### Appendix A

#### Questionnaire

*A. Instructions.* For each of the following statements, indicate whether you have heard someone say this statement. Then, indicate whether you believe the statement to be true, false, or if you are not sure whether the statement is true or false.

- 1. If the doctors know that a person is an organ donor, they will not work as hard to save that person's life.
  - $\Box$  I have heard this statement before.
  - $\Box$  I have not heard this statement before.
  - $\Box$  True  $\Box$  False  $\Box$  Not Sure
- 2. People can recover from brain death.
  - $\Box$  I have heard this statement before.
  - $\hfill\square$  I have not heard this statement before.
  - $\Box$  True  $\Box$  False  $\Box$  Not Sure
- 3. If I donate my organs, my family will be charged for the costs associated with the donation.
  - $\Box$  I have heard this statement before.
  - $\Box$  I have not heard this statement before.
  - $\Box$  True  $\Box$  False  $\Box$  Not Sure
- 4. Most religions prohibit organ donation.
  - $\Box$  I have heard this statement before.
  - $\Box$  I have not heard this statement before.
  - $\Box$  True  $\Box$  False  $\Box$  Not Sure
- 5. I am too young/too old to be an organ donor.
  - $\Box$  I have heard this statement before.
  - $\Box$  I have not heard this statement before.
  - $\Box$  True  $\Box$  False  $\Box$  Not Sure
- 6. Only the rich and famous receive organ donations.
  - $\Box$  I have heard this statement before.
  - $\Box$  I have not heard this statement before.
  - $\Box$  True  $\Box$  False  $\Box$  Not Sure

*B. Instructions.* Please read the following statements and fill in the blanks with your best guess of the correct answer(s).

According to the United States Government Information on Organ and Tissue Donation and Transplantation (<u>www.organdonor.gov</u>):

7. As of January 2011, approximately \_\_\_\_\_\_ people are on the national organ transplant waiting list (<u>http://optn.transplant.hrsa.gov/</u>).

8. Approximately \_\_\_\_\_\_ people die each day waiting for an organ donation.

9. One donor can potentially save the lives of up to \_\_\_\_\_\_ people and enhance the lives of up to \_\_\_\_\_\_ people.

10. The following organs can be donated to potentially save the lives of others:

C. Instructions. For each number below, please check the appropriate box.

- 11. Position
  - $\Box$  I support organ donation and tissue donation.
  - □ I partially support organ and tissue donation.
  - $\Box$  I do not support organ and tissue donation.
  - $\Box$  I am undecided as to whether or not I support organ and tissue donation.

12. Personal Connection (you may check more than one box)

- $\Box$  I know someone personally who is waiting for an organ donation.
- $\Box$  I know someone personally who has received an organ donation.
- $\Box$  I know someone personally who has donated an organ.
- □ I do not know of anyone personally who is waiting for, received, or donated an organ.

#### 13. Registration

- $\Box$  I am a registered organ donor.
- $\Box$  I am not a registered organ donor, but I intend to register.
- $\Box$  I chose not to be a registered organ donor.
- $\Box$  I am undecided about registering to be an organ donor.
- 14. Conversation

 $\Box$  I have shared my thoughts and feelings about organ and tissue donation with my family.

 $\Box$  I have not shared my thoughts and feelings about organ and tissue donation with my family.

### Appendix B

### **Information for Instructors**

#### Section A

Below are accurate responses to the first six statements on the questionnaire (http://www.donatelifeny.org;http://health.discovery.com/convergence/transplant/articles/myths. html; http://www.mayoclinic.com/health/organ-donation/FL00077; http://www.unos.org).

1. *If the doctors know that a person is an organ donor, they will not work as hard to save that person's life.* The doctor's first priority is to save your life. Additionally, those working to save your life are different individuals than those who would perform organ transplants. Organ donation will only be considered after a physician has declared brain death.

2. *People can recover from brain death.* While people can recover from comas, they cannot recover from brain death (<u>www.discoveryhealth.com</u>). Brain death is determined by a physician who is not associated with the transplantation team.

3. *If I donate my organs, my family will be charged for the costs associated with the donation.* The organ donor's family will not incur organ donation fees.

4. *Most religions prohibit organ donation*. The majority of major religions (e.g., Catholicism, Protestantism, Islam, and most branches of Judaism) do not oppose organ donation. However, there are a few religions that place restrictions on OTD (e.g., Jehovah's Witnesses) and others that oppose it (e.g., Shinto). Specific information about religion and organ donation can be obtained by asking religious leaders and by searching various credible websites (e.g., <u>http://organtransplants.org; http://organdonor.gov/donation/religious\_views.htm</u>).

5. *I am too young/too old to be an organ donor*. People of all ages (from newborns to those over 65) can be viewed as potential organ donors. It is best to let the appropriate medical professionals make the determination as to whether or not you could be a donor.

6. *Only the rich and famous receive organ donations*. Organs are matched using a computerized system called the Organ Procurement and Transplantation Network (OPTN) which is operated by the United Network for Organ Sharing (UNOS). The system does not select recipients based on fame or fortune. Rather, the match is based on medical urgency, medical compatibility (e.g., blood type, tissue type, organ size), waiting time, and geographic location. UNOS policies prohibit organ allocation to be based on sex, race, socioeconomic status, and social status.

