

Donate Life Organ, Eye and Tissue Donation in New York State

**Sample Strategies for Incorporating Organ, Eye and
Tissue Donation into the High School Health
Curriculum**



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Vendor Notice

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GENERAL INFORMATION AND OVERVIEW

This tool kit contains resources to assist in presenting information on organ, eye and tissue donation.

1. Overview

- a. Letter to Instructor – An introduction for classroom teachers on the need for education regarding organ, eye and tissue donation.
- b. Four Reasons to Include Organ, Eye And Tissue Donation in Your Plans
- c. Letter to Administrator – An introduction for school and district leaders providing an executive summary of the lesson and tools, as well as information on the importance of education about donation.

2. Goal and Learning Objectives – This document states the goals and objectives of the tool kit, as well as noting alignment with New York State educational standards.

- a. Goals
- b. Learning Objectives
- c. National Health Education Standards
- d. New York State Guidance Document For Achieving The New York State Standards In Health Education
- e. A Closer Look at Health Education Skills
- f. Purpose of the Contents
- g. Content Components
- h. Essential Questions Addressed In the Tool Kit
- i. Potential Lead-Off Discussion Questions
- j. Potential Concluding Discussion Questions

3. Lesson Plan – This sample lesson plan in PowerPoint format, is intended to cover essential information about donation within a single class period.

4. Suggested Classroom Activities

- QUIZ: Myths and Misconceptions: Did You Know – This quiz includes true/false questions regarding donation. The answer sheet for the instructor includes correct information and an explanation for each answer that the instructor can share.
- COMMUNICATION HOMEWORK – Tips For Talking To Your Family About Organ, Eye and Tissue Donation with homework assignment.
- SIMULATION ACTIVITY– Corneal Blindness Simulator Glasses are available from your local recovery organizations. Please see contact list to order materials.
- CONCEPT MAPPING – An opportunity to better understand the process of donation through a brief step-by-step guide.
- VIDEO AND READING RESOURCES – This document contains links to a number of videos with facts and stories relating to donation as well as links that provide opportunities for students to read and reflect upon real life stories of donors and recipients.

5. Additional Information and Activities

HANDOUTS

- GLOSSARY OF DONATION TERMS – Brief explanations of common terms in the fields of donation and transplantation.
- DONATION TERMINOLOGY – This guide provides the preferred language for discussions of donation and transplantation. Outdated language may be unintentionally hurtful to donor families.
- FACT SHEET – This two-sided sheet includes key facts and statistics regarding donation and transplantation in New York State.
- SERVICE AREA MAP – This map shows the regional organ, eye and tissue recovery agencies and the territories they cover within New York State. It also includes contact details for instructors seeking additional support and materials.
- LINKS TO OTHER TRANSPLANT RELATED RESOURCES

SUPPLEMENTAL ACTIVITIES

- COMMUNITIES OF COLOR –While the transplant waiting list includes people of all backgrounds, members of some ethnic groups are more likely to need transplants.
- Interactive activity: Time is running out
- Interactive activity: Every breath I take
- Interactive activity: Ethical questions to Consider

LINKS (Under Development)

The plans on the pages that follow were designed to serve as samples for school districts as they develop a full repertoire of integrated lessons through cooperative effort of the health teacher and the classroom teacher. The format included is only a suggested model as school districts may design or use current lesson plan formats that best suit their needs. Each one integrates health learning standards with learning standards and performance indicators in ELA, social studies, math and science.

Dear Health Coordinator and Health Educator,

As high school health teachers, you may know about recent legislation allowing 16 and 17-year olds to record their intent to be an organ, eye and tissue donor by enrolling in the New York State Donate Life Registry. In fact, all New Yorkers applying for a driver's license, permit, non-driver ID or IDNYC identification card are asked if they wish to enroll in this registry. As you know, applying for one of these documents is an activity undertaken by many high school students-- an activity during which they will have to answer this question. You are instrumental in ensuring that your students receive the correct information and can make an informed decision about this very important matter.

The New York State Department of Education has recognized the importance of this decision and accepted the challenge of providing accurate information to high school students so they can make this choice. Funds appropriated by New York State made available by contract with the NYS Department of Health made it possible for Donate Life New York State (DLNYS) to work with the State Education Department to create the attached Tool Kit, which includes a sample lesson plan, handouts, activities, materials and other tools to help teachers provide accurate information that students will need to make an informed decision.

Thousands of New Yorkers are currently waiting for a lifesaving transplant. A single organ donor can help save the lives of up to eight people. A single tissue donor can improve the lives of up to 75 people. Cornea donors restore sight to people with eye injuries or diseases. However, many students and adults have little knowledge of organ, eye and tissue donation.

DLNYS will be glad to provide additional information for your use, and the agencies serving your area may have additional resources including local stories and classroom speakers. Please refer to the enclosed service area map to find contact details for the organization serving your school district.

Thank you for your support of this important effort.

Sincerely,



Aisha Tator
Executive Director
Donate Life New York State

FOUR REASONS TO INCLUDE ORGAN, EYE AND TISSUE DONATION IN YOUR PLANS

1. There are many opportunities when teens are given the choice to enroll in New York State's organ, eye and tissue donor registry. Teaching about donation prepares them to make an informed decision.

Studies show that most Americans learn about donation from TV, media and family. Formal classroom education would be very beneficial so that knowledge is based on facts – not misconceptions! (McGregor, 2008.)

2. Donation is a complex and sometimes misunderstood topic. The classroom provides a space for open and thorough conversations about the facts of donation.
3. Teens might think the subject of donation is irrelevant to them and their loved ones and actually this may not be the case. One never knows when the topic of donation or transplantation may affect them personally.
4. The circumstances which often accompany donation, whether anticipated or unanticipated, create a sense of loss. Families may be surprised, or confused, about their loved one's final wishes. Sharing your wishes ahead of time can help a family in this time of loss.

