



A GUIDE TO ORGAN AND TISSUE DISCUSSION



UPSTATE NEW YORK
TRANSPLANT SERVICES

Donate Life Program





DEVELOPED BY



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INTRODUCTION

Each year thousands of people die needlessly waiting for a life saving “gift,” the donation of an organ. Others suffer, waiting for donated tissues which can improve the quality of their lives. Most people are unaware of the causes of organ failure and the need for both organs and tissues. In addition, very few families discuss their wishes with one another regarding end of life issues. This resource manual has been created to assist you and your loved ones in making an informed decision and in having a meaningful family discussion. After reading the information in this guide and attending the presentations in your classroom, you should be able to:

1. Recognize the urgent need for organ and tissue donation and transplantation.
2. Identify organs and tissues that can be donated for transplantation and what type of patients can benefit from transplantation.
3. Discuss who can be an organ donor, who can donate tissues, and explain why.
4. Explain brain death and how it differs from a coma.
5. Review current federal and state legislation regarding organ, tissue, and eye donation.
6. Explain the role of organ procurement organizations in organ and tissue donation and the donation process.
7. Discuss common misconceptions regarding donation.
8. Acknowledge the right of individuals to make an informed decision regarding donation.
9. Recognize the importance of having a family discussion about organ and tissue donation.
10. Develop a personal plan for decision-making regarding donation to be shared with your loved ones.



WHY IS THERE A NEED FOR ORGAN DONORS?

Currently, there are approximately **100,000** people waiting for an organ transplant. Too few organs are donated. Although the number of donors has slowly increased over the years, typically only 55-65% of Americans who were suitable actually became donors. Therefore, approximately **18 people die each day waiting** for a life saving organ.

Table 11 – 3. Reported Eligible Deaths, Actual Donors and Conversion Rates, 2002 - 2005

	<u>2002</u>	<u>2003</u>	<u>2004</u>	<u>2005</u>
Actual Donors	5,746	5,912	6,447	6,666
Eligible Donors	11,503	11,375	11,365	11,412
Conversion Rate	50.0%	52.0%	56.7%	58.4%

Source: SRTR Analysis, August 2006

WHY IS THE DONATION RATE SO LOW?

- Lack of knowledge about the critical need for organs.
- Fears and misconceptions about the donation process.
- Lack of family discussion, leading to low consent rates.

WHO CAN BE AN ORGAN DONOR?

Anyone of any age may be eligible to donate organs,

IF

they have been declared dead by neurological criteria referred to as

“BRAIN DEATH”

and their organs are being temporarily maintained by receiving oxygen through a ventilator.

****This will be explained in more detail in the following section****

WHO CAN BE A TISSUE DONOR?

Anyone of any age who has died as a result of either **“CARDIAC DEATH”** (in which the heart stops beating) or **“BRAIN DEATH”** (in which all brain function is lost).



WHO CANNOT BE AN ORGAN OR TISSUE DONOR?

Organ and/or tissue donors cannot have a communicable disease such as HIV, certain malignancies (cancer), or a disease affecting the function of the organs to be donated.

WHAT IS BRAIN DEATH?

Brain death is the irreversible cessation of function of the brain and brain stem.

COMMON CAUSES OF BRAIN DEATH:

- Head trauma
- Stroke
- Brain injury due to loss of oxygen
- Drug overdose
- Brain tumor without metastasis

HOW IS BRAIN DEATH DETERMINED?

Brain death is determined through a series of tests including the assessment of the individual's ability to breathe on his or her own and the determination of the lack of blood supply to the brain.

WHAT IS THE DIFFERENCE BETWEEN BRAIN DEATH AND COMA?

While brain death is the death of the brain (and therefore the individual), a coma is a condition in which there is a disruption of some of the brain's functions resulting in the loss of consciousness. Coma can be permanent or temporary. In this situation, the part of the brain that controls breathing (brain stem) is still functioning. Therefore, the patient can breathe on his or her own (although many coma patients may need help from a ventilator to breathe). Patients in a coma sometimes regain consciousness and recover some or all of their brain functions.

ONCE BRAIN DEATH OCCURS...why does the heart continue to beat?

The heart has its own pacemaker independent of the brain. Medications and oxygen supplied by the ventilator will allow the heart to continue to beat.

BRAIN DEATH VS. CARDIAC DEATH

Since a brain dead patient may be placed on a ventilator (meaning he or she is being provided with oxygen via a machine), the heart, with its own pacemaker, continues to beat and pump the oxygenated blood to the body's organs. This will temporarily keep the organs and tissues functioning and suitable for transplant.

On the other hand, when cardiac death occurs, the patient's heart stops beating and their organs are without oxygen and lose their ability to function. This person is not able to donate organs, but may donate tissue.

