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This toolkit was created by Lancaster-Lebanon Intermediate Unit 13 (IU13), as subcontracted by the Pennsylvania Department of Education. Published 2019. For questions about this toolkit or to request additional copies, please contact:

- Karen Herr, Organ and Tissue Donation Awareness Project Coordinator, at (717) 947-1616 or karen\_herr@iu13.org, or
- John V. Kashatus, School Safety Education Advisor, Pennsylvania Department of Education, Bureau of Curriculum, Assessment
  and Instruction Division of Instructional Quality, at (717) 783-4382 or johkashatu@pa.gov



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If you have any questions about this publication or for additional copies, contact:

Pennsylvania Department of Education Division of Instructional Quality John V. Kashatus, School Safety Education Advisor 333 Market Street, Harrisburg, PA 17126-0333 www.education.pa.gov

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# INTRODUCTION

# Introduction to the Organ and Tissue Donation Awareness Revised Toolkit *March 2019*

Organ and Tissue Donation Awareness (OTDA) education is an initiative of the Pennsylvania Department of Education (PDE) designed to provide public school students with the knowledge and skills they need to make informed decisions related to organ and tissue donation. The initiative began in 1994 when the state legislature passed the Governor Casey Act. Act 102, as it is called, stipulates that the commonwealth makes a comprehensive and collaborative effort toward increasing organ and tissue donation awareness among the citizens of Pennsylvania.

In February of 2019, Bill 108 was passed and Act 90 of 2018 was signed into law by Governor Wolfe. Within the legislation it is required that a curriculum framework be developed by the Department of Education. This curriculum toolkit fulfills the requirements set forth by Act 90 of 2018.

The OTDA Education Project is an ongoing partnership between the Pennsylvania Department of Education and the Lancaster-Lebanon Intermediate Unit 13 since 1996. The mission of the OTDA Project is to promote awareness of organ and tissue donation in the secondary schools throughout the commonwealth. It is our responsibility as educators, to provide students with the information and tools necessary to make informed decisions regarding organ and tissue donation. The revised OTDA Curriculum Toolkit was designed to reflect current legislation, research, teaching strategies, and resources.

This revised toolkit meets the requirements of PDE as described in Act 90 of 2018. These three foci include:

- 1. To provide a scientific overview of anatomical donation, its history and scientific advancement.
- Fully address the risks and benefits of and the myths and misunderstandings regarding organ and tissue donation.
- 3. Explain the options available to minors and adults, including the option of designating oneself as an organ and tissue donor and the option of not designating oneself as an organ and tissue donor.

### Schoology and Standards Aligned System (SAS)

The toolkit also provides a Schoology forum and SAS portal for Pennsylvania educators, nurses, administrators, and our PA partners to share information, lesson plans, links, articles, and more for bringing organ and tissue donation awareness to Pennsylvania students in grades 9 through 12.

The purpose of the toolkit is:

- To provide secondary educators with information about OTDA.
- To provide secondary educators with tools they can readily use to implement the OTDA Curriculum Framework.
- To provide both a concrete and web-based format so that teachers can choose the most comfortable and convenient access route to this vital information.
- To provide resources to enable students to make personal choices regarding organ and tissue donation.

# PARTNERS



The Center for Organ Recovery & Education (CORE) is one of 58 federally designated not-for-profit organ procurement organizations (OPOs) in the United States, serving more than five million people in western Pennsylvania, West Virginia and Chemung County, NY. Like all OPOs, CORE coordinates the recovery and matching of organs, tissues and corneas for transplant within our service region and works tirelessly to create a culture of donation within the hospitals and communities we serve. CORE's goal is to end the deaths of those on the transplant waiting list, all the while maintaining integrity for the donation process, dignity for the donors, and compassion for their families.



Headquartered in Philadelphia, PA, Gift of Life Donor Program is the largest organ procurement organization (OPO) in the United States, serving 11.2 million people across the eastern half of Pennsylvania, southern New Jersey and Delaware. The non-profit, federally-designated OPO is part of the national network, UNOS, the United Network for Organ Sharing. Working in partnership with the 128 acute care hospitals and 15 transplant centers in its designated service area, Gift of Life helps give people a second chance at life. Since 1974, Gift of Life has coordinated more than 47,000 organs for transplantation and approximately one million life-enhancing tissue transplants.

# PRE-TEST

- 1. How do you become an organ donor?
- 2. What organs can be used for donation?
- 3. How are donors and recipients matched?
- 4. Are there health requirements to become a donor?
- 5. Have you ever read anything about organ and tissue donation?
- 6. If you are an organ donor, do you think your organs can be used for transplant?
- 7. Do you think if you smoke or drink you can become an organ donor?
- 8. How is organ tissue donation done in other countries?
- 9. What happens during a transplant?
- 10. How long can organs be kept after recovery before they are transplanted?
- 11. What does the acronym CORE stand for?
- 12. If you are not designated as an organ donor, can your family designate for you?
- 13. If your family does not want you to donate your organs, can you still be a donor?
- 14. Does this topic scare you?
- 15. Why is it important to understand organ and tissue donation?
- 16. OPO is an acronym for \_\_\_\_\_



# Post-Test

- 1. How do you become an organ donor?
- 2. What organs can be used for donation?
- 3. How are donors and recipients matched?
- 4. Are there health requirements to become a donor?
- 5. Have you ever read anything about organ and tissue donation?
- 6. If you are an organ donor, do you think your organs can be used for transplant?
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- 15. Why is it important to understand organ and tissue donation?
- 16. OPO is an acronym for \_\_\_\_\_



# Top Myths about Donation





### **MYTH 1:**

If I am in an accident and the doctors or nurses find my donor card, they will not try to save my life.

**FACT:** Doctors, nurses and paramedics will do everything to try to save your life. In fact, an individual needs to be in the hospital, on a ventilator and pronounced dead in order to donate organs. An organ procurement organization (OPO) is not notified until all life-saving efforts have failed.

### **MYTH 2:**

I do not want my body "cut up."

**FACT:** Donated organs and tissue are removed surgically in the regular hospital operating room. Doctors maintain dignity and respect for the donor at all times.

### **MYTH 3:**

Wealthy people are the only people who receive transplants.

**FACT:** Most major insurances now cover heart, liver, kidney, and lung transplants. Donors don't need to pay for donation, either. An organ procurement organization (OPO) assumes all costs related to the donation. Additionally, organs are matched first according to clinical criteria, such as blood type, followed by medical urgency and then time accrued on the waiting list.

### **MYTH 4:**

I am not the right age for donation.

**FACT:** Organs may be donated from someone as young as a newborn. There is no age limit for organ donation. The general age limit for tissue is 80 and for corneas is 70.

### **MYTH 5:**

If I do not sign a donor card, my organs and tissues won't be donated.

**FACT:** Without a donor card or donor designation, families of suitable donors will be offered the opportunity to donate. To ensure your wishes are fulfilled, sign a donor card or place the designation on your license/state identification card.

### **MYTH 6:**

My religion does not support donation.

FACT: Major organized religions support donation.

### **MYTH 7:**

Only heart, liver and kidneys can be transplanted.

**FACT:** The pancreas, lungs, and intestines can also be transplanted, as can corneas, bone, ligaments, tendons, heart valves, saphenous veins and skin.

### **MYTH 8:**

I don't want my organs going to people who didn't take care of theirs.

**FACT:** Most recipients have illnesses or diseases unrelated to lifestyle choices. People who abuse drugs/alcohol make up less than 5% of recipients, and must stay sober for 5 months before being added to the transplant list.

### **MYTH 9:**

I have a history of medical illness. You would not want anything.

**FACT:** At the time of death, an organ procurement organization (OPO) will review medical and social histories to determine suitability. Few illnesses or conditions prevent someone from being a donor.

# Transplantation & Donation Basics



Yourself

# Deceased Donation

The sequence and time frame of the following events will vary epending upon individual circumstances. The entire donation process takes from a few hours to twenty or more hours.



### **The Organ Donation Process**



### Trying to Save a Life:

Healthcare professionals do everything possible to save a patient's life.



### Testing for Brain Death:

If patient is not responding after all lifesaving efforts, tests determine if brain death occurred.



### Hospital Alerts Organ Procurement Organization:

Hospital notifies organ procurement organization of every patient that has died or is nearing death.



### **Obtaining Authorization:**

When authorization is obtained from the registry or next of kin, medical and social evaluation occur.



### Maintaining the Donor:

The donor is maintained on artificial support, the condition of each organ is carefully monitored.



### Recovering and Transporting Organs:

Organs and tissues are recovered in the same sterile and careful way as in any surgery.



### Transplanting the Organs:

Transplant team arrives at recipient hospital with the new organ, transplant operation takes place.



### Family Aftercare:

The families of all donors are offered grief support through a Bereavement Aftercare Program.

Yourself



### **Key Vocabulary**

Regenerative, leukemia, directed donation, donor chain, hemodialysis access, hemodialysis, living kidney donor, paired donation, peritoneal dialysis, non-directed donation

Some decisions to donate and save lives can be made during one's lifetime. Living donation is a voluntary process and has nothing to do with registering as a deceased organ and tissue donor.

### REGENERATIVE DONATION

Most types of living donation consist of regenerative tissue. This type of tissue grows back naturally after some of it is removed.

### **BLOOD**

Blood donations help millions of patients in need! You can learn more about blood donation and find a local blood drive through the American Red Cross.

### **BONE MARROW**

Bone marrow often saves the lives of leukemia patients. The National Bone Marrow Program's website, Be the Match, offers information and resources about registering to be a bone marrow donor.

### **LIVER**

The liver is the body's only regenerative organ. This means that a portion of the liver can be removed from a living donor and transplanted into a recipient, and both the liver segment in the recipient and in the donor will grow to normal size in a few months. The liver is able to do the extra work necessary so that both the donor and the recipient can be healthy.

### NON-REGENERATIVE DONATION

These tissues do not grow back. However, living donors offer their loved one, friend, or an anonymous recipient an alternative to waiting on the national waiting list for an organ from a deceased donor.

### **KIDNEY**

People have two kidneys, except in rare cases. If someone chooses to donate one kidney, the remaining kidney can carry out the normal functions of both kidneys.

### LUNG

A lower lobe of a lung can be donated, although this kind of procedure is very rare.

### PANCREAS AND INTESTINE

Though extremely rare, it is also possible to be a living pancreas and intestine donor. Neither of these surgical procedures are currently performed in Pennsylvania.

# Why Do People Need Organ Transplants?

Patients on the U.S. waiting list are in end-stage organ failure. This means that their organs were formed abnormally at birth or have been damaged by disease or accidental injury. When vital organs are severely damaged, they may need to be replaced for a person to survive. The chart below details the most common reasons people need organ transplants.

Donated Organ	Disease or Disorder	Description
HEART	Congestive Heart Failure	The heart no longer pumps enough blood to meet the body's needs.
LUNG	Cystic Fibrosis	A hereditary disease causing thick, sticky mucus to build up in the lungs.
LIVER	Non-alcoholic Fatty Liver Disease	Extra fat builds up in liver cells and destroys the liver's ability to filter. This tends to develop in people who are obese, or have diabetes or high cholesterol.
KIDNEY	High Blood Pressure	Kidneys are damaged, and can no longer filter waste from the body.
INTESTINE	Blocked or twisted intestines	Some babies are born with malformations of the gastrointestinal tract, reducing their ability to digest food or absorb fluid.

# Why Do People Need Tissue Transplants?

A single tissue donor can save or enhance more than 50 lives. This is because there are many kinds of tissues which can be donated, for many different reasons:

Donated Tissue	Typical Application	Benefit for Recipient
CORNEA	Replaces diseased or damaged cornea	Prevents blindness; restores vision.
BONE	Reconstruction related to trauma, tumors, degenerative diseases	Prevents the need for amputation. Accelerates, promotes and allows healing. Restores mobility.
SKIN	Temporary biological bandages for burn victims prevent infection, decrease pain, prevent heat and fluid loss, and reduce scarring	Promotes healing; natural barrier to infection.
VALVES	Repairs congenital abnormalities	Maintains unidirectional flow of blood in the heart.
TENDONS	Reconstruction related to trauma, tears, or overuse	Rebuilds joints; restores mobility.

# COMMUNITIES OF COLOR IN CRISIS

The U.S. waiting list is comprised of people of all ages, genders, and ethnic backgrounds. However, certain ethnic groups are more prone to organ failure.

Although there are many reasons for needing an organ transplant, researchers from Oregon Health & Science University believe that a combination of genetic predisposition and inactive lifestyles foster higher rates of obesity among certain groups. Obesity is a major contributing factor to many diseases. And when untreated or uncontrolled, certain diseases often lead to organ failure (Ahmann, 2014).