This tool kit is intended to provide correct information about the basics of donation, giving an overview that can assist in making an informed decision and provide accurate information about enrolling in the registry. It can assist educators to teach donation thoroughly and accurately, whether as a stand-alone lesson, a complete unit, or in conjunction with a Donate Life presentation (free and available by request from your local Organ Procurement Organization, or Eye and/or Tissue Bank, year-round).

Dear School Administration and Coordinators of Health,

Recent legislation now allows 16 and 17-year olds to record their consent to be an organ, eye and tissue donor by enrolling in the New York State Donate Life Registry. In fact, all New Yorkers applying for a license, permit, non-driver ID or IDNYC identification card are asked if they wish to join this registry. As you know, applying for one of these documents is an activity undertaken by many high school students – an activity during which they will have to answer this question. High school students will need accurate information in order to make an informed decision about becoming an organ, eye and tissue donor and joining the Donate Life Registry. Your schools are instrumental in ensuring students have the knowledge to make this important decision.

The New York State Department of Education has recognized the importance of this decision and accepted the challenge of providing accurate information to high school students so they can make this decision. Funds appropriated by New York State made available by contract with the NYS Department of Health made it possible for the State Education Department to work with Donate Life New York State (DLNYS) to create the attached Tool Kit, which includes a sample lesson plan, handouts, activities, materials and other tools to help teachers provide accurate information students will need to make an informed decision. DLNYS, organ, eye and tissue recovery organizations and other experts from around the state worked with the State Education Department to create these tools whose use we hope you will encourage in your classrooms.

Thank you for your support of this important effort.

Sincerely,



Aisha Tator
Executive Director
Donate Life New York State

GOALS AND LEARNING OBJECTIVES**GOAL:**

Provide a better understanding of organ, eye and tissue donation through information and discussion.

LEARNING OBJECTIVES:

- Students will be able to make an informed decision about whether or not to join New York State's Donate Life Registry.
- Students will be able to cite a specific example of the impact of donation.
- Students will be able to describe the current state of donation in the country and specifically, New York State.
- Students will be able to differentiate between facts and myths related to donation.

NATIONAL HEALTH EDUCATION STANDARDS:

<https://www.cdc.gov/healthyschools/sher/standards/index.htm>

Standard 2: Students will analyze the influence of family, peers, culture, media, technology, and other factors on health behaviors.

- 2.12.1 Analyze how the family influences the health of individuals.
- 2.12.2 Analyze how the culture supports and challenges health beliefs, practices, and behaviors.
- 2.12.3 Analyze how your peers influence healthy and unhealthy behaviors.
- 2.12.4 Evaluate how the school and community can affect personal health practice and behaviors.
- 2.12.5 Evaluate the effect of media on personal and family health.
- 2.12.6 Evaluate the impact of technology on personal, family, and community health.
- 2.12.7 Analyze how the perceptions of norms influence healthy and unhealthy behaviors.
- 2.12.8 Analyze the influence of personal values and beliefs on individual health practices and behaviors.
- 2.12.10 Analyze how public health policies and government regulations can influence health promotion and disease prevention.

Standard 4: Students will demonstrate the ability to use interpersonal communication skills to enhance health and avoid or reduce health risks.

- 4.12.1 Use skills for communicating effectively with family, peers, and others to enhance health.
- 4.12.4 Demonstrate how to ask for and offer assistance to enhance the health of self and others.

Standard 5: Students will demonstrate the ability to use decision-making skills to enhance health.

- 5.12.1 Examine barriers that can hinder healthy decision making.
- 5.12.2 Determine the value of applying a thoughtful decision-making process in health-related situations.
- 5.12.3 Justify when individual or collaborative decision making is appropriate.
- 5.12.4 Generate alternatives to health-related issues or problems.
- 5.12.5 Predict the potential short-term and long-term impact of each alternative on self and others.
- 5.12.6 Defend the healthy choice when making decisions.

Standard 7: Students will demonstrate the ability to practice health-enhancing behaviors and avoid or reduce health risks.

7.12.2 Demonstrate a variety of healthy practices and behaviors that will maintain or improve the health of self and others.

Standard 8: Students will demonstrate the ability to advocate for personal, family, and community health.

8.12.1 Use accurate peer and societal norms to formulate a health-enhancing message.

8.12.2 Demonstrate how to influence and support others to make positive health choices.

8.12.3 Work cooperatively as an advocate for improving personal, family, and community health.

8.12.4 Adapt health messages and communication techniques to a specific target audience.

NEW YORK STATE GUIDANCE DOCUMENT FOR ACHIEVING THE NEW YORK STATE STANDARDS IN HEALTH EDUCATION:

<http://www.p12.nysed.gov/ciai/health/GuidanceDocumentFinal1105.pdf>

New York State Health, Physical Education, and Family and Consumer Science

- **Standard 1:** Personal Health and Fitness Students will have the necessary knowledge and skills to establish and maintain physical fitness, participate in physical activity, and maintain personal health.
- **Standard 2:** A Safe and Healthy Environment Students will acquire the knowledge and ability necessary to create and maintain a safe and healthy environment.
- **Standard 3:** Resource Management: Students will understand and be able to manage their personal and community resources.

A Closer Look at the Health Education Skills

Seven developmental personal and social skills, comprised of multiple sequential subskills, which when mastered, enable individuals to enhance personal, family and community health and safety. The seven skills include the overall encompassing skills of Self-Management and Relationship Management, as well as Stress Management, Communication, Decision Making, Planning and Goal Setting and Advocacy. The seven skills are listed below:

Self-Management: Overall personal health skill that enables an individual to assess and analyze one's current health and safety status, apply appropriate knowledge and skills, monitor, evaluate and adjust one's behavior to enhance personal health and safety. Self-management includes the personal application of Stress Management, Communication, Decision Making, and Planning and Goal Setting to enhance personal health and safety.

Relationship Management: Overall personal health skill that enables an individual to assess and analyze one's current interpersonal and intra-personal knowledge and skills, monitor, evaluate and adjust one's behavior to enhance personal, family and community health and safety. Relationship management includes the application of Stress Management, Communication, Decision Making, and Planning and Goal Setting to enhance personal, family and community health and safety.