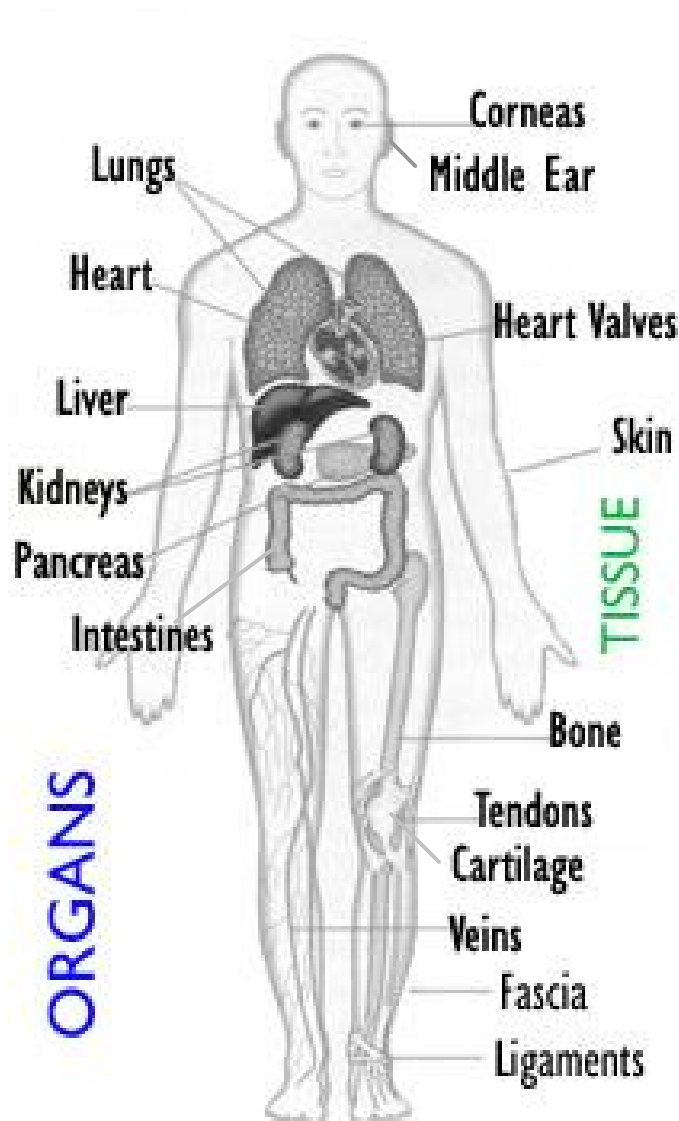
<u>Brain Death</u>	<u>Cardiac Death</u>
<p>Patient is maintained on a ventilator and oxygenated blood continues to be pumped through the body by the heart to maintain the organs. Donor organs are removed in the operating room while organ function is maintained with a ventilator, fluid therapy and medication.</p>	<p>The patient has no cardiac or respiratory activity and therefore the organs lose their ability to function. The body must be kept cool if tissues are not removed immediately to prevent deterioration. Removal of most tissues occurs within 24 hours of death.</p>
<u>Brain Death - Acceptable Donations</u>	<u>Cardiac Death - Acceptable Donations</u>
<ul style="list-style-type: none"> Heart or Heart Valves Kidneys Liver Pancreas Lungs Intestine Bone Ligaments, Tendons Cartilage Skin Veins Fascia Middle Ear Corneas 	<ul style="list-style-type: none"> Heart Valves Bone Ligaments, Tendons Cartilage Skin Veins Fascia Middle Ear Corneas

WHAT ORGANS CAN BE DONATED?

Lungs • Heart • Liver • Kidneys • Pancreas • Intestines

WHAT TISSUES CAN BE DONATED?

Corneas • Middle Ear • Heart Valves • Skin • Bone
Tendons • Cartilage • Veins • Fascia • Ligaments



STEPS INVOLVED IN ORGAN DONATION:

I. **Establishment and Declaration of Brain Death.** *How is death determined?*

A series of tests are performed by physicians to establish that the individual's brain is no longer functioning. These include documenting that the patient cannot breathe on his or her own and that the brain is no longer being supplied with oxygenated blood. Once this is established, the physician will declare the individual dead.

II. **Identification and Referral of Potential Donors.** *How do we know who may be eligible?*

By law, each and every death that occurs in a hospital must be reported to the local Organ Procurement Organization (OPO) assigned to coordinate the donation process. This ensures that each family is given the opportunity to carry out the wishes of their loved one and/or exercise their right to make the decision whether or not to donate their loved one's organs. A specially trained individual, referred to as the *OPO procurement coordinator*, reviews the medical information of each patient that has been declared brain dead to determine if the patient would be eligible to donate.

III. **Consent for Organ Donation.** *Who decides and how?*

If the donor is 18 years of age or older and has signed up to be a donor on New York State's Donate Life Registry, the procurement coordinator will talk with the family. The procurement coordinator will explain to family members that because their loved one signed the registry, their loved one gave their own legal consent to organ, tissue and eye donation upon their death (and the procurement coordinator will take the next steps).

If the donor hasn't signed up for New York State's Donate Life Registry or is under the age of 18, the OPO coordinator discusses the option of donation with the patient's family. OPO coordinators are specially trained to work with donor families and are sensitive to their needs. They explain the process of organ donation and answer the family's questions. It is important to remember that their next of kin (parent, spouse, child, etc.) is asked to sign a consent form before donation takes place. Therefore, it is important to discuss your feelings regarding organ donation with your family members and ask them to carry out your wishes.

