember that some tissue, such as bone, can be stored for many years. In these cases, it may not be possible to provide you with recipient information. Your recovery agency is available to assist you with obtaining additional information. However, this information may not be available for several months or more after the donation.

## Will I be charged for the donation?

No. There is no charge to the donor family. If you mistakenly received a bill for the cost of the donation or think you were charged extra for funeral preparation due to donation, please contact the recovery agency that assisted with your loved one's donation.



## The Gift of Life

Your decision to donate your loved one's tissue has most likely reduced the suffering of other individuals and improved or actually saved another person's life.

We hope this knowledge brings some solace during this most difficult time of living without your loved one. Others have traveled the grief journey before you and survived. Please contact the National Donor Family Council for additional resources and information. Membership in the Council is free.

## Glossary

**Bone:** Hard parts that make up the skeleton. Bone transplantation aids with limb-saving procedures and restores mobility and agility. It provides independence in activities of daily living and may be used in spine, joint and limb procedures, as well as facial reconstruction and dental surgery.

**Cornea:** The clear tissue that covers the eye. Cornea transplants prevent blindness and restore vision.

**Eye bank:** An organization that participates in the recovery, processing and distribution of ocular tissue for transplantation and research.

**Fascia lata:** Tissue that surrounds the muscles. Fascia lata is used to return mobility to orthopedic patients and is also used in joint replacement, brain surgery and tendon replacement.

**Tendons and ligaments:** Can be used for repair of torn tendons and ligaments, such as in sports medicine.

**Pericardium:** Tissue that surrounds the heart. Pericardium forms a protective covering replacement for the inner ear and can also be used in brain surgery.

**Recovery agency:** The organ, tissue or eye organization responsible for obtaining consent from family members and for procuring the organs or tissue from your loved one.

**Heart valves:** Transplanted heart valves are used to replace diseased or malfunctioning heart valves.

**Saphenous veins:** Saphenous veins allow blood to travel to the heart or extremities.

**Sclera:** Tissue that makes up the whites of the eyes. Sclera is used in glaucoma surgery and to create movement for prosthetic eyes.

**Skin grafts:** Skin grafts provide a natural barrier to infection for burn victims. The most common skin grafting provides temporary protection from infection and fluid loss following severe burns. However, this is not its only use. Because skin contains a mixture of collagen and other materials that make it stretchy, it is uniquely suited for transplant into patients whose physical activity would otherwise be restricted because of their medical problems. Skin from donor gifts can be used to repair bladder leakage problems, to restore voice loss due to damaged vocal cords and to repair facial scars.

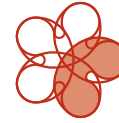
**Tissue bank:** An organization that participates in the recovery, processing and distribution of human tissue for transplantation and research.

## National Donor Family Council (NDFC)

The National Donor Family Council—the home for donor families—was founded by the National Kidney Foundation (NKF) in 1992 to serve families of those who gave the gift of life by providing a strong, unified voice in meeting their needs and a safe haven as they learn to live without the ones they love. Comprised of donor family members, friends and professionals, the NDFC supports the needs and expectations of organ and tissue donor families and assists those healthcare professionals who work most closely with this community. The NDFC collaborates with numerous organizations and professionals in the transplant and bereavement communities. Since its inception, the NDFC has worked and will continue to work diligently to increase the sensitivity and effectiveness of the organ and tissue recovery process.

As the “home for donor families,” the NDFC is also an important part of the NKF’s **People Like Us**, a growing movement to empower, educate and enable donor families, people affected by chronic kidney disease, transplant recipients and loved ones to become effective advocates on public policy and other issues related to their health. **People Like Us** includes the diverse perspectives and wealth of expertise provided by members of the NDFC and other NKF constituent councils. **People Like Us** provides training, support, resources and educational materials to help encourage people to become strong, proactive advocates for themselves and their loved ones.

Thanks to the past and present members of the NDFC Executive Committee for authoring this brochure.



National Kidney Foundation®

National Donor Family Council

## The Home for Donor Families

The National Donor Family Council is the oldest and largest national voluntary organization dedicated exclusively to the needs of tissue, eye and organ donor families.

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*Your Loved One's*

*Gifts:*

*Understanding Tissue*

*Donation*