



LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

# Ambassador Handbook



*Alabama*



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## TABLE OF CONTENTS

|   |          |
|---|----------|
| <b>1 WELCOME</b>  | <b>4</b> |
| <b>2 VOLUNTEER OBJECTIVE</b>                                | <b>5</b> |
| <b>3 LEGACY OF HOPE</b>                                     |          |
| Our Mission Statement                                       | 6        |
| Our History   | 7        |
| Our Organization  | 9        |
| What is Legacy?   | 10       |
| <b>4 VOLUNTEER DUTIES, OPPORTUNITIES &amp; EXPECTATIONS</b> |          |
| Volunteer Duties  | 12       |
| Volunteer Opportunities                                     | 14       |
| Volunteer Expectations                                      | 15       |
| <b>5 DONATION INFORMATION</b>                               |          |
| History of Organ and Tissue Donation                        | 16       |
| Who Can Be an Organ/Tissue Donor? What Can Be Donated?      | 18       |
| The Donation Process  | 20       |
| Organ and Tissue Donation Process                           | 22       |
| Flow Chart of Key Activities During a Donation              | 25       |
| Donor Designation, Alabama's Uniform Anatomical Gift Act    | 26       |
| Financial Aspects of Organ Donation                         | 29       |



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## **6 APPENDIX**

|   |    |
|---|----|
| How to Become a Donor-----                      | 30 |
| Common Myths-----                               | 31 |
| Religious Views-----                            | 32 |
| Diversity Issues-----                           | 37 |
| Vocabulary-----                                 | 38 |
| Preferred Terminology-----                      | 39 |
| Glossary of Terms-----                          | 40 |
| Fast Facts about Organ and Tissue Donation----- | 49 |
| Commonly Asked Questions-----                   | 50 |
| Important Websites-----                         | 54 |

## **7 FORMS & IDENTIFICATION**

|                                      |    |
|--------------------------------------|----|
| Volunteer Application Form-----      | 58 |
| Volunteer Emergency Information----- | 60 |
| Sharing Your Personal Story-----     | 61 |
| Confidentiality Statement-----       | 62 |
| Media Agreement-----                 | 63 |
| Volunteer Hours-----                 | 64 |
| Event Evaluation Form-----           | 65 |



# WELCOME

---

Welcome to Legacy of Hope's Ambassador Program! Thank you for your support of our cause that helps benefit the men, women and children in the state of Alabama who are in need of life-saving organ transplants and the donor families who said "yes" to donation.

We believe our volunteers are the heart and soul of our organization. You give freely of your time and talents to help Legacy of Hope achieve its purpose of advancing the awareness of life-saving organ and tissue donation. We hope that through volunteering with us, you are rewarded with the satisfaction of knowing you have contributed to something greater than yourself. In doing so, your personal actions generate enthusiasm for life and life-saving activities in our state.

More than 117,000 men, women and children in the United States need life-saving organ transplants. Of these patients, over 2,200 are waiting in Alabama. On average, one person is added to the nation's organ transplant waiting list every 10 minutes. Sadly, an average of 21 patients die every day while waiting, simply because the organ they needed did not become available in time. Your support helps raise awareness of this critical need in our local communities.

Many opportunities are available for those who wish to help at health fairs, sporting events, share personal stories at hospital training sessions and civic groups. There are always needs during April, National Donate Life Month. Other annual events in need of volunteers are the Celebration of Life Picnic, National Donor Sabbath, and National Minority Donor Awareness Day.

Thank you so much for your energy – time – and effort!

Ashley Anderson, MA  
Community Liaison  
Legacy of Hope



LEGACY *of* HOPE

Alabama's Organ & Tissue Donation Alliance

# VOLUNTEER OBJECTIVE

---

“Ambassadors,” the official volunteer program for Legacy of Hope, offers family members, transplant recipients and others who have been touched by donation or transplantation the opportunity to share their experiences and contribute to on-going community outreach efforts.

Each and every Ambassador is a valued member of the Legacy of Hope community; as such, it is our commitment that each volunteer feel appreciated and part of a well-structured, worthwhile program. Our goal is to provide you with accurate and current information about organ and tissue donation.