According to the U.S. Office of Minority Health, many ethnic groups have higher rates of potentially organ-destroying diseases, such as:

- Diabetes
- Hypertension (high blood pressure)
- · Liver disease

- Latinos, African Americans, and Pacific Islanders are three times more likely than Caucasians to suffer from obesity and diabetes.
- Native Americans are four times more likely to suffer from diabetes and heart diseases
- Asian Americans suffer significantly from liver disease and hepatitis.

At the same time, African American and Hispanic American communities have lower rates of consent to organ and tissue donation. Several studies indicate that cultural beliefs, misinformation and/or negative portrayals of donation in TV or the media regarding donation can heavily influence an individual's decision to donate.

Although organs are not matched according to race or ethnicity, all individuals waiting for an organ transplant will have a better chance of receiving one if there are large numbers of donors from their ethnic background. This is because compatible blood types and tissue markers – critical qualities for donor/recipient matching – are more likely to be found among members of the same ethnicity. A greater diversity of donors may potentially increase access to transplantation for everyone (Office of Minority Health, 2014).



# Who Gets an Organ Transplant?

Being placed on the waiting list for an organ transplant is not automatic. Because there are so few available organs, patients are carefully evaluated by their doctors, surgeons, and transplant staff prior to being placed on the national waiting list.

The decision is based on the status of the patient's health, their medical and social history, and the expectation of their stability after the transplant takes place – both psychologically and financially. A donation is a rare and special gift, so doctors must be sure that a potential recipient can take care of their new organ with medication, regular office visits, and healthy lifestyle choices. Patients who are unwilling to give up unhealthy drugs, including nicotine and alcohol, may be automatically disqualified.

If a transplant team feels that a patient is a good candidate for transplant, they will contact the United Network for Organ Sharing in order to put the patient on the national waiting list.

Waiting for an organ transplant is not like taking a number at the deli counter and waiting for your turn! There is no ranking or patient order until there is a deceased donor, because each donor's blood type, size, and genetic characteristics are different. When a donor is entered into the national computer system, only the transplant candidates who match that donor's medical characteristics will appear.

### WHAT IS THE WAITING LIST?

When a transplant hospital places a patient on the U.S. waiting list, the patients are registered in a centralized, national computer database that links all donors and transplant candidates. In the United States, this network is managed by the United Network for Organ Sharing 24 hours a day, 365 days a year.

The "list" is a computer network which tracks the following criteria about transplant candidates:

- Blood and tissue type
- Immune status
- Degree of medical urgency
- Time spent waiting

The system uses this information to match the medical characteristics of those waiting against those of a deceased organ donor.

The waiting list does not track a candidate's race, gender, fame, or financial status. This ensures that organs are matched according to strict medical criteria, and that there is no possibility of special treatment.

transplantliving.org



# How Long Do People Wait?

Once someone is added to the list, they must wait for a matching organ to become available. This may take days, weeks, months, or even years. The average wait time per organ, according to the U.S. Department of Health & Human Services, is listed in the chart below.

Where a person lives can also impact how long they must wait. For example, waiting times may be longer in large cities with large populations because the need for certain organs will be higher. Waiting times may be shorter in smaller communities. Regardless, when an organ becomes available, it is first offered to local transplant centers. If no match is found, the organ will then be shared on a regional and national level.

ORGAN	Median National Waiting Time
HEART	113 DAYS or 3.8 MONTHS
LUNGS	141 DAYS or 4.7 MONTHS
LIVER	361 DAYS or 1 YEAR
KIDNEY	1,219 DAYS or 3 YEARS, 3 MONTHS
PANCREAS	260 DAYS or 8.6 MONTHS
INTESTINE	159 DAYS or 5.3 MONTHS

# LIVING KIDNEY DONATION

### **GOT TWO, GIVE ONE**

Since 1954, when the first successful living kidney transplant in the United States took place between identical twins, living donors have been giving the gift of life and making a difference.

Why is kidney donation possible? Put simply, because we have two. Several studies have shown that donating one kidney does not change life expectancy or increase a person's risk of developing kidney disease or any other kidney-based health problems. A person can lead an active, normal life with just one kidney. Like anyone else, they are able to play sports, have children, and exercise.

Living kidney donors effectively save two lives through their single donation: the life of the recipient, and also the life of a stranger on the waiting list, for whom a chance to receive a deceased donor's kidney is now one step closer. Additionally, if ever a living kidney donor finds themselves in need of a kidney transplant later in life, they will be at or near the top of the deceased donor list, shortening their wait time.

### FINDING A LIVING KIDNEY DONOR

If you needed a kidney transplant, who would you most likely ask? Most people respond, "My family."

Unfortunately, this is not always possible. It is critical that blood and tissue types between the donor and recipient are well matched so that the chance of rejection is lessened. Nor does everyone have the option of turning to their family. For example, if someone has a family history of genetic diseases, such as polycystic kidney disease, they might not qualify to donate to a relative.

It is no small thing to try to find a living kidney donor! Some people make the decision to donate instantly — only to find that they are incompatible and cannot donate to their loved one. Fears and misconceptions can make living kidney donation a difficult subject. For example, a common misbelief is that a living kidney donor is risking their life or compromising their health. For a person who needs a kidney transplant, this misbelief may be so strong that it may prevent them from even talking to their family and friends about the possibility of living donation.

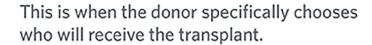
In any case, transplant centers assist transplant recipients in developing approaches to finding a living kidney donor.

# Types of Living Donation

### **Matching Donors to Recipients**

There are three categories of living donations:

### **#1 Directed Donation:**





### #2 Non-Directed Donation:

This is when the donor is neither related to nor known by the person in need. He or she makes the donation purely out of selfless reasons. The recipient is determined primarily by medical compatibility.



### #3 Paired Donations (Kidney Only)

This involves at least two pairs of livingkidney donors and transplant candidates who do not have matching blood types. The transplant candiates "trade" donors so that each recipient receives a kidney from the donor with a compatible blood type.





# How Does the Waiting List Work?

### Submitted by Dwendy Johnson, Gift of Life Donor Program

Hospitals are required by law to notify the local organ procurement organization of the impending death of a patient. The OPO staff will then consider possible medical disqualifications for organ and tissue donation. If none are readily apparent, a trained transplant coordinator will visit the hospital to further evaluate the patient. If the patient is medically suitable, the option for donation is offered to the next of kin. Once the family consents, the coordinators work with the national computerized waiting list at UNOS to match the donated organs with the most appropriate recipient(s) and arrange for the recovery surgery. They also stay with the donor's family and provide support as long as the family wishes. Immediately after the organ(s) are surgically removed from the donor, the OPO staff transports the organs to the transplant centers, where the recipients have been readied for surgery.

Individuals waiting for transplants are listed by the transplant center in their area. Their name then goes into a national computerized waiting list of potential transplants patients in the United States maintained by the United Network for Organ Sharing (UNOS). UNOS heads a 24-hour telephone service to aid in matching donor organs with patients on the national waiting list and to coordinate efforts with transplant centers.

When donor organs become available, the organ procurement organization (such as Gift of Life Donor Program or CORE) provides UNOS with information about the medical characteristics of the donor and specific organs, including medical compatibility between the donor and potential recipient(s) on such characteristics as blood type, weight, and age, as well as the recipients' urgency of need; and length of time on waiting list. Also, preference is generally given to recipients from the same geographic area as the donor, because timing is a critical element in the success of transplants.

# Frequently Asked Questions

## If I decide to register as an organ donor, will it affect the quality of medical care I receive?

No! Every effort is made to save your life before donation is considered. Donors receive the same high quality care that nondonors receive. Medical personnel must follow very strict guidelines before they can pronounce death and remove the donor's organs and tissues. The first priority for the medical personnel is to save the lives of all patients. Organ and tissue donation is not even discussed until every life-saving option is exhausted and death has been declared or is imminent. The doctors and nurses at the medical center are completely separate from those who work for the organ procurement organization (OPO). Donation occurs as an option when there is nothing more that can be done to save the donor's life.

### Who can become a donor and is there an age limit?

Anyone can be a potential organ and tissue donor, from newborns to senior citizens. Eligibility is determined on a case-by-case basis at the time of death and may be affected by medical history, the cause of death and other factors. Persons under 18 years of age must have a parent or guardian's consent.

### What organs can be donated?

The heart, lungs, liver, kidneys, pancreas, and intestines can be donated.

### What tissues can be donated?

- Cardiovascular tissue, such as heart valves and saphenous veins.
- Eye tissue, such as corneas and whole eyes.
- Bone tissue, such as ribs, bones of the arm, leg, shoulder, hip, ankle, spine and jaw.
- Connective tissue, such as ligaments, tendons, cartilage and fascia.
- Skin grafts from the front and back of the legs and the chest.

### What is the difference between organ and tissue donation?

Most of the time organ donation can only be done on a donor who has been declared brain dead, but whose other organs are kept functioning by sophisticated hospital machinery. Because brain death is not a common occurrence, viable organ donors are rare. Tissue donation can occur even after the heart has ceased beating. Most deaths produce potential tissue donors (depending on the medical history). Organ donors can also be tissue donors.

### Can I designate myself a donor before I get a driver's license or can I update my donor status even before my driver's license needs to be renewed?

Yes, you can decide to become a donor and make your wish official on the PA registry at any time. You can register online at www.donatelifepa.org. You need parental permission whether you register online or when you get your license.



### What are the benefits of organ donation?

All organ transplants are life saving, except for kidney and pancreas transplants, which are considered to enhance the recipient's quality of life. Kidney transplantation frees the recipient from needing dialysis, and, in many instances, does save or lengthen the life of the patient.

### Would my family member feel any pain if his or her organs were donated?

No. The person is deceased and no longer feels pain.

### Will donation disfigure my body? Can there be an open casket funeral?

Donation does not disfigure the body and does not interfere with funeral plans, including open-casket services. In organ and tissue donation, the body is treated with a great deal of respect and dignity. Donation typically does not delay funeral arrangements.

### What do religious groups think about organ and tissue donation?

Most religions throughout the world support organ and tissue donation. If you have concerns about your religion's position, you are encouraged to discuss this with your own religious advisor.

### Why should minorities be particularly concerned about organ donation?

Race does not play a part in the allocation of organs. Some diseases of the kidney, heart, lung, pancreas and liver are found more frequently among specific racial or ethnic populations. For example, African Americans, Asians, Pacific Islanders, and Hispanics are three times more likely to suffer from end-stage renal disease than Caucasians. Native Americans are four times more likely than Caucasians to suffer from diabetes.

Successful transplantation often is enhanced by the matching of organs between members of the same ethnic and racial group. For example, an African American patient is often less likely to reject a kidney if it is donated by an individual who is also African American. A shortage of organs donated by minorities can contribute to longer waiting periods for transplants for minorities and potentially death.

For more information on minorities and organ donation and transplantation, contact Minority Organ Tissue Transplantation Education Program (MOTTEP) at 202-865-4888, United Network for Organ Sharing (UNOS) at ww.unos.org, or the Department of Health & Human Services at www.organdonor.gov.

### Are there any costs to my family for donation?

No! Donor families are only responsible for the emergency care their loved one received prior to brain death and funeral costs. Procurement agencies pay the costs associated with recovery of organs and tissue from donors. Donor families are not responsible for any additional costs.

### Can people sell their organs, tissues, or body?

No! The National Organ Transplant Act makes it ILLEGAL to sell human organs and tissues in the United States. Violators are subject to fines and imprisonment.



### How are organs and tissues recovered?

Organs are recovered in a sterile operating room, using qualified surgical personnel and protocols. Tissue is often recovered in operating rooms, but can also be recovered in sterile surgical facilities at medical examiners' offices or at some mortuaries. All donations are a precious gift and are treated with respect and dignity. Standard surgical sutures or staples are used to close the incisions, just as with any operation. If needed following tissue donation, prosthetic devices will be used to maintain the body's original form.

### Can I change my mind?

You can register as an organ donor at donatelifepa.org or when you receive/renew your driver's license. If you wish to make changes to your designation, you may do so upon renewal of your driver's license. Always be sure to discuss your wishes with your family regarding your own organ donation.

### What is done to ensure the transplant recipient's safety?

Every effort is made to ensure the safety of organ and tissue donations. Each donor is meticulously screened for any infectious diseases, and a social history is gathered.

### What are the benefits of tissue transplantation?

Tissue transplants enhance the quality of life of the recipient, except for skin, which saves more lives than all tissues and organs combined. Listed below are some of the ways tissue is used to help recipients:

- Skin grafts for burn victims
- · Fusing of spinal defects to reduce pain
- · Replacement of benign cystic bone defects to improve mobility
- Replacement of cancerous bone tumors to prevent amputation
- Straightening and strengthening of spines distorted by scoliosis
- Replacement of hipbones to restore mobility
- Reconstruction of jaw and other bones to restore normal facial appearance
- Restoration of sight and prevention of blindness
- Heart bypass surgery through use of saphenous veins
- Restoration of blood flow through use of saphenous veins
- Replacement of defective heart valves
- Repair damaged ligaments, cartilage and tendons for improved mobility

### Can the donor's family receive any feedback after donation?

Yes. The family can request to receive information regarding how the various donated organs or tissues helped recipients.