IV. **Donor Assessment (Social and Medical History)**. *How is information obtained and why?* As stated previously, certain infectious diseases and malignancies may affect one's ability to donate. A careful medical and social history must be taken to establish that the individual is eligible to donate. This includes obtaining relevant information from the physician and the potential donor's family members.

V. **Donor Management**. *What else must be done before donation occurs?* Various body systems begin to fail after death. The donor's organs must remain in a healthy state for transplantation. Organs can only be maintained for a limited amount of time after death has been declared since the death of cells within the organs will occur, making them unsuitable for transplant.

ORGAN ALLOCATION...

HOW IS THE DECISION ABOUT WHO WILL RECEIVE ORGANS MADE?

UNOS, the United Network for Organ Sharing, is responsible for ensuring that organs are distributed to those on the waiting list in a fair and equitable manner. The procurement coordinator enters the donor information into the Organ Procurement and Transplantation Network's national database operated by UNOS. This system is designed to search the waiting list for potential recipients ranked by specific factors:

WAITING LIST CRITERIA:

- Medical urgency – severity of illness
- Amount of time on the waiting list
- Region
- Blood type
- Size/Weight
- Age

Race, sex, religion, celebrity status and financial assets are never used to determine who receives an organ



HOW IS ORGAN AND TISSUE DONATION COORDINATED LOCALLY?

Once the potential recipients have been identified, the procurement coordinator contacts the transplant center responsible for notifying the potential recipient (and their physician) and makes the arrangements for the removal and transport of organs by the transplant team.

Throughout the United States, agencies referred to as an Organ Procurement Organizations (OPO) have been established to carry out the following responsibilities: donor identification and care, organ removal and preservation, and transport of organs to identified recipients. **Upstate New York Transplant Services** is a not-for-profit organization authorized by the federal government to accept organs and tissues for transplantation and/or medical research in our area. The organization serves the eight counties of Western New York, linking donor families and hospitals to medically trained professionals who coordinate the organ and tissue donation process 24 hours a day.

Organ procurement coordinators (as well as tissue and eye coordinators) are also responsible for continuous professional education and hospital development. By maintaining a recognizable presence in hospitals and teaching hospital staff about identifying potential organ and tissue donors, Upstate New York Transplant Services are truly partners with area hospitals.

The clinical staff of Upstate New York Transplant Services works to preserve the dignity and physical appearance of all organ, tissue and eye donors.

WHAT HAPPENS AFTER DONATION HAS TAKEN PLACE?

Once the donation process is complete, a funeral or other ceremony of your choice can take place. Organ donation does not interfere with the family's ability to have an open casket if they choose to do so.

It is important to note that maintaining the confidentiality of donors and transplant recipients is important. Their privacy and wishes are always respected. Names or other personal identification is not publicly released without permission.





Shortly after donation, donor families are sent a letter with some general information about the transplant recipients. From there, Upstate New York Transplant Services can facilitate anonymous correspondence between donor families and transplant recipients. For example, if they choose to write one another and each party agrees, the letters can be sent to Upstate New York Transplant Services and then forwarded to the recipients and donor families.

Sometimes donor families ask to meet the individuals transplanted with their loved one's organs and tissues. Although such meetings are not common, they do occur. Upstate New York Transplant Services only discloses confidential information when both parties have expressed an interest to meet or communicate without the involvement of Upstate New York Transplant Services.

WHAT CAN YOU DO?

If you decide you want to become an organ and tissue donor after death you should...

STEP 1: TELL YOUR FAMILY

Tell your family. – This is the most important step. When a person decides whether or not to become an organ donor, the first thing they should do is share their feelings with their family members. Why is this important? Well, if you're under the age of 18, your surviving family members (who are sometimes called the next of kin) ultimately make the decision about donation. Why? When you're a minor (or a person under the age of 18) permission for donation is given by a person's family after that person has died. We can't stress how important it is to understand that – a person's family will have the final say in whether or not their deceased loved one will be an organ and tissue donor if their loved one is under the age of 18.

STEP 2: IF YOU'RE OVER THE AGE OF 18, ENROLL IN THE NEW YORK STATE DONATE LIFE REGISTRY

There are several ways you can do this:

- When you apply for your driver's license for the first time, you can indicate your intention to donate by checking a box.





- When you receive paperwork in the mail to renew your driver's license, you can indicate your intention to donate by checking a box.
- You can sign the registry electronically by going to UNYTS' website – www.unyts.org
- You can request a donor registry enrollment form from UNYTS or from the New York State Department of Health website at:
<http://www.health.state.ny.us/professionals/patients/donation/organ/index.htm>
Complete the enrollment form and mail it in.

The Donate Life Registry records an individual's own legal consent to organ, tissue and eye donation upon their death. If you sign up for this registry, your family will be informed of your decision and given information regarding the donation process, but their permission is not required to proceed with donation. However, please keep in mind that it is still important to tell your family members that you have signed up for the New York State Donate Life Registry. By doing so, your family members will be aware of your wishes (and your desire to be a donor won't come as a surprise to them).

SUGGESTIONS WHICH MAY HELP YOU WITH YOUR FAMILY DISCUSSION:

Discussing the topic of organ donation with your family can be uncomfortable or awkward. However if you are under the age of 18, having a family discussion is an important way to ensure your wish to become a donor is carried out. In the event of a tragic event, you may not be able to communicate your wishes. If your family is made aware of your desire to donate ahead of time, it will be easier for them to make a difficult decision during a time of grief and loss.