The objective of this Handbook is to inform our volunteers about our Mission and the History of Legacy of Hope and the critical roles that volunteers have in our activities. The Handbook contains a range of information including duties and responsibilities of a volunteer, learning how to discuss organ and tissue donation facts, and answers to commonly asked questions about donation. It also offers information about approaches to religious views, myths, and cultural protocols. We have included a glossary of terms and an index so this can be utilized as a tool at your volunteer activities. You will also find information for contacts that can assist with any questions you may have.



LEGACY *of* HOPE

Alabama's Organ & Tissue Donation Alliance

**MISSION  
HISTORY  
ORGANIZATION  
LEGACY**

---

**OUR MISSION STATEMENT**

We will end the wait and the suffering, by shepherding the gift of life to those in need of organ and tissue transplants.



## OUR HISTORY

Soon after organ transplantation began in Alabama in 1968, the need for transplantable organs quickly exceeded the supply. In those days, no systematic approach to procurement had been established. Barriers that kept health care professionals from suggesting donation included a lack of knowledge about donor criteria and procedures, a dislike of discussing the matter of donation with grieving families, lack of time, and concern about legal aspects.

Since those beginnings, many barriers have been removed, but unfortunately, some obstacles still remain. Uniform criteria for establishing death have been developed, and laws have been passed that require hospitals to offer the option of organ/tissue donation to families at the time of their loved one's death.

Organ Procurement Organizations (OPO) have been created to educate and promote organ and tissue donation. Established in 1979 as the "Alabama Organ Bank," the independent Organ Procurement Organization (OPO) for the State of Alabama was renamed the Alabama Organ Center (AOC) and grew to serve all hospitals in the state. In January 2019, the AOC changed its name to Legacy of Hope and is the federally approved OPO for Alabama.

Since its founding, Legacy of Hope has provided more than 4,000 kidneys for transplantation, as well as hundreds of other transplantable organs such as hearts, heart-lungs, lungs, livers and pancreas. Legacy of Hope played a key role in establishing the University of Alabama at Birmingham as one of the largest kidney transplant programs nationally. Legacy of Hope is approved by the Centers for Medicare and Medicaid Services (CMS) and UNOS (United Network for Organ Sharing).

Recent changes in the donation system have been implemented to improve donation in the United States. In 1998, CMS implemented regulations requiring hospitals to notify their local organ procurement organization (OPO) of every death. This process, known as "routine referral," enables the OPO to evaluate every death for donation opportunities. Regulations also require that someone from the OPO or a trained Designated Requestor, an individual who has been trained by the OPO in best practices for approaching families, speak with families about their donation options. This regulation ensures that families are given adequate support and information during this difficult time.

Alabama has achieved some exciting milestones. In 2007, Alabama had six hospitals recognized by the U.S. Department of Health and Human Services. Huntsville Hospital/Huntsville Hospital East, Flowers Hospital, Southeast Alabama Medical Center, University of South Alabama Medical Center, Children's Hospital of Alabama and Trinity Medical Center received the Department's Medal of Honor. The medals were presented to hospitals with eight or more potential organ donors who sustained a donation rate of 75 percent or more from among eligible donors for at least a year. Not surprising, Alabama had



# LEGACY *of* HOPE

Alabama's Organ & Tissue Donation Alliance

its highest number of organ donors in its history in 2007. Legacy of Hope facilitated 138 organ donors in 2010. In 2008, the Alabama Organ Center received accreditation from the American Association of Tissue Banks (AATB). Now, Legacy of Hope is part of an elite group of nearly 100 similar facilities across the United States, and abroad, that has earned their AATB accreditation.

Legacy of Hope is looking forward to a promising future. We are excited about our hospital partnerships, the support we provide donor families and the opportunity to improve lives through donation.



## **OUR ORGANIZATION**

Legacy of Hope is a member of the United Network for Organ Sharing (UNOS), which oversees the national transplant waiting list as well as all transplant centers and Organ Procurement Organizations (OPOs) in the United States. When organs are donated in Alabama, Legacy of Hope and UNOS match them with the next appropriate recipient candidate, based on donor-recipient blood type, medical urgency, body weight and size, and proximity of recipient to donor.

**Aftercare Coordinator:** The Aftercare Coordinator facilitates communication between donor families and organ recipients. Provides on-going grief support to donor families.

**Clinical Services:** Procurement transplant coordinators are on call 24-hours a day to respond to notifications from hospitals of potential donors. They coordinate all aspects of organ procurement and transplantation, including organ sharing activities. These professionals work with grieving families and offer the option of donation in a sensitive manner.