# Can recipients contact the donor's family? And how can the donor family contact the recipients of their loved one's organs?

Recipients of donated organs often want to find out specifics about the person that donated the organ they received. Also, many families that donate their relative's organs wish to know where and to whom the organs went. In general, the identity of the donor and the recipients of the organs is kept confidential to protect the privacy of each party. The regional OPOs coordinate.



### What does the recovery process involve?

Only after all lifesaving efforts have been made, is the care of the donor transferred from one medical team to another. Once the decision to donate has been made, an OPO contacts the transplant surgeons who will perform the surgery to recover the organs. An OPO staff member, called a recovery coordinator, accompanies the surgeons to the donor hospital. The recovery coordinator also is responsible for ensuring that the organs are prepared appropriately for transport to the hospital where the transplant will be performed. Once the organs are recovered, the recovery coordinators then will recover the tissue and corneas, if consent has been obtained.

### How many people can be helped through donation?

One donor can impact up to 8 lives directly, tissue can enhance up to 75 lives, and corneas can enhance up to 2 lives.

### What is brain death?

Brain death results most often from severe head injuries caused by strokes, motor vehicle accidents, shootings, acute allergic reactions or some illnesses. When the injury or illness permanently cuts the blood and oxygen supply to the brain, the brain stops working. If the brain stops working, the body will stop working and die. Brain death is permanent and irreversible. <a href="https://www.youtube.com/watch?v=Ffqz-vKZO5Q">https://www.youtube.com/watch?v=Ffqz-vKZO5Q</a>

### How is it decided who receives organs?

Donated organs are given to patients based on the match between the donor and intended recipient's height, weight, and blood type; medical urgency; and time on the waiting list. In spite of another common myth, a person's wealth, age, race and gender do not affect who receives organs.

### How else can I help?

You can help by making a contribution to the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund, which helps support donor awareness and education programs in Pennsylvania. Simply add the designation amount to the driver's license fee or car registration renewal fee to help educate others about the importance of organ and tissue donation.

FAQs compiled with IOPO, JRI/Flow, The Gift of Life



# Religions and Donations

All major religions support organ donation as a humanitarian gift giving life. If you have questions about donation, we encourage you to talk with the leader of your religious community.

Below is a basic summary of some of the key beliefs. More detailed information can be found at http://organdonor.gov/donation/religious views.htm

### **AME & AME Zionism**

(African Methodist Episcopal) Organ and tissue donation is viewed as an act of neighborly love and charity by these denominations. They encourage all members to support donation as a way of helping others.

# Anabaptism (Amish, Brethren, Mennonite)

The Anabaptist religions have no formal position on donation; however, they all support donation as a life-saving act to improve others' lives.

### **Baptism**

Organ and tissue donation is supported as an act of charity. The Baptist Church leaves the decision up to the individual.

### **Buddhism**

Buddhists believe organ and tissue donation is a matter of individual conscience and place a high value on acts of compassion. Reverend Gyomay Masao, president and founder of the Buddhist Temple of Chicago says, "We honor those people who donate their bodies and organs to the advancement of medical science and to saving lives." The importance of letting loved ones know your wishes is stressed.

### Catholicism

Catholics view organ and tissue donation as an act of charity and love. Transplants are morally and ethically acceptable to the Vatican. Pope John Paul II has stated, "The Catholic Church would promote the fact that there is a need for organ donors, and Christians should accept this as a challenge to their generosity and fraternal love so long as ethical principles are followed."

### **Christian Science**

The Church of Christian Science does not have a specific position regarding organ donation. The question of organ and tissue donation is an individual decision.

### **Episcopalian**

The Episcopal Church passed a resolution in 1982 that recognizes the life-giving benefits of organ, blood and tissue donation.

### Hinduism

According to the Hindu Temple Society of North America, religious law does not prohibit Hindus from donating their organs. This act is an individual's decision.

### Islam

The religion of Islam strongly believes in the principle of saving human lives.

### Jehovah's Witness

According to the Watch Tower Society, Jehovah's Witnesses believe donation is a matter of individual decision. Jehovah's Witnesses are often assumed to be against donation because of their opposition to blood transfusions. However, this merely means that all blood must be removed from the organs and tissue before being transplanted.

### **Judaism**

All four branches of Judaism (Orthodox, Conservative, Reform and Reconstructionist) support and encourage donation.

### The Lutheran Church of America

Lutherans passed a resolution in 1984 stating that donation contributes to the well being of humanity and can be "an expression of sacrificial love for a neighbor in need." They call on "members to consider donating... and to make any necessary family and legal arrangements, including the use of a signed donor card."

# Mormonism (Church of Jesus Christ of Latter-Day Saints)

The Church of Jesus Christ of Latter-Day Saints believes the decision to donate is an individual one made in conjunction with family, medical personnel, and prayer.



### **Presbyterianism**

Presbyterians encourage and support donation. They respect a person's right to make decisions regarding his or her own body.

### **Protestantism**

Protestants encourage and endorse organ donation. The Protestant faith respects an individual's conscience and a person's right to make decisions regarding his or her own body.

### Seventh-Day Adventistism

Donation and transplantation are strongly encouraged. They have many transplant hospitals, including Loma Linda in California, which specializes in pediatric heart transplants.

### Society of Friends (Quakers)

Organ and tissue donation is widely believed to be an individual decision. The Society of Friends does not have an official position on donation.

### **Unitarianism**

Organ and tissue donation is widely supported by Unitarian Universalists. They view it as an act of love and selfless giving.

### **United Church of Christ**

Reverend Jay Lintner, Director, Washington Office of the United Church of Christ Office for Church in Society, states, "United Church of Christ people, churches and agencies are extremely and overwhelmingly supportive of organ sharing."

### **United Methodist**

The United Methodist Church issued a policy statement regarding organ and tissue donation. In it they state, "The United Methodist Church recognizes the life-giving benefits of organ and tissue donation, and thereby encourages all Christians to become organ and tissue donors by signing and carrying donor cards or a driver's license, attesting to their commitment of such organs upon their death to those in need, as a part of their ministry to others in the name of Christ, who gave His life that we might have life in its fullness."

Donation and religion facts compiled with IOPO, Gift of Life Donor Program and CORE sources.

# Curriculum & Standards



Yourself



READING	Reading Informational Text: Students read, understand, and respond to informational text—with an emphasis on comprehension, vocabulary acquisition, and making connections among ideas and between texts with focus on textual evidence.
CC.1.2.9-10.A.B CC.1.2.11-12.A.B	(9-10) Determine a central idea of a text and analyze its development over the course of the text, including how it emerges and is shaped and refined by specific details; provide an objective summary of the text.  (11-12) Determine and analyze the relationship between two or more central ideas of a text, including the development and interaction of the central ideas; provide an objective summary of the text.
CC.1.2.9-10.C CC.1.2.11-1.C	(9-10) Apply appropriate strategies to analyze, interpret, and evaluate how an author unfolds an analysis or series of ideas or events, including the order in which the points are made, how they are introduced and developed, and the connections that are drawn between them.  (11-12) Analyze the interaction and development of a complex set of ideas, sequence of events, or specific individuals over the course of the text.
CC.1.2.9-10.G CC.1.2.11-12.G	(9-10) Analyze various accounts of a subject told in different mediums (e.g., a person's life story in both print and multimedia), determining which details are emphasized in each account. (11-12) Integrate and evaluate multiple sources of information presented in different media or formats (e.g., visually, quantitatively) as well as in words in order to address a question or solve a problem.
CC.1.2.9-10.J CC.1.2.11-12.J	(9-10)(11-12) Acquire and use accurately general academic and domain specific words and phrases, sufficient for reading, writing, speaking, and listening at the college- and career-readiness level; demonstrate independence in gathering vocabulary knowledge when considering a word or phrase important to comprehension or expression.
CC.1.2.9-10.L CC.1.2.11-12.L	(9-10)(11-12) Read and comprehend literary nonfiction and informational text on grade level, reading independently and proficiently
WRITING	Students write for different purposes and audiences. Students write clear and focused text to convey a well-defined perspective and appropriate content.
CC.1.4.9-10.A CC.1.4.11-12.A	(9-10)(11-12) Write informative/explanatory texts to examine and convey complex ideas, concepts, and information clearly and accurately.
CC.1.4.9-10.H CC.1.4.11-12.H	(9-10) Write with a sharp, distinct focus identifying topic, task, and audience. Introduce the precise claim. (11-12) Write with a sharp, distinct focus identifying topic, task, and audience. Introduce the precise, knowledgeable claim.
CC.1.9-10.U	(9-10) Use technology, including the Internet, to produce, publish, and update individual or shared writing products, taking advantage of technology's capacity to link to other information and to display information flexibly and dynamically.

# Pennsylvania Academic Standards

SPEAKING AND LISTENING	Students present appropriately in formal speaking situations, listen critically, and respond intelligently as individuals or in group discussions.	
CC.1.5.9-10.A CC.1.5.11-12.A	(9-10)(11-12) Initiate and participate effectively in a range of collaborative discussions on grade-level topics, texts, and issues, building on others' ideas and expressing their own clearly and persuasively.	
CC.1.5.9-10.D CC.1.5.11-12.D	(9-10)(11-12) Present information, findings, and supporting evidence clearly, concisely, and logically such that listeners can follow the line of reasoning; ensure that the presentation is appropriate to purpose, audience, and task.	
HISTORY		
8.1.9.A	Compare the interpretation of historical events and sources, considering the use of facts versus opinion, multiple perspectives, and cause and effect relationships.	
8.1.9.B	Compare patterns of continuity and change over time, applying context of events.	
SCIENCE AND TECHNOLOGY	Crosscutting Concepts & Unifying Themes	
Patterns	Observed patterns of forms and events guide organization and classification, and the prompt questions about relationships and the factors that influence them.	
	Students observe patterns in systems at different scales and cite patterns as empirical evidence for causality in supporting their explanations of phenomena.	
Cause and Effect	Mechanism and explanation. Events have causes, sometimes simple, sometimes multifaceted. A major activity of science is investigating and explaining causal relationships and the mechanisms by which they are mediated. Such mechanisms can then be tested across given contexts and used to predict and explain events in new contexts.	
	Students understand that empirical evidence is required to differentiate between cause and correlation and to make claims about specific causes and effects.	
Structure and Function	The way in which an object or living thing is shaped and its substructure determine many of its properties and functions.	
	Students investigate systems by examining the properties of different materials, the structures of different components, and their interconnections to reveal the system's function and/or solve a problem.	
Systems and System Models	Defining the system under study – specifying its boundaries and making explicit a model of that system – provides tools for understanding and testing ideas that are applicable throughout science and engineering.	
	Students can use models and simulations to predict the behavior of a system, and recognize that these predictions have limited precision and reliability due to the assumptions and approximations inherent in the models.	



# Lesson Plans & Activities



Yourself



## HISTORY OF ORGAN & TISSUE DONATION

Focus: History of Organ and Tissue Donation

**Lesson:** Organ Donation and Transplantation

Overview: Students will read about Dr. Thomas Starzl as the "Father of Transplantation", the medical devel-

opments of his time, and the chronological events of his work.

Time Needed: One class period

### Objectives:

- 1. During this activity, students will read the non-fiction text about Dr. Thomas Starzl, also known as the "father of transplantation." http://www.starzl.pitt.edu/about/starzl.html
- 2. Upon completion of the text, students will use a timeline to record significant events in the life of Dr. Starzl and his advancements made in transplantation.
- 3. Students will conduct a search using the internet to explore medical and technological advancements from 1950-1960. Students will use a timeline to record these findings.
- 4. After completing this activity, students will complete a written response depicting the challenges and advancements of Dr. Starzl regarding organ transplantation.

