



VOLUNTEER SPEAKERS HANDBOOK



Center for Organ Recovery & Education

A Pledge for Life



Register as an organ, tissue and cornea donor at core.org/register



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April Is NATIONAL  MONTH



National Donate Life Month

The Center for Organ Recovery & Education (CORE) is pleased you will be sharing your story for National Donate Life Month. Storytelling is one of the most powerful tools a donation advocate can use to inform others about the second chance at life donation and transplantation offers. And it is our hope that your story will move others to act.

For National Donate Life Month 2020, Donate Life America was inspired by the springtime scene of a garden. A garden and the insects within it serve as symbols of hope, courage and transformed life — themes repeatedly found within the donation and transplantation journey.

The Donate Life Garden depicts an ecosystem of plants, insects and other components working together to form an interconnected living system. Similarly, we each have the potential to nurture and enrich our communities through organ, tissue and cornea donation.

This handbook offers tips to harness the power of stories most effectively. Together, we are cultivating *The Donate Life Garden*.

Colleen Sullivan

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Director of Communications & Donor Family Services



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Using the *Right Words*

Language is very powerful; it can perpetuate misconceptions or offer a space for awareness. Help CORE foster a better understanding of donation and save lives by using the correct donation terminology.

In 2005, the Association of Organ Procurement Organizations (AOPO) standardized appropriate donation terminology. AOPO reasoned that avoiding words and phrases that cause concern among donor families and the general public would increase both understanding and acceptance of the donation process. This terminology is unanimously supported and used by the American Society of Transplantation (AST) and American Society of Transplant Surgeons (ASTS), and has been adopted by the American Journal of Transplantation.

To show respect and sensitivity to those who give the gift of life and their loved ones, we request that only appropriate terms be used when referring to organ, tissue and cornea donation.

APPROPRIATE TERMS INAPPROPRIATE TERMS

"Recover" organs "Harvest" organs

"Recovery" of organs "Harvesting" of organs

"Donation" of organs "To harvest" organs

"Deceased" donation "Cadaver" donation

"Deceased" donor "Cadaveric" donor

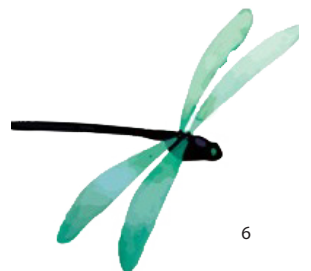
"Mechanical" support or "Ventilated" support "Life" support

Organs, tissue and corneas "Body parts"

"Brain Death" "Coma"

"Enhanced" risk "High" risk

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Messaging Tips

DONATION IS A TRIBUTE TO LIFE

Share your personal experiences with donation and transplantation, while keeping in mind that today's life is a tribute to donors and donor families.

CALL TO ACTION

The purpose of telling your story is to inspire others to register as organ, tissue and cornea donors. Our goal is that each person leaves informed of their opportunity to donate and empowered to save and improve the lives of countless donors through the decision to register. Please end all speeches with a call to action by encouraging everyone in the audience to register to be a donor on their driver's license, state ID or online at core.org/register.

DISPEL THE MYTHS

There are many misconceptions about donation, and they are a major barrier to the donation process. Time permitting, the audience should understand the facts on donation. You can read more about those myths and misconceptions on the following page.

DOs

- Keep to the allotted time.
- Use the words "recovery" and "brain death."
- Talk in simple terms.
- Please remember to speak about how your transplant or donation experience has positively affected you.
- Speak slowly, and remember to look up and make eye contact with the audience.

DON'Ts

- Use the word "harvest." It's harsh on the public ear.
- Say "they're kept on life support." Individuals being evaluated for donation have died. There is no need for life support. They simply are on a ventilator that is providing oxygen.
- Rely on note cards or papers. If you lose your place, you and your audience will be distracted. It is better to speak from the heart.
- Use clinical jargon or try to impress the audience with your knowledge of healthcare terminology.
- Think you must be an expert or professional speaker. You are sharing your story, which no one can do better than you.