After dispelling common myths, instructors may want to provide the following general procedural information. The United Network for Organ Sharing (UNOS) manages the national transplant waiting list and links the organ procurement organizations (OPOs) with transplant centers. UNOS matches donors to recipients 24 hours a day, 365 days a year. Additionally, UNOS maintains a database containing information about every transplant that takes place in the United States (http://optn.transplant.hrsa.gov/about/transplantation/matchingProcess.asp). There are 58 organ procurement organizations (OPOs) in the United States. Hospitals are required by

law to have a referral system in place through which they notify the local OPO when a patient is declared dead. If a recipient match is found, OPO personnel will work to identify the best match (based on factors such as: medical urgency, blood type, tissue type, time on the waiting list, geographical location). Additionally, OPO personnel will work with the hospital staff to find out if the person was a registered organ donor and/or to discuss the possibility of organ donation with the deceased patient's family members. An organ donor's family will not incur organ donation costs. If organs are donated, the organs are surgically removed and the donor's body is closed. Therefore, in most cases open casket funerals are still possible.

## Section B

Below are the correct answers (as of January 2011) to the fill-in-the-blank section of the questionnaire. According to the United States Government Information on Organ and Tissue Donation and Transplantation (<u>www.organdonor.gov</u>):

- 7. As of January 2011, **more than 110,000** people are on the national organ transplant waiting list (<u>http://optn.transplant.hrsa.gov</u>).
- 8. Approximately **19** people die each day waiting for an organ.
- 9. One donor can save the lives of up to 8 people and enhance the lives of up to 50 people.
- 10. The following organs can be donated to save the lives of up to 8 people: heart, lungs, liver, kidneys, pancreas, and the intestines.

## Additional Information

Instructors may want to share the following information (taken from (<u>http://optn.transplant.hrsa.gov/; www.organdonor.gov</u>) with the class as they provide the correct responses for questions 7 through 10 on the questionnaire. This information is also provided on the handout (see Appendix C).

- The following can also be donated to enhance the lives of others (e.g., restore sight, replace damaged skin, repair hearts, improve mobility): cornea, skin, bone, heart valves, tendons, veins, cartilage, ligaments, middle ear.
- Living donors can donate a single kidney, part of a lung, part of the liver, part of the pancreas, and part the intestine.
- More than 100 people on the waiting list die each week.

# Section C

Instructors should stress the importance of making an informed decision about organ donation. The handout (see Appendix C) provides a list of additional resources that students can use to learn more about OTD. The instructor should also stress that people will have different attitudes toward organ donation. While some individuals may choose to be an organ donor, others may choose not to be an organ donor. An individual's wishes should be honored. If an individual is interested in becoming a donor, they should register with their state donor registry and inform their family members. If an individual does not want to be an organ donor, it is important that they document their decision and that they inform their family members.

# Appendix C

## Handout

According to the United States Government Information on Organ and Tissue Donation and Transplantation (<u>www.organdonor.gov</u>):

- 1. As of January 2011, more than 110,000 people are on the national organ transplant waiting list (<u>http://optn.transplant.hrsa.gov/</u>).
- 2. Approximately 19 people die each day waiting for an organ.
- 3. One donor can save the lives of up to 8 people and enhance the lives of up to 50 people.
- 4. The following organs can be donated to save the lives of up to 8 people: heart, lungs, liver, kidneys, pancreas, and the intestines.
- 5. The following can also be donated to enhance the lives of others (e.g., restore sight, replace damaged skin, repair hearts, improve mobility): cornea, skin, bone, heart valves, tendons, veins, cartilage, ligaments, middle ear.
- 6. Living donors can donate a single kidney, part of a lung, part of the liver, part of the pancreas, and part of the intestine.
- 7. More than 100 people on the waiting list die each week.

# Additional Information

The following websites contain general information regarding OTD and are excellent resources for learning more about OTD:

- Coalition on Donation (<u>http://www.DonateLife.net/</u>)
- Donate Life America (<u>http://www.donatelife.net/</u>)
- Organ Procurement and Transplant Network (<u>http://optn.transplant.hrsa.gov/</u>)
- Revised Uniform Anatomical Gift Act (2006) (<u>www.anatomicalgiftact.org</u>)
- The Gift of a Lifetime: Organ and Tissue Transplantation in America (www.organtransplants.org)
- United Network for Organ Sharing (<u>www.unos.org</u>)
- United States Government Information on Organ and Tissue Donation and Transplantation (<u>www.organdonor.gov</u>)
- United States Government Information on Organ and Tissue Donation Information Regarding Religious Views (<u>http://www.organdonor.gov/aboutRelViews.asp</u>)

# Deciding to Become an Organ Donor

According to the United States Government Information on Organ and Tissue Donation and Transplantation (<u>www.organdonor.gov</u>) there are several steps you can take to become an organ and tissue donor:

- 1. Obtain a donor card (http://organdonor.gov), sign it, and carry it with you until you have registered with your state donor registry and/or have designated your decision to be a donor on your driver's license.
- 2. Register with your state donor registry. Information about different state donor registries can be found at: <u>www.organdonor.gov</u>.
- 3. Indicate your decision to be a donor on your driver's license.

4. Talk with your family. While death and organ donation may be a difficult topic to discuss, it is extremely important to talk to your family about your wishes regarding organ donation. You may want to start the conversation by discussing what you have learned in class. Or, you may want to discuss how you would want to offer the opportunity to save someone else's life through organ donation should you pass away. Please remember that your family members may not share your views. However, it is important to discuss your wishes.

### Deciding Not to Become an Organ Donor

There are also a few steps to take if you do not want to be an organ and tissue donor:

- 1. Document your "refusal to donate" decision. A documented refusal will help others honor your wishes not to be an organ donor.
- 2. Talk with your family. While death and organ donation may be a difficult topic to discuss, it is extremely important to talk to your family about your wishes regarding organ donation. You may want to start the conversation by indicating that class discussion focused on organ and tissue donation. Please remember that your family members may not share your views. However, it is important to discuss your wishes.