### Standards Match:

Reading, Writing, Speaking, and Listening	History	Crosscutting Concepts & Unifying Themes
1.1.11.D, 1.1.11.G, 1.5.11.A, 1.5.11.B, 1.8.11.B	8.1.9.A, 8.1.9.B	Structure & Function

### **Materials Needed:**

- Access to internet to read about Dr. Starzl. http://www.starzl.pitt. edu/about/starzl.html
- One timeline per student

### **Activity:**

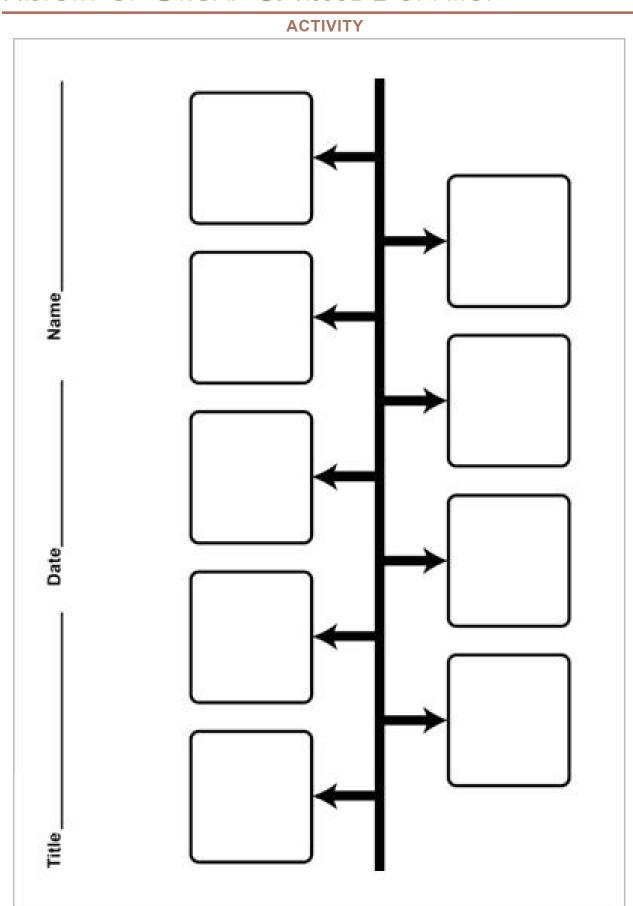
- Have students read about Dr. Thomas Starzl. Students will record significant events in his life and his medical accomplishments in transplantation.
- Divide the class in half. One group performs internet search on the medical and technological advances made from 1950-1960 and records findings on provided timeline. The other half of the students will research the life and work of Dr. Thomas Starzl and record their findings on the provided timeline.

- 3. Students discuss findings in a large group setting.
- 4. Upon completion of activity and whole group discussion, each student will reflect on the research and readings to write a response depicting the challenges that Dr. Starzl experienced as he pioneered his way to becoming "the Father of Transplantation."

### **Optional Resources:**

"A Science of Miracles" https://www.youtube.com/watch?v=EWCBxinhwbc

# History of Organ & Tissue Donation







## Your Decision to Donate

Focus: Personal Response

Lesson: Your Decision to Donate

**Overview:** Students will review the recent national and state statistics of organ and tissue donation, listen to real life stories of recipients and donor families, and know the steps to take to designate oneself.

Time Needed: Two class periods

### **Objectives:**

- 1. Upon completion of activity, students will learn about Pennsylvania's statistics regarding organ and tissue donation.
- 2. Upon completion, students will understand the steps needed to become an organ donor in Pennsylvania.
- 3. Students will complete a letter to their family describing facts of donation and personal wishes regarding their own organ donation.

### Standards Match:

### Reading, Writing, Speaking, and Listening

1.1.11.D, 1.1.11.G, 1.8.11.B

### **Materials Needed:**

- DMV Pennsylvania Department of Motor Vehicle pamphlet
- computer
- copy of decision making format, one per student
- copy of letter to parent/guardian, one per student

### Activity:

- Students will turn to a neighbor and discuss what they know about organ and tissue donation.
- Students will read the most recent Pennsylvania Department of Motor Vehicle's pamphlet on considering to become an organ donor at the time of your license and discuss.
- 3. Students will view the videos:
  - a. "Donation and Transplantation: How Does It Work?" from the United States Department of Health and Services.
  - b. http://www.donatelifepa.org/humanside/
  - \*Multiple videos of Pennsylvania's recipients and donor families

# YOUR DECISION TO DONATE ACTIVITY

When you receive your license or permit, you will be asked if you want to be an anatomical donor. What does it mean to be a registered donor?

### WHY REGISTER?

There are nearly 120,000 patients on the national organ transplant waiting list, each one reliant on the compassion and generosity of another for a life-saving gift of organ donation from a deceased donor. While many will be transplanted, there are some who sadly will not. 100 people die every week while waiting for an organ transplant.

### SHOULD THE UNTHINKABLE HAPPEN...

Registering as a donor indicates that you wish to donate any viable organs or tissues which could save someone else's life, or to restore a stranger's vision or mobility, through transplantation after you pass away. When individuals document this decision by registering – whether at the DMV or directly on their state's confidential, online registry – their family can take comfort in knowing their loved one's wishes. One organ donor can save up to eight lives and one tissue donor can help up to 100 people!

Learn more by watching videos on the website:

https://donatelifepa.org
The #Humanside of Donation

Registering as a donor does not necessarily mean you will become a donor after you pass away. In fact, less than 1 percent of the American population die under the specific, and rare, medical circumstances necessary to support organ donation.

This video explains why:

DONATION AND TRANSPLANTATION: HOW DOES IT WORK? <a href="https://www.youtube.com/watch?v=HuKx2a5HkIM">https://www.youtube.com/watch?v=HuKx2a5HkIM</a>

U.S. Department of Health and Human Service

### TALK TO YOUR FAMILY

It is extremely important for everyone to talk with their families and loved ones about their wishes regarding organ and tissue donation. If you are under the age of 18, donation never occurs without parental/guardian authorization. This is why it is important to talk to your family about your decision – whether or not you wish to be a donor, you and your family should know what everyone's wishes are. Do you know what your loved ones think about organ and tissue donation?

If you wish to document your decision to be an organ and tissue donor, you can elect to have your driver's permit/license coded at the DMV, or register directly on your state's online registry (see below). You do not need parental permission to register. More information about your state's registry and donation:

National: donatelife.net

State: donatelifepa.org

To register to be a donor: donatelifepa.org/register

"An Organ, Eye, and Tissue Donation Curriculum" education@donatelifenw.org

# Your Decision to Donate

### **ACTIVITY**

### **Decision-Making Format**

1. The Problem	1: Snould I become	e an organ donc	or and sign the org	an donor card?

2. Facts bearing on problem.

3.	List	courses	of	action.

- a)
- b)
- c)
- 4. Discuss courses of action.
- a)
- b)
- c)

5. My decision is\_\_\_\_\_\_.

This is based on:\_\_\_\_\_.

Yourself

# Your Decision to Donate

### **ACTIVITY**

### Provide to the student AFTER teaching

Dear Parent or Guardian:	
	s I learned about organ and tissue donation and trans- e need for me to talk about my wishes about donation and
My feelings are	
□ I DO wish to be an organ and/or tissue donor.	
☐ I DO NOT wish to be an organ and/or tissue don	or.
☐ I am NOT SURE at this time.	
It is important for me to know how you feel about th so that we can both understand more about each o	is subject. I want to take the time to talk with you about it ther's wishes.
Signature	Date

## Your Decision to Donate

### **ACTIVITY**

### Making a Decision about Donation

Answering the questions below will help you consider organ and tissue donation. Use the back of this paper if needed to write out your thoughts.

- 1. What are your options in terms of registering as a donor?
- 2. Does the idea of donating organs and/or tissues after you pass away conflict with or complement your personal values? Why or why not?
- 3. If you needed an organ transplant in order to live, do you think organ donation would conflict with or complement your values?
- 4. Who would be impacted by your decision to donate or not to donate?
- 5. Are there any risks to registering? What, if any, are they?
  - a. Where did you hear about this risk? Can you verify that your concerns are based on fact?
- 6. Is time a factor in whether or not to register? In other words, does it matter if you register today, or ten years from today?
- 7. How do you register as a donor in your state?



Domain: Risks and Benefits

Lesson: Myths and Truths

Overview: Students will explore and discuss the myths and truths of organ donation through whole class and

small group activities.

Time Needed: Two class periods

### Objectives:

Upon completion of this activity, students will know the "Myths and Truths" of organ donation.

### Standards Match:

Reading, Writing, Speaking, and Listening	Crosscutting Concepts & Unifying Themes
1.1.11.G, 1.6.11.A, 1.6.11.D, 1.6.11.E	Cause & Effect

### **Materials Needed:**

- "Myths and Truths" template (1 per group)
- "Myths and Truths" statement slips (1 per group)
- Top 10 myths of organ donation.
- "Organ Donation: What You Should Know" (1 per group)
- "Myths and Truths"

### **Activity:**

- 1. Students will be grouped in small groups to complete the "Myths and Truths" cut and paste activity.
- 2. In a large group, discuss the myths related to organ and tissue donation.
- Have groups use the internet to research answers to complete the "Organ Donation: What You Should Know About Organ Donation" worksheet.

4. Wrap Up Activity: Form students into two equal teams. Have each team member sit shoulder to shoulder. The last student on each team holds one set of the "myths and truths" cards. The teacher reads a statement about organ and tissue donation. If the statement is a "truth", then the "truth" card is passed all the way to the front of the line. The same applies if it is a myth. First person in line stands and announces the card chosen. First one to announce correct answer, earns a point. If the answer is incorrect, the opposing team gets a chance to steal the point if they can defend why it is incorrect. Once point is awarded, all players move one seat over to their right, with the first person going to the end of the line. Next statement is read and the game continues in the same manner.

### **Discussion Questions:**

- 1. What have you learned?
- 2. How did you feel about organ and tissue donation in the beginning?
- 3. How do you feel about organ and tissue donation now?





# Your Decision to Donate

### ACTIVITY

### **MYTHS AND TRUTHS**

TRUTH	MYTH

## Your Decision to Donate

### **ACTIVITY**

### **MYTHS AND TRUTHS**

Students: Please cut the following strips and place under appropriate column on the "MYTHS and TRUTHS" template.

Some people are too old to be organ donors.

All major organized religions support organ donation.

Only 3 out every 1,000 people die under circumstances appropriate for organ donation.

The donor's family pays for organ recovery.

If an adult hasn't made a decision about organ donation, only her spouse or adult child can legally consent to organ donation.

If a person has a medical condition, they cannot be an organ donor.

If medical staff see that I am an organ donor, they will not try to save my life.

A national computer system matches donated organs to recipients.

My family won't be able to have an open casket funeral if I'm a donor.

The majority of deceased organ donors are patients who have been declared brain dead, meaning there is no chance of recovery.

## Your Decision to Donate

### **ACTIVITY**

### MYTHS AND TRUTHS - Teacher Answer Key

Some people are too old to be organ donors. (M)

All major organized religions support organ donation. (T)

Only 3 out every 1,000 people die under circumstances appropriate for organ donation. (T)

The donor's family pays for organ recovery. (M)

If an adult hasn't made a decision about organ donation, only her spouse or adult child can legally consent to organ donation. (M)

If a person has a medical condition, they cannot be an organ donor. (M)

If medical staff see that I am an organ donor, they will not try to save my life. (M)

A national computer system matches donated organs to recipients. (T)

My family won't be able to have an open casket funeral if I'm a donor. (M)

The majority of deceased organ donors are patients who have been declared brain dead, meaning there is no chance of recovery. (T)

# Your Decision to Donate

1. What does OPO stand for?

### **ACTIVITY**

### **ORGAN DONATION: What You Should Know About Organ Donation**

Please use the internet to complete the following questions.
Use www.donatelife.net; www.unos.org; www.donors1.org; www.core.org

- 4. How many recipients die every 24 hours waiting for organs?
- 5. A person must be in a hospital on a ventilator and be declared brain dead before organs can be recovered. Explain the process (tests) done to determine if a patient is brain dead.

# YOUR DECISION TO DONATE ACTIVITY

### **ORGAN DONATION: What You Should Know About Organ Donation (continued)**

6. When someone's heart stops instantly, or the individual dies outside the hospital setting, can an individual still donate? If so, what can be donated?

7. How long does a recipient have to take an anti-rejection medicine?

8. Three organs can be donated from a live donor. What are they?

a. \_\_\_\_\_

b. \_\_\_\_

C.

9. With one donor, how many people can be saved? \_\_\_\_\_ Be helped? \_\_\_\_\_

10. What is the organ in greatest demand?

11. If three recipients all have one month to live and are equally sick, how is the decision made as to who receives the organ?

12. Will the family be charged for organ donation?

# ourself (

## Your Decision to Donate

### **ACTIVITY**

### ORGAN DONATION: What You Should Know About Organ Donation - ANSWER KEY

Please use the internet to complete the following questions.
Use www.donatelife.net; www.unos.org; www.donors1.org; www.core.org

1. What does OPO stand for?

Organ Procurement Organization

- 2. List five organs that can be used in transplants.
  - a. Heart
  - b. Liver
  - c. Lungs
  - d. Kindeys
  - e. Intestine
  - f. Pancreas
- 3. List three tissues that can be used in a transplant.
  - a. Bones
  - b. Corneas
  - c. Tendons
  - d. Heart Valves
  - e. Skin
  - f. Veins
- 4. How many recipients die every 24 hours waiting for organs?