**Hospital Development/Community Liaisons:** Hospital Development/Community Liaisons educate administrative and professional staff in hospitals on an on-going basis, help develop protocols to ensure that hospitals are prepared for organ and tissue donation and are fully compliant with applicable laws and regulations. They also provide education in our communities.

**Family Support Services Coordinators:** Family Support Services provide specialized support for newly bereaved families of potential organ and tissue donors, conducting an assessment of their needs and providing on-going support and information about their loved one's condition.

**Multicultural Educator and Community Liaison:** These two positions provide education to schools, civic groups and attend community and company health and wellness fairs.

**Quality Assurance staff:** The QA staff facilitates and maintains the integrity of donor charts and Standard Operating Procedures.

**Tissue Recovery staff:** The Tissue Recovery staff recover bone and tissues for transplant and research.

**Perfusionists:** The Perfusion team facilitates the perfusion of kidneys for transplant, keeping them viable until surgery or transport.

**Administrative staff:** The Administrative staff facilitates the daily functions and operations of Legacy of Hope.

**Call Center Staff:** Alabama Donor Services enables Legacy of Hope to operate on a 24/7/365 basis by responding to notifications from hospitals of potential donors, triaging import organ offers, and successfully responding to over 24,000 phone calls a year.



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## **WHAT IS LEGACY?**

Legacy is a non-profit organ, eye and tissue registry for the state of Alabama. Legacy serves as the voice of the donor when he cannot speak for himself. Everyone who says “yes” to organ donation at the Department of Motor Vehicle (DMV) office is on Legacy. Once every quarter the new donor designations are transferred from the DMV to Legacy. You can also designate your donation decision through our website at [www.legacyofhope.org](http://www.legacyofhope.org) or by downloading a registration form from our website. You can also call our office at 1-800-252-3677 or 1-205-731-9200 and we will mail you a brochure/form.

Legacy of Hope and the Alabama Eye Bank have access to the Legacy data and can share an individual's donor designation with his or her family. While we encourage people to have family discussions about donation, not everyone does. Legacy can be the voice of the potential donor. As a registered donor, you are choosing to make a difference with your gift. It's a legacy that will live on long after you've gone.



LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

# VOLUNTEER DUTIES, OPPORTUNITIES & EXPECTATIONS

---

## DUTIES

We value your time, talent, abilities and willingness to assist us in promoting organ and tissue donation awareness within your communities. As a volunteer with Legacy of Hope, you have an obligation to the public we serve to demonstrate a high level of integrity and ethical standards in both your personal and official conduct. You are a source of vital information for the general public. Legacy of Hope, and the general public, rely on you for politeness and accuracy of information that supports the organization and its programs. We ask that you be mindful of the following:

- Provide accurate and current information about organ and tissue donation.
- Greet and assist every person that approaches you at a health fair or other Legacy of Hope event.
- You are the first, best opportunity to represent the more than 112,000 people on the national waiting list.
- Show a positive attitude toward everyone. Acknowledge people and treat them with respect.
- Be courteous – Give an amiable greeting and friendly demeanor.
- Be patient – Our cause can be confusing to a first-time visitor. Take time to explain the options.
- Please, do not use your cell phone when working as an AOC Ambassador. If there is an emergency, please excuse yourself to another area.

Please remember, you are often the first person a visitor interacts with, and you will leave a lasting impression. Do your best to ensure that the impression is a positive one.

Please do not give incorrect information or information you are not sure about. If you are uncertain about the information, try to find the answer. Feel free to call Legacy of Hope at 1-800-252-3677 or 1-205-731-9200.

Stay current on donation facts and events by reading your volunteer e-mails and take the extra time to inform your fellow volunteers about any organ and tissue news.



### Handbook

Please refer to this Volunteer Handbook for guidelines and privileges applicable to all volunteers.

### Complete Volunteer Hours Form

Please sign up whenever you are on duty, training, or whenever you donate time for Legacy of Hope. It is important for us to have a record of your volunteer hours, and, you may choose to use the hours for tax benefit toward travel to and from Legacy of Hope. If you would like a record of your hours, please request this from the Community Liaison at least two weeks before you require them.