Stress Management: Personal and social skills comprised of multiple subskills, that when performed together, enable an individual to manage positive and negative change in health enhancing ways. Stress management is performed as a separate skill and often in conjunction with the other health skills.

Communication: Sequential personal and social skills comprised of multiple subskills, that when performed together, enable an individual to listen, understand and express oneself in respectful, safe and health enhancing ways. This skill includes verbal and non-verbal communication, assertiveness, refusal, negotiation, conflict management and collaboration.

Decision Making: Sequential personal and social skills comprised of multiple subskills, that when performed together, enable an individual to make well informed choices that enhance personal, family and community health.

Planning and Goal Setting: Sequential personal and social skill comprised of multiple subskills, that when performed together, enable an individual to develop health enhancing short-term and long-term goals, and develop, implement, evaluate and revise health enhancing plans to accomplish the goals.

Advocacy: Sequential personal and social skill comprised of multiple subskills, that when performed together, enable an individual to persuade others to promote, support or behave in ways that enhance personal, family and community health. Advocacy is a natural outgrowth of Self-Management, Relationship Management and the other four Health Education Skills.

PURPOSE OF THE LESSON PLAN

This lesson will introduce students to the basics of organ, eye and tissue donation.

Movies, TV and the Internet often portray donation incorrectly and in general, there are myths that may be inadvertently perpetuated. Because teens are a target audience for these media, it's important to provide the facts about donation. Many young adults will encounter the option to enroll in the registry at 16 years of age when they apply for their Learner's Permit at the DMV or when signing up to vote at age 18. This lesson plan is to educate students on the topic, empowering them to make an informed decision.

This lesson provides students with an overview of donation; the benefits of donation; what donation encompasses, the donation process; a brief history of donation; and statistics regarding the need for donated organs, eyes and tissue.

ESSENTIAL QUESTIONS ADDRESSED IN THE LESSON PLAN:

- What is organ, eye and tissue donation, and what are the benefits?
- What is the need for donated organs? How many lives can be saved from one organ donor? Why is there a waiting list for donated organs?
- What is the need for donated eyes and tissue? How many lives can be improved by a corneal and tissue donation? Is there a waiting list for donated eyes/tissue?
- Who can be a donor?
- What organs and tissues can be donated? What can be donated by a living donor?
- How does someone become a donor?
 - How does someone become a deceased donor?
 - How does someone become a living donor?
- How can we overcome myths and misconceptions about donation?
- What is the process for receiving a donated organ or tissue?
 - What role does the United Network for Organ Sharing (UNOS) play in facilitating transplants?
 - What role does the local recovery organization play? (Organ Procurement Organization (OPO)/Eye/Tissue Bank (ETB))

POTENTIAL LEAD-OFF DISCUSSION QUESTIONS:

- What is organ donation? What is tissue donation?
- What have you seen or heard about donation?
- Were your parents or guardians involved in the decision?
- Can you imagine what it would be like to need a transplant?
- Do you know anyone who needs a transplant, or is on kidney dialysis?
- Do you know anyone who has donated a loved one's organs when they died or anyone who has been a living organ donor?
- How would you feel if someone you loved died and donated organs and tissues that saved the lives of many people?

POTENTIAL CONCLUDING DISCUSSION QUESTIONS:

- How would you feel if you were waiting for an organ, cornea or tissue?
- What is important information about donation that you think others should know?

CONTENT COMPONENTS

Current Data

The following links provides direct access to current data.

<http://www.alliancefordonation.org/county-map/new-york-state-donate-life-registry> NEW LINK COMING!

<https://data.ny.gov/>

- More than 118,000 people in the U.S. are currently awaiting a lifesaving organ transplant.
- Nearly 10,000 of those waiting live in New York State.
- Unfortunately, 22 people die each day because they were not able to receive an organ transplant in time.
- One New Yorker dies every 15 hours waiting for a life-saving organ.
- The average New Yorker waiting for a kidney will have to wait 7-8 years for the organ.
- More than 1 million tissue transplants are performed in the U.S. each year.
- Nearly 50,000 corneal transplants are performed in the U.S. each year.
- One donor has the potential to save 8 lives through organ donation and enhance up to 75 more through corneal and tissue donation.
- 52% of adults (18 and over) in the U.S. have joined state organ, eye and tissue donation registries.
- New York State has the lowest donor registration rate in the country at 28%.
- 83% of New Yorkers say they support donation.
- New York State is the only state that allows residents to sign up as an organ and tissue donor when they register to vote.

What is the need for organ, eye and tissue donation?

- The number of people needing a life-saving organ transplant far exceeds the availability of donated organs. Many wait years for a transplant, and some will die before the organ they need becomes available. This is in part because at times, the organs that are available do not meet necessary criteria for transplantation, leading to a very important reason why more people need to enroll in the registry.
- There is also a great need for life-improving cornea and tissue to be donated.

What organs and tissue can be recovered from deceased donors?

- Transplantable organs are: heart, liver, pancreas, kidneys (two, as they may go to different recipients), lungs (two, as they may go to different recipients), and intestines.
- Transplantable tissue includes: cornea, heart valves, bone, skin, tendons, ligaments, veins, nerves, cartilage and other tissue.

What organs can be donated by a living donor?

- Living donors can save lives by choosing to give a kidney, one of two lobes of their liver, a lung or part of a lung, part of the pancreas, or part of the intestines to someone in need of a transplant. A living donor can give to a person they know, or to a stranger, as long as they are a match. A potential living donor has to go through a series of medical tests to determine if they are eligible to donate.
- Blood and bone marrow, while not part of the organ, eye and tissue donor registry, are also considered tissue that can be donated.

How does the organ recovery and allocation process work?

The following video presents a clear portrayal of the process: [HRSA video](#)

What do the local recovery organizations (OPO/ETBs) do?