22

5. A person must be in a hospital on a ventilator and be declared brain dead before organs can be recovered. Explain the process (tests) done to determine if a patient is brain dead.

There are a number of conditions that must be met for brain death to be declared. While state or local laws may require additional actions, the construct of the diagnosis is universally accepted as being definitive. In short, to declare someone brain-dead:

- 1. The coma must be irreversible with either a known or proximate cause.
- 2. The person must have no brainstem reflexes.
- 3. The person has no respiratory function.

All three conditions must be satisfied for brain death to be declared.

ourself (

## Your Decision to Donate

### **ACTIVITY**

### **ORGAN DONATION: What You Should Know About Organ Donation (continued)**

6. When someone's heart stops instantly, or the individual dies outside the hospital setting, can an individual still donate? If so, what can be donated?

Yes, an individual can still donate corneas and tissues.

7. How long does a recipient have to take an anti-rejection medicine?

Every day for the rest of their lives

- 8. Three organs can be donated from a live donor. What are they?
  - a. One Kidney
  - b. Partial Liver
  - c. Partial Lung
- 9. With one donor, how many people can be saved? \_\_\_\_8 \_\_\_ Be helped? \_\_\_over 75
- 10. What is the organ in greatest demand?

The Kidney

11. If three recipients all have one month to live and are equally sick, how is the decision made as to who receives the organ?

Unos is the official organization that uses a nationwide computer system used to match organs to those on the waiting list. The UNOS computer generates a list of potential transplant candidates who have medical and biologic profiles compatible with the donor. The computer ranks candidates by this biologic information, as well as clinical characteristics and time spent on the waiting list. These characteristics are: medical urgency, time spent on the waiting list, organ size, blood type and genetic makeup.

https://unos.org

- 12. Will the family be charged for organ donation?
  - No. Your family pays for your medical care and funeral costs, but there is no charge for donation.



## Organ Transplants-Spare Parts for Broken Hearts

Focus: Scientific Advancement

**Lesson:** Organ Transplants-Spare Parts for Broken Hearts

**Overview:** Students will answer questions related to the scientific advancements made in the area of donation and transplantation while learning about its challenges

Time Needed: One class period

### Objectives:

- 1. Upon completion, students will be able to articulate the importance of science in their personal lives and the lives of family members.
- 2. Upon completion, students will be able to discuss obstacles and challenges of organ and tissue transplants.

### Standards Match:

Reading, Writing, Speaking, and Listening	Crosscutting Concepts & Unifying Themes
1.1.11.A, 1.1.11.F, 1.1.11.G, 1.6.11.A, 1.6.11.B, 1.6.11.C, 1.6.11.D, 1.6.11.E, 1.6.11.F	<ul><li>Systems and System Models,</li><li>Cause and Effect</li></ul>

### **Materials Needed:**

- Computers
- Organ Transplants "Spare Parts/ Broken Hearts" Reinforcement Activity
- Passage

### **Activity:**

- 1. Students will read the passage below silently.
- In small groups, students will discuss the passage and utilize the internet to complete the worksheet.
- 3. The entire class will discuss the passage andmake additions to the worksheet.

Have you ever considered the thousands of things that take place in your body? Think of your body as an automobile. Mechanics are always busy replacing this belt or that valve. The brakes, tires, battery and spark plugs are all parts that often need to be changed. When an accident occurs, fenders, doors or a hood may need to be replaced. Auto mechanics go to the local junkyard where usable parts can be recycled from cars that are no longer drivable. Who would have thought that a similar idea could some-

day be used to save lives? Organ transplants have become quite common in today's medical world. You may have heard of the kidney transplant. This surgery is fairly common. Hearts and lungs have also been transplanted separately and together.

Today, hearts, kidneys, livers and other organs are transplanted. Doctors believe that someday, with more research, certain animals could be raised specifically to supply organs for human transplants. Yet, other exciting ideas are being considered. For example, can one part of the body be used to replace another? Scientists have already constructed a heart for a dog using the muscle taken from the dog's back. Where will technology end? Someday scientists may be able to grow new organs in the laboratory using organ tissue. We may each have our own spare organs on the shelf ready to fix our broken parts!



# Organ Transplants-Spare Parts for Broken Hearts

### **ACTIVITY**

Name \_\_\_\_\_ Date \_\_\_\_\_

Answer the following questions.

- 1. Why would someone need a kidney transplant?
- 2. What problems can result from organ transplantation?
- 3. What precautions do doctors take to minimize complications in organ transplants?
- 4. Why does the body sometimes reject a donated organ?
- 5. What is the purpose of the drug, cyclosporine? How does it work?
- 6. What are two ways in which scientists might someday be able to make more organs available for transplantation?
- 7. Which organs are typically transplanted into humans?

Procedures	Routine	Experimental	Untested
Blood transfusions			
Growing new organs from organ tissue			
Constructing new organs from animal tissue			
Transplanting human kidneys into humans			
Transplanting organs from animal to a human			
Use of cyclosporine			
Transplanting human livers into humans			
Raising animals specifically for human transplants			
Matching donor and recipient organs			
Transplanting human hearts into humans			



## Organ Transplants-Spare Parts for Broken Hearts

### **ACTIVITY**

Have you ever considered the thousands of things that take place in your body? Think of your body as an automobile. Mechanics are always busy replacing this belt or that valve. The brakes, tires, battery and spark plugs are all parts that often need to be changed. When an accident occurs, fenders, doors or a hood may need to be replaced. Auto mechanics go to the local junkyard where usable parts can be recycled from cars that are no longer drivable. Who would have thought that a similar idea could someday be used to save lives? Organ transplants have become quite common in today's medical world. You may have heard of the kidney transplant. This surgery is fairly common. Hearts and lungs have also been transplanted separately and together.

Today, hearts, kidneys, livers and other organs are transplanted. Doctors believe that someday, with more research, certain animals could be raised specifically to supply organs for human transplants. Yet, other exciting ideas are being considered. For example, can one part of the body be used to replace another? Scientists have already constructed a heart for a dog using the muscle taken from the dog's back. Where will technology end? Someday scientists may be able to grow new organs in the laboratory using organ tissue. We may each have our own spare organs on the shelf ready to fix our broken parts!

# Schoology for OTDA



Yourself

# SCHOOLOGY

OTDA Team Share is a group site on Schoology which brings ideas for OTDA activities, lesson plans, links, and more to present grantees, future grantees, and all those involved in our mission to educate!

Please use this as not only a resource for ideas, but an opportunity to collaborate, plan activities with your local high schools, and save money on your budget ideas by combining with your neighboring schools.

The more you share, the less time you have to spend planning. Meaningful and creative activities are at your fingertips!

We invite you to use this new resource to expand your activities and provide the very best experiences for your students!

### How can you access OTDA Team Share on Schoology?

Please contact Karen Herr at karen\_herr@iu13.org to receive an access code.









# GENERAL GLOSSARY OF TERMS

CORE- Center for Organ Recovery and Education; PA O.P.O.

G.O.L.- Gift of Life; PA O.P.O

O.P.O.- Organ Procurement Organization

**OTDA-** Organ and Tissue Donation Awareness

P.D.E.- Pennsylvania Department of Education

**Anatomy-** The dissection of a plant or animal to study the structure, position, and interrelation of its various parts

**Brain Death**- Is death. All brain tissue is dead. There is no blood flow to the brain and no electrical activity occurs in the brain during this state

**Donor-** An individual from whom blood, tissue or an organ is taken for transfusion, implantation or transplant

**Ethics**- The rules or standards governing the conduct of a person or the members of a profession (eg). Medical ethics

Implantation- To insert surgically (eg.) To implant a heart

**Informed Decision**- The act of reaching a conclusion or making up one's mind after acquainting oneself with knowledge of a subject

**Initiative-** The ability to begin or to follow through energetically with a plan or task (eg). The OTDA Curriculum Framework Initiative was started in 1997 between two organizations, PA Departmentment of Education and the Lancaster-Lebanon IU 13.

Organ- A differentiated part of an organism, such as an eye, that performs a specific function

Physiology- The study of the functions of living organisms and their parts

**Procurement-** to obtain or acquire for another

Recipient- One who receives blood, tissue, or an organ from a donor

**Resources**- Something that can be used for support or help. The OTDA toolkit gives a teacher resources (cd rom/ dvd, sample lesson plans, OTDA facts and myths, etc.)

**Tissue-** An aggregation of morphologically similar cells and associated intercellular matter getting together to perform one or more specific functions in the body. There are four types of tissue: muscle, nerve, epidermal & connective

**Toolkit-** A set of resources (i.e.: sample lesson plans, cd rom, OTDA classroom activities, real life stories, etc.) used to aid a teacher in educating students on OTDA

**Transfusion**- The transfer of whole blood or blood products from one individual to another

Transplantation- To transfer (tissue or organ) from one body or body part to another



# GENERAL SUBJECT GLOSSARY

### http://www.transplantawareness.org/resguide/chap42.htm

As you learn more about transplantation, your vocabulary will begin to expand rather rapidly. We have noted here a number of the terms frequently used in transplantation. Remember this is just a sample.

### Acute

Having severe symptoms and a short course

### Acute tubular necrosis (ATN)

Reversible kidney damage resulting in delayed kidney function after transplant. Among other factors, it may be caused by sub optimal organ storage before transplantation or medication used to prevent rejection

### **Allocation**

The system of ensuring that organs and tissues are distributed fairly to patients who are in need

### Allogenic

Refers to genetically different members of the same species. See transplantation

### **Allograph**

An organ that is removed from a donor to be used in another person

### Anemia

A condition characterized by too few red blood cells in the bloodstream, resulting in insufficient oxygen to tissues and organs

### Antibody

A serum protein consisting of soluble molecules that is produced by the body's immune system, they are produced in response to and bind to substances, usually foreign, known as antigens, antibodies to transplantation antigens are one of the mediators of graft rejection

### Antibiotic

A drug used to fight bacterial infections

### Antigen

A substance, such as a transplanted organ, that can trigger an immune response. This immune response may be the production of antibodies

### **Apheresis**

An apheresis donation returns unwanted portion of blood to the donor. Usually relating to a platelet donation

### Arteriogram

An x-ray of the arteries taken with the aid of a dye, sometimes referred to as angiography

### **Ascites**

Accumulation of fluid in the stomach

### Aseptic necrosis

One or both hip joints may suddenly undergo massive deterioration in patients using a high dosage of steroids for a prolonged time. Dietary calcium and/or supplements are recommended for prevention

### **Atherosclerosis**

The disease in which fatty deposits build up on the inner walls of the arteries, causing narrowing or blockage that can lead to heart attack. Commonly known as "hardening of the arteries"

### **Autoantibody**

An antibody that reacts with antigens on a person's own cells and tissues



### **Autoimmunity**

The condition in which the immune system mistakenly attacks the body's own cells and tissues; this immune reaction is the basis of a variety of autoimmune diseases including diabetes, rheumatoid arthritis, and system lupes erythematosus, among others

### B cell

A specialized white blood cell responsible for the body's immunity. B cells play a central role in antibody production

### **Bacteria**

Microscopic organisms that invade human cells, multiply rapidly and produce toxins that interfere with normal cell functions

### Beta blockers

A class of drugs that lower blood pressure

### Bile

Fluid produced by the liver that is transported to the intestine to help digestion and remove waste products.

### Bile ducts

Passageways in and from the liver that transport bile.

### Bilirubin

Substance in bile that is produced when the liver processes waste products. A high bilirubin level causes yellowing of the skin.

### **Biliary cirrhosis**

Slow, progressive scarring of the bile ducts in the liver

### **Biopsy**

Removal of tissues for examination under a microscope

### **Bladder**

The part of the urinary tract that receives urine from the kidneys and stores it until urination

### **Blood vessels**

The arteries, veins and capillaries through which blood circulates. Blood vessels can be donated and transplanted

### **Bone**

Dense tissue that forms the skeleton. Bone can be donated and transplanted

### **Bone marrow**

Spongy tissue in the cavities of large bones, where blood cells are produced. Sometimes referred to as a tissue donation.

### **Brain death**

The condition in which the brain has permanently ceased functioning as determined by the medical team. Cadaveric organs are recovered from persons declared brain dead in the US.

### BUN

Stands for Blood Urea Nitrogen, a waste product normally excreted by the kidney, Your BUN value represents how well the kidneys function.