Dispelling the Myths

MYTH	FACT
My body will be mutilated and disfigured if I would donate.	Organ and tissue donation will not interfere with traditional funeral arrangements such as an open casket. Doctors maintain the utmost respect for the donor and organs are removed in a routine operation similar to other types of surgeries.
Organs go to people who didn't take care of theirs.	Organs go to people who were born with or developed diseases that have caused organ failure. Less than 5 percent of those waiting need a transplant because of their own behaviors or choices. For those people, they must achieve and sustain sobriety before they can be listed for a transplant.
I am too old to become an organ donor.	No one is ever too old or too young to give the gift of life. Every potential donor is evaluated on a case-by-case basis at the time of their death to determine which organs and tissue are suitable for donation.
I am too sick to donate.	Few illnesses or conditions prevent someone from being a donor. People with diabetes, heart disease, cancer, hepatitis and even HIV have saved lives through organ and tissue donation. At the time of death, CORE reviews medical and social histories to determine suitability for donation. Although someone may not be able to donate blood, it does not always prevent the individual from donating organs and/or tissue.
My family will have to pay for costs related to my donation.	Donors and their families are not responsible for any costs related to donation. All costs are incurred by the organ procurement organization.
My religion does not support donation.	All major religions consider organ donation to be an individual decision, or support it and see it as the final act of love and generosity toward others.
Wealthy people are the only people who receive transplants.	Financial and celebrity status do not determine who receives a transplant. A national computer network, maintained by the United Network for Organ Sharing (UNOS), matches organs according to height, weight and blood type, followed by medical urgency and then time accrued on the waiting list. Age, race, gender, religious affiliation or financial status are not factors that determine who receives a transplant.
EMTs and hospital staff members don't work as hard to save your life if you're a	When you go to the hospital for treatment, all staff members are focused on saving your life, not somebody else's. You'll be seen by a medical team whose specialty most closely matches your particular emergency.

Speech Guidelines

TRANSPLANT RECIPIENT

- I. Personal Introduction
 - II. Story
 - a. Life Before Transplant
 - b. Realizing the Need for Transplant
 - c. The Wait
 - d. Impact on Family and Friends
 - e. The Transplant
 - f. Life After Transplant
 - g. Reflection on Donor and Donor Family
 - III. Questions (if appropriate and with time permitting)
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WAITING LIST CANDIDATE

- I. Personal Introduction
- II. Story
 - a. Life Before Need for Transplant
 - b. Realizing the Need for Transplant
 - c. The Wait
 - i. Limitations
 - ii. Fears
 - iii. Reflection on Potential Donor and Donor Family
 - iv. Impact on Family and Friends
- III. Questions (if appropriate and with time permitting)

DONOR FAMILY

I. Personal Introduction

II. Story

- a. Reflecting on the Life of Loved One
- b. Prognosis / Accident
- c. Hospital – Donation Process
- d. Impact on Family and Friends
- e. Honoring Loved One
- f. Donation / Transplantation Reflection
- g. Contact With Recipients

III. Questions (if appropriate and with time permitting)

LIVING DONOR

I. Personal Introduction

II. Story

- a. Life Before Donation
- b. Deciding to Become a Living Donor
- c. Testing
- d. Impact on Family and Friends
- e. Life After Transplant
- g. Reflection on Recipient and Recipient Family

III. Questions (if appropriate and with time permitting)

Transplantable Organs & Tissues

HEART

The heart is a muscular organ that pumps blood through the blood vessels of our circulatory system. A heart transplant gives patients with congenital heart disease or ailments like cardiomyopathy and myocarditis the opportunity to have a normal heart with normal blood circulation. While a heart transplant is a major operation, chance of survival is good with appropriate follow-up care. A heart must be transplanted within four hours.

LUNGS

Lungs extract oxygen from the atmosphere and transfer it into our bloodstream. Donated lungs save the lives of those afflicted with conditions such as cystic fibrosis, pulmonary hypertension, pulmonary fibrosis and end-stage chronic obstructive pulmonary disease (COPD). Lungs must be transplanted within six hours.

KIDNEYS

These organs are essentially sophisticated trash collectors. Every day, your kidneys process about 200 quarts of blood to sift out about two quarts of waste products and extra water. Donated kidneys replace diseased or damaged kidneys due to conditions such as high blood pressure, diabetes and polycystic kidney disease (PKD). This is the most frequent and the most successful organ transplant procedure. Kidneys can be transplanted up to 48 hours after being recovered.

TISSUE & CORNEA

Although less widely publicized than organ donation, tissue and cornea donation saves or enhances the lives of more than one million people in the U.S. each year. Donated tissue can be used for up to five years after it's recovered.