Ways to Start the Conversation:

1. Look for opportunities to talk about organ donation. For example, the unexpected, sudden death of a young person can be an opening to bring up the topic for discussion with your family. "If something like that ever happened to me, I would want my organs to be donated. What about you?"
2. Use your signed donor card to start the discussion. By showing your family members your signed donor card, you're bound to get questions and comments that could start a meaningful discussion about donation.





3. Wear a “Donate Life” bracelet, t-shirt or pin to show that you are in full support of organ/tissue donation.
4. Many people learn to drive when they are in high school. When you get your learner’s permit or driver’s license, tell your family that you plan to sign the back of your license to show your intent to donate.

COMMONLY ASKED QUESTIONS

If there is such a serious shortage of organs why don’t more people choose to donate?

Many people are unaware of the need for organs. Some people are afraid of donation because they do not know the facts about the donation process. Others do wish to donate their organs after death, but because they did not share this decision with their family members, their wishes are not carried out.

Would removing the respiratory support from a brain dead patient be the same as not giving him or her all possible chances for survival?

No. When a patient is brain dead, the brain will never recover. Respiratory support only keeps the heart beating by supplying the vital organs with oxygen. There are no clinically documented cases where a patient is declared brain dead and later restored to a normal life. *The recorded time of death is when the patient is declared brain dead, not when the heart actually stops beating after ventilation is removed.*

How do I become an organ, tissue and eye donor?

Enroll in the New York State Donate Life Registry by signing the donor box on your driver license or non-driver identification (ID) card application or renewal form. You can also enroll through UNYTS’ website at www.unyts.org

Is there any age restriction on joining the registry?

Yes. You must be at least 18 years of age to register.

Will the donor’s family members be charged for donating organs and tissues?

No. The gift of donation costs nothing to the donor’s family or estate.



Is it true that if a person is in an accident and the hospital staff knows that they want to be a donor, the doctors will not try to save that person's life?

No. The recovery of organs and tissue only takes place after all efforts to save life have been exhausted and death has been legally declared. In fact the medical team treating the person is completely different from the transplant team. The organ procurement organization (OPO) is not notified until all lifesaving efforts have failed and death has been determined. The OPO does not notify the transplant team until the donor's family has given permission for donation to occur.

Can anyone who dies in a hospital be an organ donor?

No. The person must be declared brain dead and the body must have ventilator or breathing machine support in order for organ donation to occur. A very small number of people die in this manner each year.

How do religious groups view organ and tissue donation?

Most major religions support organ and tissue donation and consider it an act of charity. Some groups have adopted resolutions to encourage people to seriously consider the matter and plan accordingly. Very few religious groups oppose organ/tissue donation and transplantation. If you have specific concerns about whether donation is permitted by your religion, please contact your religious leader. For a complete list of religious views regarding organ donation, please visit: www.unyts.org/religious.htm.

Will organ and tissue donation disfigure my body?

No. Donated organs and tissues are removed surgically. Donation does not disfigure the body. Normal funeral arrangements are possible.

Can a person be too old to donate?

No. Organs may be donated from newborns on up. There really is no set upper age limit for organ donation. The general age limit for *tissue* donation varies, but some people are able to donate up to age 75.

Can a person with a past medical history of illness donate organs and tissues?

Yes. The appropriate medical professionals will determine whether organs and tissues are suitable for transplant at the time of death. Only a few illnesses prevent donation.

Do rich and famous people get transplanted sooner than “regular” people?

No. The system that decides who receives a transplant is blind to wealth and celebrity status. The length of time it takes to receive a transplant is based on many factors including: severity of illness, length of time on the waiting list, blood type, body weight, and other medical criteria. Factors such as race, gender, age or income are never considered when determining who receives a transplant.

Is there a “black market” for the buying and selling of organs and tissue?

No. There is a law that makes it illegal to sell human organs and tissues. Organ and tissue donation is a gift given freely.

Can only hearts, liver and kidneys be transplanted?

No. Needed organs include the heart, kidneys, pancreas, lungs, liver and intestine. Tissue that can be donated includes the eyes, skin, bone, heart valves, middle ear, veins, fascia, cartilage, ligaments and tendons.

ONE DONOR...

CAN SAVE OR ENHANCE THE LIVES OF UP TO

FIFTY PEOPLE!

PERSONAL STORIES

The following section contains stories written by members of our local community who wanted to share their experiences with you and your family members. Some of these individuals are organ recipients others are organ donors and family members of an organ donor. Each has a unique story to tell you about the way organ donation touched their lives and how this generous act made a difference in the lives of others. It is hoped that their personal stories will help you to understand the importance of organ donation and the importance of sharing your wishes with your loved ones.



JEFF, HEART RECIPIENT

Although what we do may be small, we can and will aspire to accomplish great things.

Signing an organ donor card may have seemed like a trivial act to a 35 year-old New York City woman, but it became a miracle to me. August 21, 1994 was the day I received my heart transplant, the gift of life.