- Medical personnel work hard to save patients' lives, but sometimes there is a complete and irreversible loss of brain function resulting in brain death. In that case, the patient is declared clinically and legally dead and could be considered as a potential donor. Increasingly, organs may be recovered from a donor who died from a circulatory death, where the heart or the lungs cease to function.
 - In addition to referrals from OPOs, eye and tissue banks may receive notification of potential donors from other sources such as coroners, nursing homes and funeral homes.
- Hospitals are required by law to contact their designated recovery organization when a patient dies or death is imminent. The recovery organization checks the donor registry. If there is an opportunity for the person to donate, the family will be informed that the person was a registered donor. If the deceased was not on the registry, a family member or another representative may be asked to authorize donation.

Who decides who gets an organ, corneas or tissue and when?

- A national electronic system matches available organs with people on the waiting list. Factors in making the match include: blood type, body size, how sick the patient is, the distance between the donor and the potential recipient, and how long the patient has been waiting.
- Physicians and surgeons work with the organ procurement organizations, eye and tissue banks to develop the recovery procedures.
- Tissues are prepared and distributed for transplantation in a way that doesn't require matching.
- In the U.S., it is illegal to buy or sell organs or tissue for transplantation.

Overcoming Myths and Misconceptions

Doctors, nurses and paramedics do everything they can to save a person's life.

- Organ and tissue donation is generally considered favorably regardless of race, religion, culture, or country of origin.
- People of all ages, ethnicities and backgrounds are in need of transplants.
- Organs and tissues can be donated to people of different ethnicities and genders.
- Donation does not generally affect funeral arrangements or viewings.
- No one should rule themselves too old or too sick to register as a donor. For example, a person who has had cancer might be able to be a donor. It depends in their individual situation. Suitability is determined at the time of death.
- There is no cost to the donor or their family for organ, eye or tissue donation.

Who can register as a donor in the NYS Donate Life Registry and how do they enroll?

- In New York State, anyone 16 years of age or older can enroll in the registry.
 - The New York State Donate Life Registry is a confidential, secure registry that is only accessed at the time of death by state and federally regulated recovery agencies.
 - Young adults, aged 16 and 17 years old, can enroll in the Registry. Parents and guardians of 16 and 17 year olds must give their consent if the death and potential for donation happens to occur before the registered teenager reaches the age of 18.
 - At the time of a person's death the recovery organization evaluates the patient's current and past medical histories to determine if their organs, eyes and tissue can be donated.

If a person doesn't make the decision about organ, eye and/or tissue donation for themselves, someone else can. Usually, the decision is then left up to the family. Documenting your personal choice by joining the New York State Donate Life Registry takes the burden off of your family or those who have been designated to make health care decisions on your behalf (health care proxy).

What can you do?

- Talk about what you now know about organ, eye and tissue donation with your family.
- Share your personal wishes, whatever your decision, with your family.

This information is also provided in PPT format/

SUGGESTED HIGH SCHOOL HEALTH CLASSROOM ACTIVITIES

- **QUIZ** – This quiz includes true/false questions regarding the myths and misperceptions surrounding donation. The answer sheet for the instructor includes correct information and an explanation for each answer that the instructor can share.
- **COMMUNICATION HOMEWORK** – Tips For Talking To Your Family About Organ, Eye and Tissue Donation with homework assignment.
- **CORNEAL BLINDNESS SIMULATION** – Corneal Blindness Simulator Glasses are available from your local recovery organizations. Please see contact list to order materials.
- **CONCEPT MAPPING THE DONATION PROCESS** – An opportunity for students to enhance their concept mapping skills as they review the donation process in New York State.
- **VIDEO** – This document contains links to a number of videos with facts and stories relating to donation.
- **READING ASSIGNMENTS** – If the instructor prefers readings to videos, these links provide opportunities for students to read and reflect upon real life stories of donors and recipients.

MYTHS AND MISCONCEPTIONS: DID YOU KNOW? A True/False Activity

Donor families must pay for the costs associated with organ, eye and tissue donation.

FALSE:

- There is no cost to donor families. Costs are taken care of by the recovery organization. Families are still responsible for funeral and burial arrangements.

Even if you have a history of illness, you can still be a donor.

TRUE:

- There are very specific criteria for what makes an organ, corneas or tissue suitable. Do not rule out your eligibility to be a donor.

You can choose what is donated if you enroll in the New York State Donate Life Registry.

TRUE:

- At the time of enrollment and any time later you can specify or limit the organs and tissues you consent to donate. All Donate Life Registry enrollees will receive confirmation of their enrollment. This notification provides information about how to specify or limit the organs and tissues you would like to donate.

Donors can have an open casket funeral.

TRUE:

- Donation generally does not affect funeral arrangements or viewing.

It is illegal to sell your organs/tissues.

TRUE:

- The sale of organs and tissues in the United States is prohibited by law.

Rich people in need of an organ transplant are given preferential treatment when an organ becomes available.

FALSE:

- There are specific criteria that make someone a suitable recipient when an organ becomes available, and money is not one of them.

A person who wears glasses or contacts can be a corneal donor.

TRUE:

- People who wear glasses or contacts can still be donors. The corneas may be suitable for transplant.

Doctors are aware of who is registered as a donor and won't try to save their lives.

FALSE:

- Medical professionals have one ultimate goal and that is to preserve life. Doctors and other health care practitioners involved in a potential donor's care follow their wishes regarding their health care and practice in accordance with established standards of medical care. Doctors who treat a person who eventually becomes a donor are not involved in the organ and tissue recovery process.

It is recommended to communicate your wishes with your family, especially if you are registered.

TRUE:

- There are many instances when the first time the next of kin is made aware that their loved one is registered as a donor is at the time of his or her death. If a tragedy occurs, it eases the burden of families to know their loved one's wishes. It is especially important that you discuss your decision with your loved ones. If you are younger than 18 years of age and join the registry your family will make the ultimate decision about whether donation will proceed.

TEACHER NOTE:

A handout without answers is provided on the next page.