### Cadaveric organ

An organ from a person who has been declared brain dead

### Candidate

A person awaiting an organ or tissue transplant



### Cardiac

Relating to the heart

### Catheter

Small, flexible plastic tube inserted into the body to administer or remove fluids

### CellCept

A new drug used to assist the immune system in transplanted patients, is approved for renal allograft rejection in combination with cyclosporine and corticosteroids (prednisone)

### Chronic

Persisting for a long time

### Cirrhosis

Irreversible scarring of the liver. Can be caused by a variety of conditions

### **Clinical trail**

A prospective, scientific evaluation of a treatment regimen, agent (e.g. drug), device, or procedure used for the prevention, diagnosis, or treatment of a disease

### Coagulation

Relating to the process of clotting, usually the body's system of controlling bleeding

### Cocktail

Refers to a combination of drugs prescribed to prevent rejection consisting of cyclosporine, imuran, and prednisone. This combination's success allowed transplantation to proceed beyond the experimental stage

### Connective tissue

Forms the supportive and connective structures of the body

### Cornea

The transparent outer coat of the eyeball that covers the iris and pupil. Corneas can be donated and transplanted

### Corticosteroids

Hormones secreted by the adrenal gland. Corticosteroids can be manufactured. In high doses, corticosteroids cause immunosuppression. See prednisone

### Creatinine

A product of muscle metabolism. Creatinine level is referred to as a number that is watched closely and serves as an indicator of kidney function

### Crossmatch

A test for recipient antibodies versus donor antigens. A positive crossmatch means the recipient and donor are incompatible. A negative crossmatch means there is no reaction between donor and patient and that the transplant may proceed

### Cyclosporine

A drug commonly used after transplantation to suppress the immune system of the recipient and prevent rejection by the immune system of the transplanted organ or tissue. See cocktail

### **Deceased donors**

Donors who donate their organs or tissue after they have been declared brain dead

### **Dialysis**

Mechanical ways of cleaning the blood in kidney failure

### **Diastolic**

The bottom number of a blood pressure reading measuring the heart at rest



### Diuresis

Significantly increasing the production of urine

### **Donation**

Is the act of giving one's organs or tissue to someone else

### Donor

One who gives of themselves

### Edema

Abnormal accumulation of fluid in the body

### **Encephalopathy**

Confused, fuzzy, or slowed thinking when the liver is not properly functioning

### **End-Stage Organ Disease**

A disease that leads, ultimately, to functional failure of an organ. Some examples are emphysema (lungs), cardiomyopathy (heart) and polycystic kidney disease (kidneys)

### End-stage renal disease (ESRD)

A very serious and life-threatening kidney disease that minorities suffer much more frequently than do Whites. ESRD is treatable with dialysis; however, dialysis is costly and can result in a poor quality of life for the patient. The preferred treatment of ESRD is kidney transplantation. Transplantation offers the patient "freedom" from dialysis to lead a more normal lifestyle and can successfully treat ESRD for many years

### **Exacerbation**

An increase in activity of a disease, a relapse

### **Febrile**

Running a fever

### FK-506

Pre-approval designation for immunosuppressant drug Prograf

### **Fulminant**

Happening very quickly and severely

### Gene

A unit of genetic material (DNA). A gene may be defined in different ways as follows:

- •Gene pattern of inheritance A segment of DNA that is transmitted, intact, from parent to offspring
- •Gene structure A segment of DNA encoding a protein molecule
- •Gene function A segment of DNA that contains the information for a specific function
- •Gene therapy Treatment of genetic diseases by providing the correct or normal form of the abnormal gene causing a disease

### Genetic disease

A disease due to an abnormal condition of one or more genes. While most diseases have some genetic component, the genetic disease is usually applied to those cases where one or two genes determine the disease, such as sickle cell anemia, Tay Sachs disease, and cystic fibrosis

### Gastrointestinal

Relating to the stomach and intestines

### Gastroenterologist

A physician trained in treating gastrointestinal disease

### Gingival hypertrophy

Enlargement of the gums as a side effect of certain medications, especially cyclosporine. Managed with good oral hygiene



### Glucose

A type of sugar in the blood

### Graft

A transplanted tissue or organ

### **Graft failure**

Absence of adequate function in a transplanted organ or tissue

### **Graft survival rates**

The percentage of patients who have functioning grafts; graft survival rates are usually given for chronological landmarks (e.g., 1 year, 5 years)

### Graft-versus-host disease

A life-threatening reaction in which transplanted immunocompetent cells attack the tissues of the recipient. This is most commonly seen in bone marrow transplantation but is also known to occur in transplantation of organs, such as the liver and the lung, that contain significant numbers of immunocompetent cells **Heart** 

A muscular organ that pumps blood through the body. The heart can be donated and transplanted

### **Heart valves**

A tissue that prevents the back flow of blood into the heart. The heart valves can be donated and transplanted

### Helper T cell

The specialized white blood cell that tells other parts of the immune system to combat infection or foreign material. A transplanted organ is foreign material

### Hemorrhage

Excessive bleeding

### **Hepatic**

Relating to the liver

### **Hepatitis**

Inflammation of the liver

### Hirsutism

Excessive increase in the hair growth

### Histocompatibility testing

Determining how closely the HLA (or transplantation) antigens of the donor and recipient are matched and the likelihood that the recipient will reject the donor tissue

### **HLA Human Leukocyte Antigen**

There are over 10,000 HLA types, with three major genetically controlled groups,: HLA-A, HLA-b and HLA-DR. In organ transplantation HLA-A types are important

### Hypertension

High blood pressure

### **Immune Response**

The body's defense against things that are not normally part of the body, such as bacteria, viruses or transplanted organs or tissue

### Immunocompetent

Capable of developing an immune response

### **Immunodeficiency**

The lack of an adequate or normal immune response



### Immunologic disease

A disease due to a dysfunction of the immune system. These are the autoimmune, allergic, and immunodeficiency diseases

### **Immune system**

The body's natural defense mechanism against invasion by foreign bodies. In transplantation, the transplanted organ is considered a foreign body and the recipient's immune system will naturally want to defend against it through rejection of the organ

### **Immunosuppression**

The artificial suppression of the immune response, usually through drugs, so that the body will not reject a transplanted organ or tissue. The drugs commonly used to suppress the immune system after transplantation include prednisone, azathioprine (Imuran), CellCept, cyclosporine, Prograf (FK506), OKT3, and ALG

### **Imuran**

A drug commonly used after transplantation to suppress the immune system of the recipient and prevent rejection by the immune system of the transplanted organ or tissue. An "AZT family" drug. See cocktail

### **Immunosuppressive Drugs**

Chemical agents that cause the human body not to produce antibodies that normally fight off foreign material in the body. The production of these antibodies needs to be suppressed in order to permit the acceptance of a donor organ by the recipient's body

### **Intestines**

The portion of the digestive track extending from the stomach to the anus, consisting of upper and lower segments. The intestines can be donated and transplanted

### Intravenous (IV)

Into a vein

### **Jaundice**

Yellowing of the skin and eyes. A sign that the liver or bile duct system is not working properly

### Kidneys

A pair of organs that maintain proper water and electrolyte balance, regulate acid-based concentration, and filter the blood of metabolic waste, which is excreted as urine. Kidneys can be donated and transplanted

### Leukocyte

A white cell of the blood

### LifeNet

Tissue procurement organization for Washington DC and Virginia

### Living-related donor (LRD)

A "blood" relative who donates an organ, usually kidney, also partial livers, lungs, and pancreas lobes from LRDs are used for infants and small children when that is the appropriate transplant.

Match The compatibility between recipient and donor. The more closely the donor and recipient "match" the greater the potential for a successful transplant

### Made

Used by recipients for their prescribed medications. Taking them at the appropriate time(s) is most important

### NCAC

Nation's Capital Area Chapter, Initials often used to denote the local TRIO chapter

### **Noncompliance**

Failure to follow the instructions of your health care providers such as not taking prescribed medications or not showing up for prescribed clinic visits



### Neoral

Emulsified cyclosporine immunosuppressant drug manufactured by Sandoz

### **NSF**

formerly initials for the National Sanitation Foundation. Now the organization is known as NSF International or NSF in their logo. Provides drinking water standards, and standards for associated equipment, including water purification filters

### **Organ Preservation**

Organ preservation is used so that organs or tissues can be kept outside the body before being transplanted. The length of time varies per type of organ, the preservation fluid, and temperature

### **Organism**

An individual, living thing

### Orthotopic

A graft that is transplanted into its normal anatomical position (e.g. livers, hearts, lungs, and intestines)

### OPO

Organ Procurement Organization

### OPTN

Organ Procurement and Transplant Network

### **OTC**

Over The Counter, non-prescription drugs or other medications

### **Pancreatic**

Relating to the pancreas

### Panel Reactive Antibody (PRA)

The percentage of cells from a panel of donors with which a potential recipient's blood serum reacts. The more antibodies in the recipient's blood, the higher the PRA. The higher the PRA, the less chance of getting a good crossmatch. Patients with a high PRA have priority on the waiting list

### Patient

A person under a physician's care as a living donor, transplant candidate or recipient

### **Platelets**

The smallest elements in the blood, needed to control bleeding

### **Prednisone**

A steroid drug commonly used after transplantation to suppress the immune system of the recipient and prevent rejection of the transplanted organ or tissue. See cocktail

### **Peritonitis**

Inflammation of the abdominal cavity due to intestinal perforation

### **Prognosis**

The predicted or likely outcome

### **Prograf**

A drug (Tacrolimus, FK-506) used after transplantation to suppress the immune system of the recipient and prevent rejection of the transplanted organ or tissue. Initially used for liver transplants, recently an option for all organ transplants

### **Protein**

A type of organic compound that is one of the major components of cells and tissues



### **Protocol**

The plan of treatment

### **Pulmonary**

Relating to the lungs

### Recipient

A person who has received an eye, organ or tissue transplant

### Rejection

An event in which the immune system tries to fight off a transplanted organ or tissue by making antibodies. Immunosuppresive drugs help prevent rejection

### Remission

Return to good health

### Renal

Relating to the kidneys

### RS-61443

Preapproval number assigned to CellCept. See CellCept

### Sandimmune Cyclosporine

immunosuppressant drug manufactured by Sandoz

### Sensitization

When there are antibodies in the blood of the potential recipient, usually because of pregnancy, blood transfusions or previous rejection of the organ transplant. Sensitization is measured by PRA. Highly sensitized patients are more likely to reject an organ transplant than unsensitized patients. See PRA

### **Steroids**

A group of medications including Prednisone

### Systolic

The top number of a blood pressure reading measuring when the heart is contracting

### T cell

A white blood cell responsible for the body's immunity. T cells can destroy cells infected by viruses, graft cells, and other altered cells (e.g. cancer cells)

### **Tacrolimus**

A drug (Prograf, FK-506) used after transplantation to suppress the immune system of the recipient and prevent rejection of the transplanted organ or tissue

### **Thoracic**

Relating to the chest

### **Tissue**

A term applied to actual tissue (skin), blood products, and bone marrow

### **Tissue typing**

The examination of human lymphocyte antigens (HLA) in a patient; a blood test identifying genetic markers. Tissue typing is done for all kidney donors and recipients to determine a proper match

### **Tolerance**

A state of immunologic non-responsiveness to one or more antigens

### Tolerance, donor-specific

Tolerance of the donor's antigens by a transplant recipient



### Transplant patient

A person waiting to receive an organ or tissue transplant or a person who has already received a transplant

### **Transplantation**

Transfer of cells, tissues, or organs from one area of the body to another or from one organism to another

### Transplantation, allogenic (allograft)

Transplantation between genetically different members of the same species. Nearly all organ and bone marrow transplants are allografts

### Transplantation, autologous

Transplantation of an organism's own cells or tissues, autogous transplantation may be used to repair or replace damaged tissue; autologous bone marrow transplantation permits the usage of more severe and toxic cancer therapies by replacing bone marrow damaged by the treatment with marrow that was removed and stored prior to treatment

### Transplantation, syngenic

Transplantation between genetically identical members of the same species (e.g., identical twins)

### **TRIO**

Transplant Recipient's International Organization - membership includes candidates, recipients, their families, donor families, medical professionals and other interested parties

### UNOS

United Network for Organ Sharing, the designated OPTN operator

### **Varices**

Enlarged veins that develop in the esophagus and stomach

### **Vascular**

Relating to blood vessels

### Viatical

Viatical settlement allows one to sell their Life Insurance policy to obtain funds for medical care

### WRTC

Washington Regional Transplant Consortium OPO

### Xenographs

Organs transplanted from animals, ongoing research is a result of the tremendous shortage of donor organs

# ourself (

# Website Resources

### C.O.R.E (Center of Organ Recovery Education)

https://www.core.org/

### **Donate Life America**

https://www.donatelife.net

### **Donate Life PA**

https://www.donatelifepa.org/

### Gift of Life

https://www.donors1.org/

### **National Kidney Foundation**

https://www.kidney.org/

### Pennsylvania Dept. of Education

http://www.pde.state.pa.us/

### Pennsylvania Department of Health-Organ Donation Awareness

http://www.dsf.health.state.pa.us/health/site/default.asp

**TRIO** Provides organ donation reading and reviews https://www.trioweb.org/resources/book-reviews.html

### **UNOS** (United Network for Organ Sharing)

https://www.unos.org/

### U.S. Department of Health and Human Services/FirstGov

https://www.organdonor.gov

# Toolkits

### Organ and Tissue Donation Awareness (OTDA) Curriculum Toolkit 2011

https://www.iu13.org/images/uploads/documents/IS/OTDA/OTDA Classroom Toolkit 2010 11.pdf

### **Donate Life America - Youth Educational Guide**

https://www.donatelifetexas.org/wp-content/uploads/2015/02/Youth\_Educational\_Guide\_DLA\_111717.pdf

### **RecycleYourself Classroom Tools**

http://gorecycleyourself.com/classroom-tools/

# Real-Life Stories



Yourself

# JOE MANSARAY

It all started in the beginning of the summer of 2015. On June fifth of 2015, a Friday morning, I woke up finding it very difficult to breathe. I woke up my dad and he decided to take me to Pinnacle Hospital where they began some tests. After a chest x-ray, the doctor came in with a very worried look on his face. He said that my heart was enlarged and that it was a very serious concern. He showed us the picture of the x-ray and I was able to see that my heart actually was enlarged and it was pretty terrifying. I've never been sick before so this was a huge shock. I wondered if they could fix this issue, if I was going to be ok, and I wondered if I would be I able to play



soccer, which was starting soon. The doctor told us that they were unable to manage my heart issue and that we needed to go to Hershey Medical Center immediately by an ambulance.