### Training / Workshops

New volunteers need to develop a strong familiarity with the facts regarding organ and tissue donation. The Community Liaison will arrange additional training sessions and you will need to attend at least one of these sessions each year.

### Insurance / Liability

UAHSF will provide protection for volunteers for general or professional liability claims that could be made against them related to services that they provide within the duties assigned by Legacy of Hope. However, volunteers use their own vehicles on UAHSF business at their own risk and volition. UAHSF cannot provide automobile liability insurance for volunteers' personal vehicles.

### Injury While Volunteering

The UAHSF workers' compensation insurance program covers only employees and does not extend to volunteers. All Legacy of Hope volunteers should have health insurance to cover medical expenses that may be incurred as a result of accident or injury.

### Absences

If you must miss your scheduled shift, you are expected to make a serious attempt to find another volunteer to take your shift, and to call the Community Liaison at least 24 hours in advance. For last minute, weather-related absences or personal emergency absences or lateness, please notify us at 1-800-252-3677 or 1-205-731-9200 as soon as possible. If you are required to be away for an extended period of time, please notify the Community Liaison. Absence of more than one year may require re-training and re-acceptance to the program.

### Breaks

We really appreciate all your time and effort to assist us getting out the word about the importance of organ donation, and understand transplant recipients and waiting list



volunteers may have serious health issues. Therefore, for each 4-hour shift, you may take a 20-minute break.

#### Reimbursement

Individuals performing services for Legacy of Hope who receive no compensation from any source for this service are referred to as volunteers.

#### Infection Control Policy

Legacy of Hope's infection control policy focuses on "hand hygiene," a general term that applies to hand washing or the use of antiseptic hand washes.

#### Attire

You represent Legacy of Hope when you are volunteering. Please dress neatly and use your best judgment. Be professional at all times. Your dress, behavior and speech create a total package.

#### Confidentiality Form

All volunteers must sign a confidentiality form. This form alerts our volunteers about our responsibility to safe-guard confidential information including any information regarding laboratory, medical, surgical, social, employee, business operations or donor charts.

#### Media Consent Form

This form gives permission for the media (both internal and external) to use your likeness or feature products created by you (stories, photos, artwork, etc., developed within the course of your work as a volunteer) in publications, news stories or other medium.

#### Volunteer IDs

For identification purposes, Legacy of Hope will create photo IDs. Please wear your IDs when coming to the office or when representing the AOC at an event.

#### Interns/Volunteers 18 and Under

Volunteers under 18 years of age must have their parent/guardian complete a Parent/Guardian Permission Form consenting to participation in the Ambassador Volunteer Program, along with proof of necessary working papers.



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## **VOLUNTEER OPPORTUNITIES**

### Church/Clergy

- Donor Sabbath (annually celebrated 2 weekends prior to Thanksgiving)
- Speak at churches
- Church health fairs
- Church family days

### Hospital Development

- Raise awareness within hospital itself through health fairs
- Participate in hospital staff meetings and classes by sharing personal story

### Driver's Education

- Through schools and independent driver education classes

### Speakers Bureau

- Make presentations to civic groups

### Health Fairs

- Display and offer donation information to health fair participants

### Special Projects

- Special events such as Donor Sabbath
- Donate Life Month (April)
- UAB/Legacy of Hope Celebration of Life Picnic
- National Minority Donor Awareness Day (Gospel Fest)
- Sporting events

### Office Projects

- Donor Sabbath mailing and returning requested material
- Celebration of Life Picnic registrant information envelope stuffing



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## **VOLUNTEER EXPECTATIONS**

An effective volunteer program is the cornerstone of Legacy of Hope community outreach programs. Through the work of volunteers, we ensure that each year thousands of people throughout the Legacy of Hope region learn about the importance of organ and tissue donation.

You, as a volunteer of Legacy of Hope, represent the more than 117,000 candidates on the organ waiting list in the United States, and specifically there are over 2,100 waiting here in Alabama, as well as those needing tissues. Since most of these people are ill, they cannot speak for themselves, so we represent them.

Our job is not only to create awareness about the importance of organ and tissue donation, but it is to actually enroll more people on Alabama's Legacy Organ & Tissue Donor Registry – in affiliation with Legacy of Hope. Out of the more than 4.8 million people we have in the state of Alabama, only 2.8 million of them are registered as donors. Our challenge is to increase this number by registering even more Alabamians to be organ, eye and tissue donors. Donate Life America is the not-for-profit alliance of national organizations and local coalitions across the United States dedicated to inspiring all people to donate life through organ and tissue donation.