A birth defect, a collapsed aortic artery, caused my problems. I underwent an operation to repair the artery and had years of annual check-ups at Children's Hospital of Buffalo. In the fall of 1985, I was diagnosed with cardiomyopathy, a disease of the heart whereby the muscle deteriorates slowly over time until it ceases to function. It would be an understatement to say that I was shocked at the news. It was one month before my 22nd birthday. I was told to watch my diet, limit my working hours and avoid heavy physical activity. I thought to myself, "this could not be happening."

For the next few years, my condition was monitored and treated with medication. Although the muscle of my heart was weakening, I generally felt pretty good as long as I didn't push myself beyond my physical limits. This meant that most things a person of my age would do and take for granted were restricted for me. I could not stay up or go our late with my friends, play football or basketball, work a normal full-time job, or really enjoy life.

Even though I was aware that I would eventually need a heart transplant, I kept myself blissfully ignorant about the facts regarding organ donation.

I did manage to get by – that is, until May of 1994, when a routine visit to the emergency room for an elevated heart rate brought on complications that led to surgery. A pacemaker and a defibulator (a device to deliver an electric shock to the heart when it beats irregularly) were installed. During the operation, my heart was racing between 350 to 450 beats per minute. The doctors were able to bring my heart rate down after a few minutes, but I suffered a severe drop in cardiac output.

Through the next month, I was placed on several medications to stabilize my condition. I was told that I would soon need a new heart to survive. I was evaluated for a heart transplant and placed on the waiting list on July 5. My condition deteriorated over the next few weeks. I was placed on an L-VAD machine (Left Ventricular-Assist-Device – a device that helps the heart pump blood through the body).

One cannot describe the feeling one has while waiting for an organ transplant. When you understand that someone has to die in order for you to live, it is somewhat difficult to fathom. My donor was a 35 year-old woman who died in a motor vehicle accident. Whenever I think about my donor and her family, I am forever grateful that they were able to look beyond their own grief to help someone like me. I consider myself lucky as my waiting time was short due to my deteriorating condition. I certainly couldn't have waited much longer. I was so weak that when the doctor told me the heart was available, I simply said, "okay" and slept through all the pre-testing and preparation for surgery.

The transplant went well and my post-surgical recovery took only three weeks. The first year as I recovered strength, I realized the miracle that happened to me because of the anonymous kindness of someone else. I felt compelled to generate awareness about the wonders of organ and tissue donation.

I now enjoy many activities with family and friends that were impossible since my teens. At age 31, I have a new lease on life, and thank my donor and her family every day.



DARLENE, LIVING DONOR & DONOR MOM

In 1991, at the age of 50, my brother was told that his kidneys were only functioning 20%. The doctors explained that his kidneys could shut down at any time. As a result, he was placed on a strict diet and decreased fluid intake.

My brother rarely went to a doctor, much less go to regular checkups. He had been told on several occasions that his blood pressure was elevated, but my brother never followed up. Consequently, his kidneys were irreversibly damaged due to untreated hypertension.

Three months after his diagnosis, my brother experienced a total kidney failure. He had been given three choices (1) peritoneal dialysis that he could perform at home, (2) hemodialysis that is done at the hospital or dialysis center, or (3) a kidney transplant. My brother chose peritoneal dialysis. Peritoneal dialysis is a one hour procedure that had to be performed every six hours, every day, under sterile conditions to prevent infection. My brother had the surgery which placed a tube in his abdomen where he would "hookup" the cleaning fluids that would enter his stomach and draw out all the body waste and toxins that were collected by the blood as it circulates through the body. Although peritoneal dialysis is an effective way to clean the blood of toxins, it can cause deterioration of the stomach lining over a period of time. In addition, infection can occur if the opening where the tube enters your body gets infected. As careful as my brother was, he repeatedly developed "peritonitis" (an infection of the stomach lining).

I wanted to be an organ donor for my brother from the first time I had heard of his failing kidneys. At that time, he said no because he was more concerned for my well-being. I approached my brother's doctor and asked for information on transplantation. I received numerous references on the subject of kidney transplantation. I spoke with my son and daughter and explained to them that I would continue to live a normal life after the transplant and that there were few risks involved. I was in good health and there was nothing for them to worry about.

My brother finally agreed to do the testing to see if we would be a good match for transplantation. We were an excellent match. I was also required to have a psychological evaluation to make sure that I had not been pressured into this donation and that it was something I really wanted to do. The surgery to perform transplantation was scheduled December 9, 1993. It went very well. The transplanted kidney started working immediately. I was home from the hospital in six days and my brother was home for Christmas. He told me at a Christmas that it was the best he had felt in years. It was one of the happiest holidays our family ever experienced.

As a living kidney donor, I have limited restrictions – namely, no competing in contact sports or any event that would possibly cause an injury to my remaining kidney. I eat a well balanced diet with is something everyone should do. I have no regrets about donating my kidney to my brother and would do it again without questions.

DARLENE, LIVING DONOR & DONOR MOM

The death of a loved one is very difficult thing to deal with, and when it's a child it's even worse.