MYTHS AND MISCONCEPTIONS: DID YOU KNOW? A True/False Activity

- True False Donor families must pay for the costs associated with organ, eye and tissue donation.
- True False Even if you have a history of cancer, you may still be a donor.
- True False You can choose what is donated if you enroll in the New York State Donate Life Registry.
- True False Donors can have an open casket funeral.
- True False It is illegal to sell your organs, eyes or tissues.
- True False Rich people in need of an organ transplant are given preferential treatment when an organ becomes available.
- True False A person who wears glasses or contacts can be a corneal donor.
- True False Doctors are aware of who is registered as a donor and won't try to save their lives.
- True False It is recommended to communicate your wishes with your family, especially if you are registered.

TIPS FOR TALKING TO YOUR FAMILY ABOUT ORGAN, EYE, AND TISSUE DONATION

1. Ask your family to sit down with you to talk. Tell them what you learned in class about organ, eye and tissue donation and transplantation and the potential to save the lives of up to eight people and enhance the lives of more than 75 others. Make sure they know and understand your own personal feelings about organ, eye and tissue donation. Show them the materials you received in the classroom so they have a better understanding of organ, eye and tissue donation.
2. Inform your family of your decision, whatever it may be. Remember the best way to make your wishes known to be a donor is to enroll in the New York State Donate Life Registry when you are able.
3. Share with your family some of the stories and videos from DonateLifeNYS.org and other websites to show how donation gave people a new chance at life. www.donatelifenewyork.com
4. Be certain to clear up any misconceptions that your family members may have about the donation and transplantation process.
5. Encourage your family members to make their own decisions about organ, eye and tissue donation.

TEACHER NOTE:

A sample take-home communications assignment may be found on the next page.

**TIPS FOR TALKING TO YOUR FAMILY ABOUT ORGAN, EYE, AND TISSUE DONATION:
COMMUNICATION HOMEWORK**

Dear Parents or Guardians:

In our class we have been learning about being an organ, eye and tissue donor. This assignment is for you and your teen to discuss what we have learned at school and to discuss what you know about this topic. My goal for this assignment is for you to enjoy talking with your teen while helping them get class credit!

Here is your assignment to do together. Please give this letter to your student, and sign when completed.

Nothing discussed needs to be written down, only this worksheet needs to be signed and then turned in by your student.

DUE DATE: _____

Check list for topics for discussion:

Students should check off each area after they have discussed this with the adult.

_____ Share with your parent or guardian some of what you have learned in class about organ, eye and tissue donation. (Hint: you might bring home some of what you used in class to show them)

_____ Share when you might be asked to make a decision about enrolling in the New York State Donate Life Registry (at the DMV, for example).

_____ Share what you have learned about how others benefit from donations and that people should not assume they cannot be a donor because of an illness. (How many people can be helped through the generosity of one donor?)

_____ Ask if your parent or guardian knows anyone who has been a donor, or received a donation or needs a transplant? (Discuss how they feel about this donation)

_____ If you intend to become a donor, share some of your thoughts with your parent or guardian about making this decision. (Share the steps of decision making and the important details of documenting the decision to enroll in the New York State Donate Life Registry.)

_____ **Have your parent or guardian sign this and return it to your teacher for class credit.**

Thank you so much for communicating your ideas, thoughts and wishes.

Sincerely;

Health Teacher

Signature of Parent or Guardian/Date

CORNEAL BLINDNESS SIMULATION ACTIVITY

Corneal Blindness Simulator Glasses are available from your local recovery organizations. This allows your students to try on glasses that simulate corneal blindness, the type of blindness treated through corneal transplantation.

It must be stressed that simulating a visual impairment is not the same as having the visual impairment. The sighted person has the visual memory and experiences to draw from and assist them in identifying information and navigating their way through the environment. Keep in mind that it is critical to ensure that everyone stays safe during any type of simulation especially during any movement activities. Each person under simulation should have a sighted monitor to ensure safety.

- As a seated activity, project 2 or 3 slides containing a symbol or large writing. With glasses on, ask students to identify what is being projected.
- Walk in a hallway to locate specific room numbers or areas. You may choose to provide the person with a verbal prompt or provide them with a card with the room number in print/braille and request they find the room.
- Locate a doorway leading to the outside.
- Go outdoors and locate a specific car in the parking lot or locate the correct bus.
- Walk in well-lit and dimly lit areas. Similarly, walk from a brightly lit to a dimly lit environment and vice versa.
- Provide the person with a coin purse and encourage them to use a vending machine.
- Request the person locate and use a water fountain.
- Find a requested item in a familiar and unfamiliar classroom.
- Provide the student with a set of keys and request that they open a locked door.
- Play catch with a playground ball, tennis ball or a beach ball.
- Get a wet paper towel and clean the table top and sweep up crumbs from the floor.
- Arrange for participants to go through the lunch line and get their lunch.
- Alternatively, provide a "potluck" meal. Prepare labels in different fonts and sizes and have participants fix themselves a plate.
- Provide items to create a simple snack and encourage participants to assemble their snack including spreading cream cheese, peanut butter, etc.

CONCEPT MAPPING: WHAT IS THE DONATION PROCESS IN NEW YORK STATE?