Once we got to Hershey I ended up being admitted and staying there for about twelve days. They ran a bunch of tests on me and decided that they also were unable to fix my heart issue. At this point I was losing hope. From someone who ran track and played soccer my entire life, laying in a hospital bed every day, all day was horrible. I didn't feel like myself and I wasn't sure if I would ever get to be myself again. Hershey told me that CHOP in Philadelphia would be better to help me, so they were transferring me to CHOP by helicopter. Even though this was all very scary for me, the helicopter ride was pretty cool and it was the most exciting part of this whole process.

Once I got to CHOP, the doctors began to run even more tests on me. It felt never-ending. Finally, after a few days, they told us that I was suffering from a heart condition called cardiomyopathy. Not long before this my mom had actually also been diagnosed with this, while at CHOP we found out it was hereditary. When they found out how bad my heart was, they told us that they would have to put in an LVAD, to support my heart function, since it was no long able to do it on its own. Since I had no idea what an LVAD was, and because it was all happening so fast I felt like I wasn't able to process any of it. My dad and I asked a lot of questions. The doctors were very helpful and explained everything to me so I could understand which helped me feel calmer. The doctor's hopes were the LVAD would help improve my heart enough that eventually, it could be removed and I could go back to normal life. They installed the LVAD on July 24th, - at this point I had been living in hospitals for almost 2 months. It was mainly my dad and I this whole time, my mom remained home with my other siblings. Recovery from the surgery was difficult, but I did begin to feel better. I was finally discharged from the hospital in September – after 3 months in the hospital! Because of my situation, I was unable to go back to school and unable to play soccer in my junior year of high school - which was really upsetting. The doctors and nurses suggested we stay at the Family House after my discharged for about a week to be close to the hospital – and they also felt like it was an amazing place, and it would be a very supportive environment for us. When we went home I finally began to feel normal again and really felt like I would get better.

Unfortunately, that was not the case, and around October everything began to fall apart and our lives were turned upside down. I remember going back to CHOP for a checkup and being told that my heart was not healing and that I would need a heart transplant. I was very frustrated; I remember thinking that this can't be

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## JOE MANSARAY (CONTINUED)

happening to me. I honestly thought that my heart would heal because I was a healthy kid. I played soccer and ran track and never got sick. I was very scared and freaked out.

It all became even scarier because around this same time my mom became very sick. She was being evaluated for her own heart transplant at Penn and ended up being admitted. Because of how sick her heart was, she was very quickly listed for a heart and waited for her transplant in the ICU. Not long after being listed she received her new heart. This time we were not staying at the Family House because of my health, we were staying at the Family House to be closer to my mom.

Things continued to get worse. She had major complications and did not recover well from her heart transplant. It was constant ups and downs and it was so difficult for me to watch, knowing I could go through the same thing. On November 3rd, 2015 my mom passed away in the ICU at Penn with all of us at her side. Watching my mom's transplant and what happened to her afterwards was so hard for me. I was so sad that my mom had passed and also so scared that this was going to happen to me. I thought if I get a heart transplant and have to go through what she did, I might not make it either. The support from my doctors at Chop, who knew that my mom passed, helped quite a bit. They reassured me that I was young and healthy and I would do well with my surgery.

So we buried my mom and went home to wait for my transplant. On February 24th at around two a.m. they called us saying they had a heart for me. I remember being excited to get a transplant and have a normal life again, but I was also extremely scared. I went into the ICU and all the nurses and doctors were so excited for me. I remember going into the OR and saying bye to my dad, brother and sister, and still being unsure if I would wake up again. Obviously, I woke up. I was back in the ICU and my dad was there smiling. The first thing I said was, do I still have the LVAD? And my dad said no you have a brand new heart.

My recovery went so well and in only a couple of days I was out of bed working on getting back in shape. It was very hard work because I would get tired very easily but I kept working at it. My dad and siblings were able to stay at the Family House during this time and after only about 10 days I was discharged to the Family House. CHOP still wanted to keep an eye on me so we stayed at the family house for another few weeks. It was great because the entire staff was so welcoming and supportive – and had been through our entire transplant journey. The House made life easier for me and my family during this time and I am very grateful for that.

A couple of weeks later I was cleared to go home and be a normal teenager again. I was able to play soccer again in my senior year in high school. I am hoping to play soccer in college - hopefully Temple University, where my oldest brother goes, but also to remain close to the hospitals.

I am very grateful to my donor and their family, and I hope to express my gratitude towards them someday. My family and I are also extremely grateful to my mother's donor and their family since they gave her a second chance and gave us a bit of extra time with her. I am very thankful for everybody at CHOP, the doctors and nurses are amazing and without them I might not be here today.

# ROGER WEAVER

### WHY NOT?

### Why?

Around two years old this question begins to surface and never fades. We are constantly asking why. It seems we want to understand, we want our world to make sense, but often the answer eludes us or at least is unsatisfactory. Now I realize this is a bit philosophical for a bio, however, I am afraid that in my attempts to answer the why to my donation it may not make sense because I am not sure I totally understand it myself.

Nearly a year prior to my donation I felt what I can best describe as a nudge. There were a few things that took place that led me to consider the possibility of being a living donor. Sure, I have been donating blood for many years, but this was... let's just say a little more involved. So, I looked up the number and again it's difficult to define but I had a real sense of calm with stepping out in faith and calling them. I was not donating to a specific person or on behalf of someone to help them move up the chain. was what they call an altruistic donor. That word is not



often used and seeing it written out it looks like some type of medical condition; it simply means my kidney had no designated recipient.

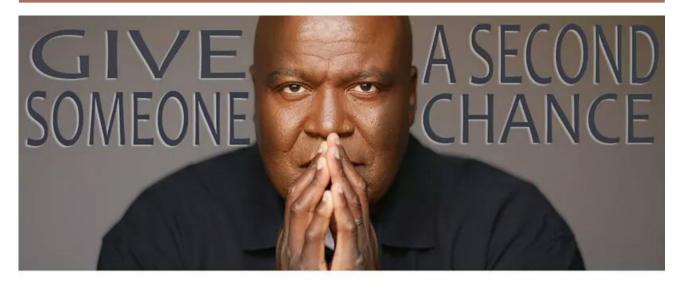
My journey began after that initial call; everything starting lining up – a supportive family, a job that was flexible and a boss that was generous. Of course, like all journeys there were some hiccups along the way; lots of additional tests and then four days before the surgery they noticed something in my lungs from the chest x-ray; this postponed it for a month until I was cleared. In the end I kept feeling a peace about simply taking the next step and these steps eventually led to my kidney being successfully transferred into someone who desperately needed it.

I call myself a Christian and I want my faith not to be just words but action. If I believe that God loves and cares for others than I need to demonstrate that myself. However, I want you to understand this was not to show my kindness or generosity (In fact normally I am not a very kind person), no this was simply about being obedient. The cool thing about being obedient is a husband and father of three was given a second chance and I got a card from his son that said, "Thank you for saving my dad's life".

The funny thing in all of this I feel that I have received more than I gave! And it makes me wonder when and where the next 'nudge' may come. Maybe you are feeling it too? So, I will add one word to the first question and ask you...

Why not?

# RON GOODEN



Words cannot begin to express how grateful I am to receive this wonderful gift of life. My name is Ron Gooden and I am a heart transplant recipient. My family has a long history of heart disease. My father passed away at the early age of 63 due to heart failure and my sister currently has Dilated Cardiomyopathy and Lupus. When I was growing up, I was always involved in sports, primarily football. I was fortunate enough to play at all three levels without any problems. So, over the years, I was very active, playing tennis, golfing, hiking, and coaching high school.

In 2005, I started to notice I was having a hard time doing the things I had come to enjoy. I had shortness of breath and always seemed to be tired. I thought it was due to me just getting older and pushing myself too hard. I went to my primary doctor who in turn recommended me to a cardiologist. After many tests, I was diagnosed with Dilated Cardiomyopathy and I started a regimen of cardiac medication. In 2007, I was implanted with an ICD, Implanted Cardio Defibrillator, due to some arrhythmias. My symptoms kept getting worse over the years, with swelling starting in my ankles and abdomen, along with palpitations.

In January 2011, my cardiologist referred me to the Heart Failure Clinic at Allegheny General Hospital, saying there was nothing more he could do for me. My girlfriend and I met with the doctors at AGH to discuss what the next steps would be. At that time, they tweaked my medications and suggested that I may need a heart transplant in a couple of years. My health started to deteriorate rapidly after January 2011. I was having difficulty climbing stairs and just walking in general. Every so often I would have to stop just to catch my breath. In August 2011, I had a routine heart catheterization that indicated the pressures in my heart were very low and that some of the oral medications were not effective enough. We met with the doctors and it was determined that I should be evaluated for an immediate heart transplant. I began to receive my cardiac medication intravenously 24 hours with a pump. In late August, I started the process for the transplant evaluation. On September 7, 2011, I was placed on the transplant list and could be called at any time. Being a high school football coach, this time of the year is really busy for me. I have been coaching for the past 25 years and enjoying every minute of it. My heart problems made in increasingly difficult to coach.

I had another heart catheterization on September 23, 2011, and as a result, I was admitted to the hospital. It was a Friday, and I begged to be able to coach the game and come back on Saturday, but to no avail. The doctors said I would not be on the sidelines for a while. I was placed at the top of the transplant list due to my low heart pressures. Due to my condition, the doctors recommended that I receive a LVAD, Left Ventricular Assist Device, while I waited for a transplant. They did not feel that my heart would hold out long enough for a new one without some assistance. On October 3, 2011, I received a LVAD and I remained in the hospital until October 19, 2011. Life with my LVAD was not easy for me, but I knew it was helping to keep me alive

## RON GOODEN (CONTINUED)

and live the best life I could have, given my circumstances. My girlfriend and I had been together for 8 years and I decided to propose to her on November 11, 2011. She said yes and we decided to have a small family wedding on November 26, 2011, the Saturday after Thanksgiving. But fate had charted a different course for us.

On November 22, 2011, at 5:45am, I received the call from my heart transplant coordinator. THEY HAD FOUND A HEART! With this new heart, I am able to live my life to the fullest extent possible. I am able to walk, jog, and coach again. I look at life with a whole new appreciation. I was able to make my girlfriend my wife, see both of my kids graduate college, walk my daughter down the aisle at her wedding, and witness my son's wedding. I was appointed by the governor to sit on the Organ Donation Advisory Committee. The committee is responsible for advising the Secretary of Health on matters relating to the administration to the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund.

Every day I thank God and my donor family for the wonderful life I have been given, because without them and their decision I would not be here today. I plan to be the best steward possible to my gift of life. I hope that by reading my story, others will choose to support organ and tissue donation, so that those on the waiting lists can receive their gift of life.

# MATTHEW BYRNE

I've been called many things in the past 42 years but never in my wildest dreams did I ever think I would be called a 2 time transplant survivor. I had a normal childhood, typical colds and the occasional sprained ankle from my skateboarding days. It wasn't until my late teens, early twenties that I started to get repeated sinus infections. While on vacation for my 22nd birthday, I became very ill. Thinking it was the flu, I rested and took the week off from work. Five days after initially getting sick I had a fever of 104.5 and my fiancé, at the time, took me to the hospital emergency room. My blood levels were critically low and I was ordered to receive



blood transfusions and strong antibiotics for the next five days as doctors scrambled to figure out what was wrong with my immune system. Two bone marrow aspirations later, the oncologist believed I had MDS, a type of bone marrow cancer that usually happens to older women. We tested my siblings to see if their immune system could be a match for me. Two of my siblings were a perfect match and we set the transplant date for a few weeks later.