Around 7:30 a.m. on Sunday, October 27, 1996, I received a phone call from the state police telling me that my daughter, Shannon, had been injured in a motor vehicle accident. She was taken to Erie County Medical Center. I arrived at the hospital 30 minutes later and was told that Shannon was in surgery. I was directed to the ICU waiting room and sat for hours, but it seemed like days. A number of my family members joined me at the hospital and we all waited and prayed together.

After what seemed like an eternity, a doctor came into the waiting room and described Shannon's condition: she had a severe laceration to the liver and a gash from a blow to the back of her head. Additional tests had to be run on Shannon to determine the extent of her injuries before I could see her. When she was brought into the ICU unit she was hooked to a ventilator (a machine to help her breath) and several intravenous lines. Although she did not have any facial injuries, her face was slightly swollen and a little jaundice (yellow). She appeared to be okay.

Two neurosurgeons came into the room to tell me the results of the tests. There was no brain activity on the EEG, no pain or pupil response, nor any blood flow to her brain. As an RN I understood what that meant – but did not want to believe it. I was asked to sign consent to perform an apnea test – a test to see if Shannon could breathe on her own. She failed the test and was reconnected to the breathing machine. The apnea test was repeated a second time to confirm the results of the first test. The doctors were sure the result would be the same – Shannon was brain dead. I was numb with pain. A man approached me who was sympathetic to my circumstances and asked if I would consider organ/tissue donation. I was able to answer without hesitation, “yes, definitely.” Even though that was the most tragic day of my life, I was able to answer the man's question regarding donation because Shannon and I discussed donation when my brother needed a kidney. She said, “I hope that someday I'll be able to save someone's life by donating my organs.” That is exactly what we were able to do – donate her organs. I know that she's looking down and saying, “thanks mom for letting me give the gift of life.”

Approximately one year after Shannon's death, I received a letter from Upstate New York Transplant Services telling me that one of the recipients of Shannon's kidneys would like to contact me by letter. Donors and recipients are asked to wait one year before making contact and it has to be a mutual agreement. I was so excited that I checked the mail everyday just waiting for that letter to arrive. Finally, just before Thanksgiving, I received a card from the kidney recipient. The letter was sent to me by through Kidney Foundation. We could not exchange names and addresses right away. When I opened the card, I must have read it over and over again and cried tears of happiness. There is a woman who is alive and well due to Shannon's kidney and because of this I felt that Shannon's' legacy continues. I had an inner peace just knowing that Shannon's death was not in vain, as something very positive resulted.

The kidney recipient and I finally met. It was one of the most inspiring things I have ever experienced. We hugged, laughed, and cried all at the same time. We then talked for hours. It was unbelievable. We still keep in touch and sometimes do speaking engagements together. We want others to know what donation has done for us. Not only does part of Shannon live on, but now I have a new and wonderful friend.

SUE, DOUBLE LUNG RECIPIENT

Journal Entry 12/10/93 “There is no Angel of Death. When you die, an angel greets you to let you know you’re still alive.” The Angel Book by Karen Goldman. Somehow that is such a comforting thought. The book says there is an angel in each of us. We can find it in our hearts, in every act of love. I must have faith and trust in God, knowing my life is in his hands.

I was born in 1955 and diagnosed with Cystic Fibrosis (CF) at the early age of 17 months. CF is a progressive disease. I led a relatively normal life. I went to school, got married, and worked in my field of education – special education.

CR makes the mucus in your body thick and sticky, clogging organs like the pancreas and the lungs. Bacterial infections are constantly damaging the lung tissue. The lungs become scarred and, over the years, it becomes more difficult to breathe.

In May of 1992, I went into the hospital needing oxygen 24 hours a day. I had reached “end-stage” lung disease and was dying. Since 1980, I became friendly with many other people with CF, many of whom I watched die young. I knew what was in my future. However, there existed a possibility for a miracle – a double lung transplant. It was almost surreal. I tried to make myself understand that I would die unless I received the transplant. I cried and through my fear I asked about the process.

My husband and I traveled to the transplant center at the Pittsburgh Presbyterian University Hospital for an evaluation in September of 1992. God was with us. I was accepted and placed on the national computerized transplant waiting list and was told to expect about a 10 to 14 month wait. We actually waited 22 months for the transplant. During that time, it took most of my energy to take care of myself. Just showering and dressing in the morning would exhaust me. Every few hours I would need to do breathing treatments and chest physiotherapy to jar mucus in my lungs so I could cough it up. Coughing wore me out, but it was vital to my survival. I was attached to a 50 foot oxygen hose in my house and a portable tank with a 7 foot “leash” while away from home. When I slept, I was hooked up to a machine to help me breathe easier and get better rest. I looked like a monster in head gear, but it was keeping me alive.

By January of 1994, my anxiety level was rising.

Journal Entry: 1/13/94: Please God, let me fly though the surgery and wake up to my husband and family. I want more time. I want to do more things together – with more energy – I want to share all the calm, simple moments and joyous, thrilling ones. I want to see my brother’s new baby and watch it grow... Please God, may I have more time? We have been blessed in so many ways – I have had a wonderful and full life.

On July 3rd, we received “the phone call” for the second time letting me know that my wait may finally be over. We flew back to Pittsburgh. At this point, I believed that either way I would have a new life if I died and went to God or if I survived the surgery. The ten hour surgery began the next morning. Everything went well, although not without complications – a deadly fungal infection and a severe bowel blockage. The strong antibiotics saved my life but caused temporary kidney failure. The wonderful transplant team and nurses helped my body overcome these obstacles.