1. A person dies or faces imminent death from an irreversible brain injury.
2. Hospitals are required to report every death or imminent death by contacting their regional organ procurement organization (OPO) or eye/tissue bank.
3. The patient is evaluated to determine if he/she is medically suitable to donate organs and/or tissues for transplantation.
4. Once it has been determined that the patient is medically suitable, the authorized OPO or eye/tissue bank personnel search the New York State Donate Life Registry database to ascertain if the individual enrolled and documented their consent to make an anatomical gift by donating their organs, eyes and tissues.
5. If the person is registered, the family is notified, educated and supported through the donation process and the process proceeds.
6. If the person is not found on a registry, staff from the authorized OPO or eye/tissue bank will offer the opportunity to the family (or lawful agent) and with their consent, the donation process moves forward.
7. The authorized OPO and eye/tissue bank coordinators are responsible for working to assure that the donor's wish to save and improve the lives of as many people as possible is carried out. The coordinators also provide support and counseling to the families. Other people who may be involved in the process include hospital caregivers, grief counselors and pastoral care personnel.
8. When an organ transplant recipient is identified:
 - All patients awaiting transplantation are listed on the national wait list maintained by the United Network for Organ Sharing (UNOS) in an online database.
 - There are separate lists for each organ needed. Factors in making the match include: blood type, body size, how sick the patient is, the distance between the donor and the potential recipient, and how long the patient has been waiting.
9. For organs, recovery is performed in the operating room by surgeons, usually in the location where the donor dies. The donated organ is then transferred to the transplant center where the person who has matched to the organ is and the transplant is performed.
10. Tissue and eye donations may be recovered either in the hospital or at an off-site surgical recovery facility by a trained recovery specialist. The donated tissue(s) is transferred to an eye and/or tissue bank and is/are prepared for transplant. The corneas and/or tissue are then transferred to a medical facility where the transplants will be performed.

TEACHER NOTE:

As a homework or graded assignment, students may be asked to demonstrate their understanding of this process as a concept map.

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DONATION TERMINOLOGY – The preferred language for sensitive discussions of donation and transplantation. Outdated language may be unintentionally hurtful to donor families.29

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FACT SHEET – A link to a two-sided sheet that includes key facts and statistics regarding donation and transplantation in New York State.

SERVICE AREA MAP – A link to a map which shows the regional organ, eye and tissue recovery agencies and the territories they cover within New York State. It also includes contact details for instructors seeking additional support and materials.

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GLOSSARY OF ORGAN AND TISSUE DONATION TERMS

Adapted from the glossary at OrganDonor.gov, available online at <https://www.organdonor.gov/about/facts-terms/terms.html>.

A

Allocation—A system of rules and guidelines used to determine how organs are distributed among the patients in need of an organ transplant. These policies and guidelines make sure that organs are distributed in a fair, ethical and medically sound manner.

Allograft—Describes when a transplant of an organ or tissue is between two people of the same species, for example from one human being to another.

B

Blood Vessels—is a term that refers to the arteries, veins, and capillaries that blood flows through in the body. Blood vessels can be donated and transplanted.

Bone—is dense tissue that forms the skeleton and supports the body. Bone can be donated and transplanted.

Brain Death—is a term that means the person's death is due to their brain shutting down and becoming permanently non-functional. A person that is declared brain dead is not awake and cannot be woken up. They are not aware of anything around them, no longer breathes on their own and have no purposeful movement.

C

Circulatory Death— is when a person's death is due to their heart stopping. There are many causes of cardiac or circulatory death. Just like brain death, there is no recovery from circulatory death.

Connective Tissue—are the parts of the body that form the supportive and connective tissues of the body, such as tendons, ligaments, cartilage and bone. Connective tissue surrounds many organs.

Cornea—is the transparent outer covering of the eye's iris, colored part, and pupil. Corneas can be donated and transplanted to give people back their sight.

D

Deceased Donor—is a person who has been declared dead and whose organs and/or tissues have been donated for transplantation.

Donation—is the act of giving organ(s), tissue(s), or blood to someone else. It is illegal in the US to be paid or to receive something of value in exchange for the donation of an organ or tissue.

Dialysis—is a process used to remove excess fluid and toxic substances from the blood when the kidneys are not working right and unable to do so. See hemodialysis and peritoneal dialysis.

Donor Designation—is documentation that a person has decided to donate their organs, eyes, and/or tissues after death. This is usually found on a driver's license or non-driver's identification card or through enrollment in a donor registry.

Donor Registry—is a confidential electronic database in which people enroll and document their wish to be an organ and tissue donor. Most registries are for a single state, but a few serve more than one state.

People can enroll in most donor registries in a number of ways. Enrollment in most state donor registries is through the motor vehicle department offices. Many also have ways to join the registry online.

E

End-Stage Organ Disease—a term that refers to advanced disease that is permanent and results in the failure of an organ to function the way it should. Examples are emphysema (lungs), cardiomyopathy (heart), and polycystic kidney disease (kidneys).

End-Stage Renal Disease (ESRD)—is the complete or almost complete failure of the kidneys to function. The kidneys no longer remove wastes, toxins, fluid or other substances from the body like they would if they were working properly.

G

Graft—is a transplanted organ or tissue.

H

Heart—is a muscular organ located in the human chest that pumps blood through the body. The heart can be donated and transplanted.

Heart Valves—Are the parts of the heart that prevent the back flow or leakage of blood as it is being pumped and flows through the heart. Heart valves can be donated and transplanted.

I

Intestines—include the different parts of the digestive tract starting below the stomach including the upper segment (small intestine) and lower segment (large intestine.) The intestines can be donated and transplanted.

K

Kidneys—Are a pair of organs that work to filter wastes and maintain the proper amount of water and other substances in the body. Kidneys can be donated for transplantation by deceased and living donors.

L

Ligaments—are fibrous tissues that link bones, cartilages, and other structures together. Ligaments provide stability and protection to and around joints throughout the body. Ligaments can be transplanted. See Connective Tissue.

Liver—is a large reddish-brown organ that makes substances that your body needs to process the foods you eat and forms certain blood proteins. The liver, like the kidneys, also helps remove wastes and toxins from the blood. The liver can be donated by deceased donors, and a section or part of a liver (lobe) can be donated by a living person for transplantation to a person in need. The liver of both the living donor and the part transplanted into the recipient will grow to full size with time.

Living Donor—is a person who donates an organ or tissue to another person while they are still alive.

Lungs—are organs that enable breathing to take place, providing life-sustaining oxygen to the body and its organs. The lungs of a person that has died can be donated and transplanted, and a portion of a lung, a lobe, can be donated by a living donor.