I kept getting a lung infection that would delay the date of my transplant. After months of treating lung infections and getting better, the pulmonary doctors ordered a lung biopsy. The result was a common viral infection that most healthy people's immune system could keep in check. But since mine was compromised I didn't have that ability.

About a year after first getting "sick" I went to Sloan Kettering in NYC for a second opinion. They reviewed the bone marrow slides from University of Pennsylvania and could not confirm the diagnosis without getting their own bone marrow slides. I was so traumatized from the the first two rounds of bone marrow aspirations that I declined. I was young, 24, and at this early stage tired of constantly having to consent to painful procedures.

Years passed with infections, antibiotics and hospitalizations. With the urging of my sister I went to Johns Hopkins in Baltimore. They determined that I didn't have bone marrow cancer but an immune system defect. My doctor worked with a doctor who recently moved to the NIH (National Institute of Health). The NIH is a government run research hospital that helps people with rare diseases. They had me there for a few days of testing and said I had a immune system defect. They have seen other people who had a similar health background and wanted me to participate in a case study. That single decision changed the course of my health care for the better.

October 2008 I stopped working and was placed on oxygen 24/7 due to my pulse oxygen levels being too low. A wheelchair was soon to follow. I was in and out of the hospital monthly.

In May 2009, after 10 years of fighting my failing immune system, I conceded to do a Stem Cell Transplant. NIH wrote a specific protocol for the transplant for my disease. I was patient "0", the first to receive a BMT for this disease. The disease is now called Gatta2 referring to the defective gene that superseded my immune system. I spent 28 days in the hospital after my transplant. I slowly got better and a year later decided to take a 10-week cross country trip with my dog to see the USA.



## MATTHEW BYRNE (CONTINUED)

In 2012, my breathing became worse and was placed back on oxygen. Now hospitalizations lasted months instead of weeks. I was told we had exhausted all options and I should consider a double lung transplant. I interviewed at INOVA a transplant hospital in Virginia. I was accepted for the transplant and placed on the list. I spent five months hospitalized, waiting for the gift of life.

September 23, 2013, we received the call that I had a matching donor. A joyful day for me and a sad and heart breaking decision for someone else. Recovery took four months. It was hard living on a ventilator for weeks. Then a tracheotomy for a few more weeks. Learning to sit up, move my hands and legs, and swallow were all things I had to teach my body to do again. I was out for seven days and my body started to break down. Each day I tried more than the last.

Sometimes failing but not giving up. My family was by my side the whole time; they were strong when I couldn't be.

It took a long time to regain my ability to function physically but more mentally. I still suffer from PTSD and trauma from years of pain and months spent in physical isolation from staff and especially other patients. My donor was a 17 year old young man from Clinton, South Carolina named Eugene Kinard. He was the victim of a single gun shot wound to the head. His mother, in her darkest hour decided his senseless death was not going to be the end of his story. As long as I speak his name he lives on. In me.

In April 2015, I had a heart attack. Not a big deal considering my past. Then a few months later, I met Jenna, my fiancé. I was told I would probably not be able to have children due to chemo and radiation I received during stem cell transplant. Now we have a son named Noah and he's going to be 3 in June. Don't believe everything your told.

My sister would always say during my seemingly endless hours attached to a breathing machine, "Don't give up before the miracle happens."

# ZACHARY SWEITZER

### By Missy Sweitzer, mother

On October 19, 1988, our lives were changed forever. We were blessed with the first of our three children, Zachary Daniel Sweitzer. He was an energetic and passionate boy who grew up to be a compassionate young man with a great desire to help others. He was a talented athlete, a dedicated volunteer firefighter, and an amazing son and friend.

Our lives were changed forever once again on November 27, 2008, Thanksgiving morning. We received a phone call that our son was involved in an accident. We didn't know what to expect when we got to the hospital, but nothing could have prepared us for what we were about to see. He was admitted to the trauma ICU at York Hospital with closed head trauma. He had been ejected when an underage, DUI driver hit his truck. He was on his way home to celebrate Thanksgiving with our family.



The surgeon explained they were going to attempt to alleviate the pressure that was building in his brain. Zac survived the surgery but he would never regain consciousness. Never again would we see his beautiful brown eyes. Never again would we hear him say "I love you." We never gave up hope or stopped praying for a miracle but there came a time when we knew that our boy was gone. There's something that a parent experiences when their child dies...something that really can't be explained or described...but a part of you is gone...forever...and you feel it in your deepest being.

Zac made the decision to be an organ donor when he got his driver's license, a decision for which later we would always be grateful. We informed the nursing staff that if we were faced with a decision, Zac was a donor and would want to help as many people as he could. We met our transplant coordinator, who explained the transplant process to us. Never once did we feel pressured or that the decision was not ours to make. But after hearing the story of a mom who got to hear her son's heart beating in another man's chest, we knew that Zac's decision was right. We never really thought about organ donation, other than deciding to be one, and now we found ourselves as a donor family. Even though we have never met or heard from any of his recipients, we feel as though his six recipients have become a part of our family. We think about them and pray for them all the time.

In life, Zac's mission was helping others...and in his death, that legacy continues. And we're still praying that someday we get to hear Zac's heart of gold beating in another man's chest.

# RYAN LEE MOHN

### By Alison Mohn, mother

This is the story about my 16 year old son Ryan Lee Mohn. In 2004 Ryan was a junior in high school. He led his team to a district football championship earlier that fall as the team's quarterback, and he was also one of the starting pitchers on the school baseball team. He was in the middle of basketball season as a reserve guard. On January 31, 2004, Ryan was on his way to the local mall with two of his best friends when the car he was riding in went out of control and hit a tree. The impact of the accident was all on Ryan's side. In addition to other less-serious injuries, Ryan suffered massive head trauma and was flown to a local trauma hospital by helicopter transport. His situation was very grave because of the massive head trauma he suffered from the accident. After a week in the hospital on artificial breathing support and various brain stem activity testing, Ryan passed away.



One month before his accident when he got his driver's license, Ryan signed up to be an organ donor. Because of that decision, six people received life-saving transplants and over 100 others' lives were enhanced through his tissue donations. My life and my family's life were forever changed that day by what happened to Ryan. As a way to help us deal with our grief and continue Ryan's legacy, the Ryan Lee Mohn Memorial Foundation was created. This foundation provides scholarships to graduating seniors from his high school, promotes organ and tissue donation awareness, and makes donations to other organizations in Ryan's memory. My family has also had the honor of meeting four of Ryan's transplant recipients and we have developed beautiful friendships with them. Losing a loved one, especially at such a young age, is really hard and my faith plays a major role in dealing with Ryan's loss.

Knowing that Ryan saved and enhanced so many lives also helps with our grief. Organ donation works. We never know if we could one day be on the other end of needing a life-saving transplant, and I believe if that would happen, we all hope that even in an extreme time of grief, others would say yes to organ and tissue donation.

# EILEEN KLINE

Eileen Kline was born and raised in Meadville, PA, a small town an hour and a half north of Pittsburgh, PA. Growing up, she volunteered at Spencer hospital where she developed a passion to care for patients. After graduating high school, she attended St. Francis School of Nursing, graduated in 1981 and then returned to her hometown to work as an ICU nurse at Spencer Hospital. During her first year of nursing, she realized how much she loved critical care nursing, validating her decision to pursue it as her career. Following her ambitions and desire to learn and experience more, Eileen moved to Pittsburgh, PA, a larger city with more critical care units and cutting-edge treatments and research.

In the early 1980's, the pioneer of liver transplantation, Dr. Thomas Starzyl started a liver transplantation program at Presbyterian Hospital (now known as UPMC). As Eileen reviewed nursing positions available in Pittsburgh, she jumped at the opportunity to work at Presbyterian Hospital, one of only a few hospitals in the world performing liver, heart, heart-lung and kidney transplants. At Presbyterian Hospital, Eileen went on to not only care



for Dr. Starzyl's patients, but also patients of other renown physicians pursuing successful transplantation techniques and treatments. While working in the ICU, Eileen cared for patients waiting for life-saving surgeries, as well as those who received transplants. Eileen remembers how difficult it was to care for patients who died waiting for organs. She also recalls the excitement of witnessing miraculous recoveries and seeing a patient receive a second chance at life. She knew that with time, the sciences and procedures at Presbyterian Hospital would advance medicine and science for the future.

Eileen's time at Presbyterian Hospital was incredibly rewarding. She worked alongside the sharpest minds in medicine, met lifelong friends and formed life shaping bonds with her patients. For example, during this time, she cared for Father Michael, a Priest from Montana who received a liver transplant (the most complicated organ at that time to transplant). She cared for him for several months because of complications following his surgery, providing him faith and encouragement that he would recover and be able to return to Montana to resume his prior responsibilities to the Church. Eileen maintained a close relationship with Father Michael after his recovery and return to Montana. When it was time for Eileen to become married, Father Michael was there to officiate the wedding.

When Eileen and her husband started a family, she left Presbyterian Hospital. During this time, they raised 4 children. Eileen was an active volunteer in their schools and loved working with children. Ten years after leaving nursing Eileen decided to return to school to earn her certification in school nursing. After receiving her school nurse certification, Eileen was hired by the Baldwin-Whitehall School District as the school nurse for Paynter Elementary and McAnnulty Elementary School. Eileen worked as the school nurse for 10 years.

In October 2009, Eileen woke up on a weekend morning with a sore throat. She went to Med Express where she tested negative for Strep throat and was informed that it was just virus. Eileen's sore throat continued for approximately 2 weeks. She recalls that this sore throat was different than any other sore throat that she had experienced.

## EILEEN KLINE (CONTINUED)

One month later Eileen felt her heart beating fast and went to see a cardiologist. She was diagnosed with atrial fibrillation with a rapid heart rate. Medication was ordered to convert her heart rhythm to a normal sinus rhythm. Over the next couple of months, Eileen began to feel better, continuing to work full-time, despite her heart rate at times going in and out of atrial fibrillation. Her medication was adjusted multiple times with continued followed—up testing. With each adjustment, Eileen's medication would initially control her heart rhythm, but it would later return to atrial fibrillation. Other treatments, including cardioversion were attempted, but ultimately her heart would return to its abnormal rhythm.

At 6AM on January 20, 2010, when Eileen would normally get up to prepare for work, she did not wake up. When her youngest child, James, woke up for high school, he found her not breathing in her bedroom. James, along with her husband, called 911 and immediately initiated CPR. Eileen was rushed to a nearby hospital and was life-flighted from there to Allegheny General Hospital in Pittsburgh, PA. She had suffered a cardiac arrest and remained in the hospital for 2 weeks. During that stay, a Pacemaker and Implantable Cardioverter Defibrillator (ICD) was implanted into Eileen's chest to stabilize her heart. Multiple tests were completed so that doctors could diagnose the cause of the cardiac arrest. Eileen was diagnosed with "viral cardiomyopathy," a virus that caused her heart to enlarge and not properly function. The doctors believe that the virus from her sore throat a few months earlier traveled to her heart and ultimately caused her cardiac arrest.

Doctors informed Eileen and her family that her condition would continue to worsen, and that she would eventually require a heart transplant. Eileen and her family were shocked, as Eileen had always been positive, healthy and energetic. For Eileen in particular, this was difficult to process, as only 25 years earlier she had cared for patients requiring heart transplants. This time she herself was the patient waiting for a second chance at life.

Eileen was closely followed by her cardiologist, which required multiple tests, increased hospitalizations and further adjustments to medication. Every test result showed that her heart functionality was declining and eventually it stopped responding to treatment. Later that same year (early December 2010), Eileen was placed on the heart transplant list. On December 20, 2010, Eileen's heart function further worsened and she was now too weak to breath on her own. She was admitted to the ICU and placed on a ventilator and heart-lung machine (Extracorpeal membrane oxygenation) to allow the heart to rest.

On the morning of December 23, 2010, 3 days after being placed on life support, Eileen's family received news that a donor's heart became available and that Eileen would undergo a heart transplant, providing Eileen a second chance of life and her family hope that she would be able to return to her previous level of activity.

Eileen will forever be grateful to the donor who provided her with the greatest gift she will ever receive. Because of the amazing care of the doctors and nurses, and the support and prayers from her loved ones, Eileen has been able to return to her previous lifestyle. She lives every day to the fullest and cherishes the memories she makes with her friends and family. Eight months following her surgery, she returned to work full-time as a school nurse and has been working ever since. She plays an active role in providing education to High School students on Organ and Tissue Donation to increase awareness. Not a day that goes by that Eileen does not thank God for her donor and her second chance at life.