After almost eight weeks, we drove home to Buffalo to my whole family. It was thrilling to be alive and to see everyone again. Since my transplant, our holidays are very special.



PEGGY, DONOR MOTHER

During the Christmas season of 1982, my three-year-old son Jeffrey died of an intra-cerebral hemorrhage. There had been no indication that anything was wrong with Jeffrey. The day had been a very ordinary day in his life. Jeffrey had a long nap, was quite cheerful and he stayed up to play with his brothers he was exhibiting normal three-year-old behaviors. Several times that day he went to a corner of the living room, patted the floor, and announced to the family that he wanted the Christmas tree put there. At 11:00 p.m. after his prayers and good night kisses, he went to bed with his favorite teddy bear and a Christmas book. I heard him talking and singing in his bed shortly before I heard a cry I never heard before. I found Jeffrey holding the left side of his head rolling back and forth in his crib. I carried him into the living room. As he lay on the couch, he began to vomit.

Jeffrey was unconscious by the time the paramedics arrived he was transported to the local community hospital where within minutes after arrival he went into respiratory arrest and was placed on a respirator. After three hours, Jeffrey was transferred to a university-affiliated children's hospital where a computerized axial tomography (CAT) scan revealed a massive brain hemorrhage. At 4:00 a.m., I learned my son was brain dead and that nothing could make him well again. I was stunned and could not believe what was happening. I soon became aware that in spite of being on a ventilator, Jeffrey's body was deteriorating.

I offered to donate Jeffrey's organs for transplantation. The physician seemed surprised when I raised the subject of organ donation. A transplant coordinator from the local organ procurement organization arrived at 12 noon and began preparations for the removal of Jeffrey's kidneys, liver and eyes. My only stipulation with the donation was that the organs be sent not only as gifts of life, but with the message that they were also gifts of love.

During the course of the day, Jeffrey's brothers, grandparents and a few of our close friends came to the hospital to spend time with him and give much needed support. It was an extremely painful experience to explain to Michael and Jay that their little brother, who had been running around the house a few short hours before, was breathing only through the assistance of a mechanical device.

While in the intensive care unit, I was provided with a rocking chair in which I could sit and hold Jeffrey. I was given time to cuddle him, talk to him and say a very special good-bye to my youngest child. When I requested hand and foot prints, the nurses found ink pads, inked Jeffrey's hands and feet and I got my prints. I was also given a pair of scissors to cut a lock of his hair.

At 4:00 p.m., 18 hours after Jeffrey became ill, he was taken to surgery for the removal of the donated organs and tissue. I left behind his favorite blue blanket that went everywhere with him and asked the doctor to cover Jeffrey with it following surgery. The doctor assured me he would be cared for as the little boy he was, and that my wish would be carried out.

It was quite easy for me to make the decision to donate Jeffrey's organs. Several factors made my decision easy. When I was 12, a friend and I made our own non-legal wills donating our organs to our local organ bank. It was at this time that I first became aware of such medical advances as transplantation. Another seed relating to organ donation was planted when I was taking medical terminology class the summer before Jeffrey died. After a serious class discussion about transplantation, I continued to give the idea of organ donation much thought. I even arrived at a very conscious decision that I would donate my child's organs if faced with that decision, so very unaware that within six months I would be faced with carrying it out. My purpose in sharing this experience is to convey to others that even in this dark tragedy, new hope and new life can result. I view Jeffrey as a very precious gift – a gift for five other people and their families.

Today I am employed as Public Education Coordinator for one of the organ procurement organizations in Ohio. Everyday people on transplant waiting lists are dying because there is a shortage of donors. Please do your part in sharing the **Gift of Life**.



“TO REMEMBER ME”

The day will come when my body will lie upon a white sheet neatly tucked under four corners of a mattress located in a hospital busily occupied with the living and dying. At a certain moment a doctor will determine that my brain has ceased to function and that, for all intents and purposes, my life has stopped.

When that happens, do not attempt to instill artificial life into my body by the use of a machine. And don't call this my deathbed. Let it be called the "Bed of Life," and let my body be taken from it to help others lead fuller lives. Give my sight to the man who has never seen a sunrise, a baby's face or love in the eyes of a woman. Give my blood to the teenager who was pulled from the wreckage of his car, so that he might live to see his grandchildren play. Give my kidneys to the one who depends on a machine to exist from week to week. Take my bones, every muscle, every fiber and nerve in my body and find a way to make a crippled child walk. Explore every corner of my brain. Take my cells, if necessary, and let them grow so that someday, a speechless boy will shout at the crack of a bat and a deaf girl will hear the sound of rain against her window. Burn what is left of me and scatter the ashes to the wind to help the flowers grow. If you must bury something, let it be my faults, my weaknesses and all prejudice against my fellow man.

Give my sins to the devil. Give my soul to God. If, by chance you wish to remember me, do it with a kind deed or word to someone who needs you. If you do all I have asked, I will live forever.