M

Marrow—is a thick liquid substance found in the body's hollow bones, such as the leg, arm and hip bones. Marrow consists of specific cells that make different types of blood cells (platelets, red blood cells, and white blood cells). Marrow for transplant is usually collected from the pelvic bone.

Match—is a term used to describe the degree of similarity or likeness in very specific ways, such as blood type, between a donor and a recipient.

N

National Organ Transplant Act (NOTA)—is a law passed by Congress in 1984. NOTA started the development of a national system of organ sharing and the collection of transplant data for analysis and quality improvement. This law also outlawed the sale of human organs in the United States.

O

Organ—is a part of the body which performs a particular function. Transplantable organs are: heart, intestines, liver, lungs, kidneys, and pancreas.

Organ Donation—is the giving an organ or a part of an organ for the purpose of transplantation into another person or research. Organ donation can involve a donor that has died, who can give kidneys, pancreas, liver, lungs, heart, intestinal organs, or a living donor, who can give a kidney or a portion of the liver, lung, or intestine.

Organ Preservation—are methods used to maintain the “health” of organs between removal from the donor and transplantation into the recipient. These methods include use of preservation solutions, pumps, and cold storage. Organs differ in how long they can be preserved. Preservation times can vary from 2 to 48 hours depending on the type of organ.

Organ Procurement Organizations (OPO)—are organizations located throughout the U.S. designated by the Centers for Medicare and Medicaid Services (CMS) that are responsible for managing the organ donation process, including the surgical recovery of donated organs, and promoting organ and tissue donation in their service areas. OPOs evaluate potential donors, discuss donation with family members, and arrange for the removal and transport of donated organs. To increase donor registration, OPOs perform community outreach events to encourage people to sign up in their state donor registry. [Find your local OPO and Eye and Tissue Bank \(LINK\)](#)

P

Pancreas—is a long, irregularly shaped gland that lies behind the stomach. Certain cells in the pancreas make and secrete insulin. Pancreas transplants give patients with diabetes a chance to live without insulin injections. Other pancreatic cells make substances that helps in the digestion of food.

Procurement, also referred to as Recovery—is the process of surgically removing the organ(s), eyes, cornea(s) or other tissue(s) from a donor for transplantation. See Recovery.

R

Recipient—In the context of transplantation, the recipient is the patient receiving the donated organ or tissue.

Rejection (Acute and Chronic)—is a process the body uses to protect itself against “foreign invaders”, that in most cases are germs that cause infections. In the case of a person who has received a transplanted organ, the body thinks the new organ is a foreign invader and attempts to destroy it (just like it would do with any germs that invaded your body). Acute rejection of a transplanted organ happens very quickly; chronic rejection is a slow process resulting in the failure of a donated organ to function.

S

Skin—Covers the outside of the entire body and is the largest organ of the body. Skin has several different functions including protecting the inner body from infection, helping maintain the bodies fluid balance and cooling. Skin grafts can save the life a burn victim and can provide severely scarred individuals with a better quality of life.

T

Tendons—Are tough, flexible bands of fibrous tissue that connects muscles to bones. Tendons help with walking, jumping, lifting, etc. Tendons can be transplanted. See Connective Tissue.

Tissue—is a body part consisting of similar cells that perform a special function. Examples of tissues that can be transplanted are bones, corneas, heart valves, ligaments, veins, and tendons.

Transplantation—is the placement of cells (e.g. stem cells), tissue, or organs removed from one person into another.

Transplant Recipient—is a person who has received a tissue or organ transplant.

V

Vascularized Composite Allograft (VCA)—is transplanted tissue of several different kinds such as skin, bone, muscles, blood vessels, nerves, and connective tissue. Examples of VCAs include: hand(s), arm(s), or face transplants. "Vascularized" means that the transplanted tissue, aka graft, require the surgical connection of blood vessels.

W

Waiting List—is a national database of all patients waiting for an organ transplant. It is generally broken up into "sub-lists" of patients waiting for different types of organs, e.g. kidney, liver, heart, etc.

DONATION TERMINOLOGY

The preferred language for sensitive discussions of donation and transplantation. Outdated language may be unintentionally hurtful to donor families.

Certain terms and phrases, when used in the context of donation and transplantation, may be inaccurate or unintentionally hurtful to the families of organ, eye and tissue donors. Even professionals may mistakenly use outdated terminology.

Inappropriate Term	Appropriate Term
"harvesting" of organs	"recovery" or "donation" of organs
"declare brain death"	"determine brain death"
"life" support	"mechanical" or "ventilator" support
"body parts"	"donated organs and tissues"
"cadaveric" donation	"deceased" donation
"cadaver" (when used in a donation context)	"deceased donor"

The Donor Family Council of the Association of Organ Procurement Organizations has approved the terminology above. The language is also supported by the American Society of Transplantation and American Society of Transplant Surgeons.

ADDITIONAL DONATION-RELATED RESOURCE LINKS**LINKS TO FURTHER RESOURCES:**

For information on organ, eye and tissue donation in New York State, visit: Donate Life New York State:

www.donatelifenys.org

New York State Organ Procurement Organizations

Center for Donation and Transplant: <http://www.cdtny.org/>

Finger Lakes Donor Recovery Network: <http://www.donorrecovery.org/>

LiveOnNY: <http://liveonny.org>

Unyts: <http://www.unyts.org/>

New York State Eye and Tissue Banks

Central New York Eye and Tissue Bank: <http://www.cnyetb.com/>

Eye Bank for Sight Restoration: <http://www.eyedonation.org>

Lions Eye Bank for Long Island: <http://www.lebli.org/>

Musculoskeletal Transplant Foundation: <https://www.mtf.org/>

New York Firefighters Skin Bank: www.nyffbourncenter.com/incs/skinbank.htm

Sight Society of Northeastern New York: <https://www.lionseyebankrochester.org/>

<http://www.lionseyebankalbany.org/>

New York State Organ Transplant Centers

Albany Medical Center - www.amc.edu/patient/services/surgery/transplant_surgery/index.cfm