LIVER

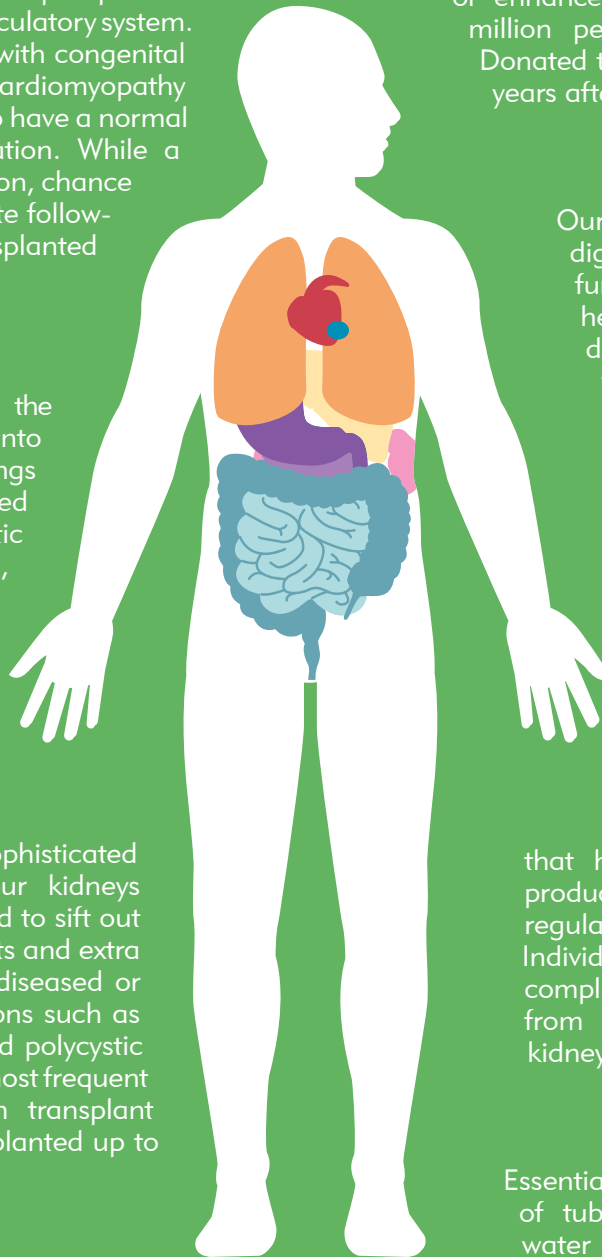
Our liver is the workhorse of the digestive system and performs 500 functions that help keep the body healthy. Donated livers replace diseased or damaged livers due to conditions such as birth defects or bile ducts as well as infections like hepatitis. A liver can be replaced with all or part of a healthy donor liver, from a living or deceased donor. Livers can also be split into two segments for transplantation.

PANCREAS

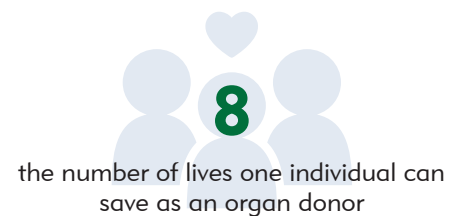
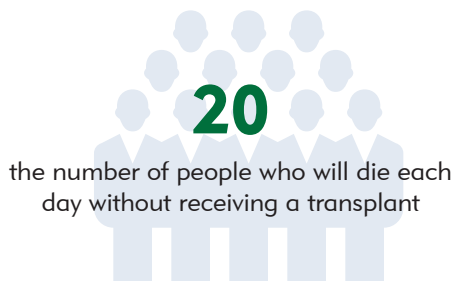
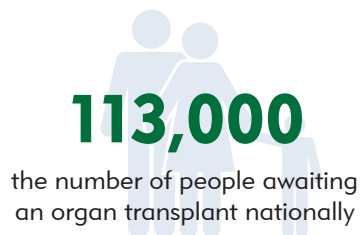
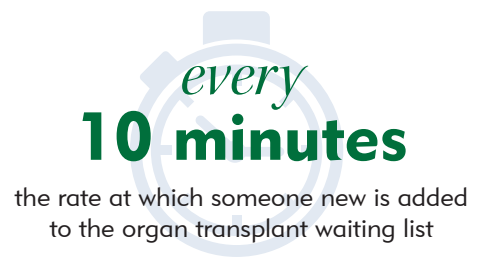
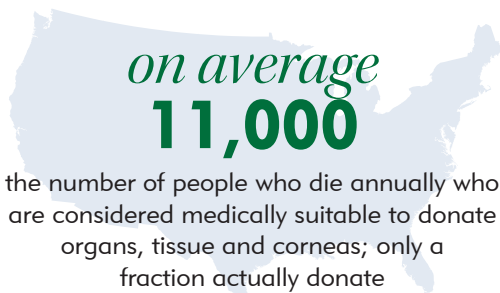
The pancreas creates digestive juices that help break down food that has left the stomach. It also produces the hormone insulin which regulates the body's sugar level. Individuals who have severe complications from diabetes can benefit from pancreas and/or combined kidney/pancreas transplants.

INTESTINES

Essentially, intestines are a long system of tubes that absorb nutrients and water from the food we consume and processes them in stages. Most intestinal transplants are performed on infants or children to heal conditions such as twisted or blocked intestines, or short gut syndrome (SGS). Intestines are often transplanted with a liver and pancreas. Intestines must be transplanted within 12 hours.



By the Numbers



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