Robert N. Test

The Cincinnati Post



APPENDIX



BRIEF HISTORY OF ORGAN DONATION

The first successful organ transplant took place in 1954. This was referred to as a “living-related” form of donation since in this case a family member (identical twin) donated a kidney to another family member while alive. In 1962 the first “post mortem” (after death) kidney donation took place. In 1967, the first heart and liver transplants occurred. Since that time the field of transplantation has progressed rapidly and enabled thousands of people to live active, productive lives. This would not be possible, however, without the generosity of those who choose to be organ or tissue donors and their family members.

MAJOR LEGISLATION AND REGULATION

- 1968 Uniform Anatomical Gift Act – Authorizes the gift of all or part of the human body at death for transplant, research, education or other therapies. Includes a description of who may donate, how to execute the donation and who may receive the donation.
- 1972 Public Law 92-603, End Stage Renal Disease Act – Provides complete reimbursement under Medicare for all persons covered by social security – regardless of age – for dialysis, kidney acquisition and kidney transplantation.
- 1978 End Stage Renal Disease Amendment – States that patients covered by Medicare because of renal failure retain benefits for only three years after transplant (unless transplant fails).
- 1980 Uniform Determination of Death Act – Recognizes death as either a determination of irreversible cessation of circulatory and respiratory functions or irreversible cessation of functions of the entire brain stem.
- 1984 Public Law 98-507, National Organ Transplant Act – Established a task force on organ transplantation to examine medical, ethical, legal, economic and social issues related to organ transplantation. This act led to the establishment of the United Network for Organ Sharing (UNOS) and Required Request laws. It also made the buying and selling of organs illegal.
- Required Request Legislation – Establishes laws, which act as professional reminders, on the need for organ donation by mandating that families are offered the opportunity to donate in cases concerning brain death.
- 1985 Consolidated Omnibus Budget Reconciliation Act – Recognizes end-stage liver disease as a national concern, covering liver transplants for individuals under 18 and opening the

door for medical insurance companies to cover this procedure, since it would no longer be considered experimental. Also states that Medicare would cover liver transplants when reasonable and medically necessary.

- 1986 Omnibus Reconciliation Act – Mandates that hospitals eligible for Medicare and Medicaid must establish policies and procedures for organ procurement in order to receive reimbursement. The act sets standards for organ procurement agencies, related to the suggested number of donors, for the size of the population served. These regulations compelled smaller agencies to merge to become more efficient. The act also ensured the coverage of immunosuppressive drugs taken by transplant recipients to help ward off rejection of a new organ.
- 1998 “Routine Referral Act” – Mandates that hospitals notify the organ procurement organization of all deaths which occur in the hospital to ensure that each family is given the option to consent to organ and/or tissue donation.

ORGAN FUNCTIONS AND APPLICATION

<u>Organ</u>	<u>Function</u>	<u>Application</u>
Heart	Pumps blood to all body systems	Transplant is treatment for <i>End-Stage Heart Disease</i> due to heart failure for example, cardiomyopathy or congestive heart disease
Intestine	Digestive organ that absorbs water, electrolytes and nutrients for the body	Transplant is treatment for <i>Malabsorption</i> , a disease that prevents the absorption of necessary nutrients
Kidneys (2)	Extracts waste from the blood and produces important hormones	Transplant eliminates need for dialysis for patients with <i>End-Stage Kidney Disease</i> which is often a complication of <i>Diabetes</i> and <i>Hypertension</i>
Liver	Instrumental in energy regulation, makes proteins, removes waste from blood	Transplant is treatment for <i>End-Stage Liver Disease</i> which may occur due to <i>Hepatitis</i> or <i>Biliary Disease</i>
Lungs (2)	Organ of respiration	Transplant treats <i>Cystic Fibrosis</i> , <i>Emphysema</i> or other <i>End-Stage Lung Disease</i>
Pancreas	Secretes enzymes necessary for digestion, secretes insulin and helps regulate blood sugar	For treating <i>Diabetes</i> . The transplant eliminates the need for insulin injections and reduces the risk of losing sight or limbs

TISSUE FUNCTIONS AND APPLICATION

<u>Tissue</u>	<u>Function</u>	<u>Application</u>
Bone – femur, tibia, humerus, ribs, spinal fusion and fibula	Supports the body and protects vital organs	Facial reconstruction, prevents amputation, correction of birth defects, cancer treatment and oral surgery
Cartilage	Connective tissue that serves as skeletal tissue in some parts of the body (i.e. nose and outer ear)	Facial and other reconstruction
Corneas	Allow light to enter the eye	Restoration of sight to those with corneal damage
Fascia	Fibrous tissue that covers the ligaments and restores mobility	Used to repair tendons and muscles
Heart Valves	Direct flow of blood through heart	Replacement of diseased heart valves (donor valve usually preferred over mechanical valve)
Ligaments	Strengthen bone joints	For use in joint injuries
Middle Ear	Tissue for hearing	Replaces damaged middle-ear structures
Skin	Protects the body from dehydration, injury and infection	Treatment for burn patients, decreases pain, infection, scarring, heat and fluid loss
Tendons	Attaches muscle to bone	For use in joint injuries, often relates to sports injuries
Veins	Transport blood	Used for coronary bypass surgery to replace diseased or blocked arteries