Cohen Children's Transplant Center - ccmc.northshorelij.com/ccmcny-our-services/nephrology-and-kidney-transplantation

Erie County Medical Center - www.ecmc.edu/health-services-and-doctors/renal-care-kidney-and-pancreas/

James J. Peters VA Medical Center - www.bronx.va.gov/services/RenalTransplantProgram.asp

Montefiore Medical Center - www.montefiore.org/transplantation

Mount Sinai Hospital - www.mountsinai.org/patient-care/service-areas/organ-transplants

NewYork-Presbyterian NYP/Columbia University Medical Center - www.nyp.org/transplant

NewYork Presbyterian - Weill Cornell Medical Center - www.cornellsurgery.org/transplant

North Shore University Hospital Transplant Center - www.northwell.edu/find-care/locations/transplant-center

NYU - Langone Medical Center - www.nyulangone.org/locations/nyu-langone-transplant-institute

Stonybrook University Hospital Transplant Center - www.stonybrookmedicine.edu/patientcare/transplant

Strong Memorial Hospital - www.urmc.rochester.edu/surgery/transplant.aspx

SUNY Downstate Medical Center - www.downstate.edu/transplant/index.html

SUNY Upstate Medical Center - www.upstate.edu/surgery/healthcare/transplant/index.php

Westchester Medical Center - www.westchestermedicalcenter.com/wmc/Transplant.aspx

State and Federal Government Resources

HRSA, Division of Transplantation: <https://organdonor.gov/about-dot.html>

New York State Department of Health: <https://www.health.ny.gov>

Scientific Registry of Transplant Recipients (SRTR): <https://www.srtr.org/>

United Network for Organ Sharing: <https://www.unos.org/>

United States Department of Health and Human Services: <https://organdonor.gov/index.html>

General Donation and Transplantation Resources:

American Association of Tissue Banks (AATB): <http://www.aatb.org/>

Association of Medical Schools of New York: <http://www.amsny.org/>

[Association of Organ Procurement Organizations \(AOPO\): www.aopo.org](http://www.aopo.org)

Donate Life America: <https://www.donatelife.net/>

Long Island Transplant Recipients International Organization: <http://www.litrio.org/>

National Kidney Foundation: <https://www.kidney.org/>

National Marrow Donor Program: <https://bethematch.org/>

New York Cardiothoracic Consortium: <http://nycardiothoracic.org/>

New York Center for Liver Transplantation: <http://www.nyclt.org/>

Organ Donation Alliance: <https://organdonationalliance.org/>

Transplant Support Organization: www.transplantsupport.org

United Network for Organ Sharing: <https://www.unos.org/>

COMMUNITIES OF COLOR IN CRISIS

- African Americans are the largest group of minorities in need of an organ transplant. African Americans have higher rates of diabetes and high blood pressure than Caucasians, increasing the risk of organ failure.
- Hispanic Americans, African Americans, and Pacific Islanders are three times more likely than Caucasians to suffer from diabetes.
- Mexican Americans suffer disproportionately high rates of 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.

The U.S. transplant waiting list is comprised of people of all ages, genders, and ethnic communities. 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.

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

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 on 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, individuals waiting for an organ transplant will have a better chance of receiving one if there are large numbers of donors from a variety of ethnic backgrounds. 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).

INTERACTIVE ACTIVITY: TIME IS RUNNING OUT**Time Needed**

Minimal (Enough time to instruct the student assigned to timer and to explain to the entire class the significance of the activity.)

Materials

A kitchen timer

Instructions

At the beginning of class, assign one student to set the timer for 14 minutes and to reset it for another 14 minutes each time it goes off. Remind students that another person is added to the national organ transplant waiting list every time it goes off.

Student Writing Activity

Have students complete the activity by writing an essay about what things they do that take about 14 minutes. The significance of this portion of the activity is to help students to realize how easy it is to take 14 or 15 minutes for granted and yet how significant that same period of time is to someone else. Discuss as a whole group.

INTERACTIVE ACTIVITY: EVERY BREATH I TAKE

Note: Care needs to be taken with children with asthma, reactive airways, cystic fibrosis, etc. when contemplating this exercise.

Time Needed

Approximately 5 minutes

Materials

1. Small straws/stirrers (the type that are used for coffee and tea drinks) – 1 per student

Instructions

Give a small straw/stirrer to each student. Have the students hold their nose and breathe through their straw for 20 seconds. This demonstrates what it is like to be waiting for a lung transplant, struggling for each breath. Ask your students to imagine what it would be like to wait this way, often needing to use an oxygen tank for months.

Curriculum Connection

Discuss the impact that smoking has on lung function and increased risk of cancer and emphysema.

Supplemental Activity

After the activity, ask the students to write a short story or journal entry as someone who is waiting for a lung transplant. Encourage them to imagine what it would be like to do everyday activities that they now take for granted and to write about it.

INTERACTIVE ACTIVITY: SOME QUESTIONS FOR FURTHER THOUGHT:

- Doctors decide based on medical need who receives an organ. Are there other variables that should be considered?
- Should children be given precedence on the waiting list? Why?
- Should people who have enrolled in the Donate Life New York State Registry receive priority in obtaining a transplant?
- Do you think people should have the right to sell their kidneys for money? Why or why not?
- In several countries, everyone is considered a donor unless they state otherwise. Do you think this is a good idea? What impact do you think this has on donation?
- Would you be willing to donate a kidney to someone you loved? What about to a stranger? To a neighbor?

TEACHER NOTE:

You may wish to pick one or more of these questions for student response.

There are no right or wrong answers to these questions. They are meant to engage critical thinking, debate and reasoning skills. See what you can do to incorporate these or other questions into a lesson.

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Publications

Mcgregor, J. L., Verheijde, J. L., & Rady, M. Y. (2008). The Entertainment Media Framing of Organ Donation: Second-Hand Reality Balancing the Ideological Bias of Education Campaigns. *Health Communication, 23*(4), 394-395. doi:10.1080/10410230802282174