# DONATION INFORMATION

---

## HISTORY OF ORGAN & TISSUE DONATION

- 1869 – First skin transplant
- 1906 – First corneal transplant (Dr. Edward Zirm)
- 1949 – Establishment of U.S. Navy Tissue bank leads to increased use of tissue donations
- 1954 – First successful living-related kidney transplant by Dr. Joseph Murray and Dr. David Hume, Brigham Hospital, Boston
- 1962 – First successful (deceased) kidney transplant by Dr. Joseph Murray and Dr. David Hume, Brigham Hospital, Boston
- 1963 – First successful lung transplant by Dr. James Hardy, University of Mississippi Medical Center, Jackson, MS
- 1967 – First successful liver transplant by Dr. Thomas Starzl, University of Colorado, Denver, CO
- 1967 – First successful heart transplant by Dr. Christian Barnard, Groote Schuur Hospital, South Africa
- 1968 – First kidney transplant performed in Alabama by Dr. Arnold G. Diethelm, Veteran's Administration Medical Center, Birmingham
- 1968 – Uniform Anatomical Gift Act – Adopted in Alabama (Alabama code 22-10-40) establishes Uniform Donor Card as a legal document for anyone 18 years of age or older to legally donate his/her organs upon death.
- 1972 – End State Renal Disease Act (ESRD) paves way for Medicare Coverage or Renal Dialysis and Kidney Transplants
- 1979 – Alabama Pronouncement of Death law passed
- 1979 – Alabama Organ Bank established. This organization was created to coordinate the recovery and transplantation of donated organs and tissues.
- 1981 – First successful heart/lung transplant by Dr. Norman Shumway, Stanford University Medical Center, Palo Alto, CA
- 1981 – First Heart Transplant performed in Alabama by Dr. Robert Karp, UAB Hospital.
- 1982 – First bone procurement completed by Alabama Regional Organ Center
- 1983 – FDA approves Cyclosporine, the most successful anti-rejection medication developed to date
- 1983 – First liver transplant performed in Alabama
- 1984 – National Organ Transplant Act (NOTA) establishes nationwide computer registry operated by the United Network for Organ Sharing (UNOS); authorizes financial support for



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

Organ Procurement Organizations (OPOs); prohibits buying or selling of organs in the United States

1986 – Required Request Laws require hospitals to develop policies to identify patients as potential donors and approach families about organ donation

1988 – FDA approves Viaspan that greatly extends the preservation of donated livers

1988 – First successful small intestine transplant

1988 – 2,000<sup>th</sup> kidney transplant performed in Alabama

1988 – First pancreas transplant in Alabama

1988 – First heart/lung transplant in Alabama

1989 – First successful living-related liver transplant

1989 – First lung transplant performed in Alabama

1990 – First successful living-related lung transplant

1992 – Baboon liver transplanted into man dying of liver failure

1992 – First double-lung transplant performed in Alabama

1992 – 3,000<sup>th</sup> kidney transplant performed in Alabama

1993 – 300<sup>th</sup> heart transplant performed in Alabama

1995 – First combined heart and kidney transplant performed in a single recipient in Alabama

1996 – 4,000<sup>th</sup> kidney transplant performed in Alabama

1997 – 500<sup>th</sup> heart transplant performed in Alabama

1998 – First small bowel-liver transplant performed in Alabama

1998 – 30<sup>th</sup> anniversary of kidney transplantation in Alabama

1998 – 500<sup>th</sup> liver transplant performed in Alabama

1998 – National Conditions of Participation enacted; required hospitals to refer all deaths and imminent deaths, to the local Organ Procurement Organization (OPO)

2001 – Living Donors (6,528) exceeds deceased donors (6,081) for the first time in the U.S.

2008 – June 12, 2008 – Uniform Anatomical Gift Act (UAGA) passed in Alabama. Changed the legal hierarchy for next of kin; strengthens donor designation or first person consent

2016 – Organ transplant increases by nearly 20% since 2012.

2018 – Celebrating 50 years of transplantation success.

2019 – The Alabama Organ Center changes its name to Legacy of Hope.



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## WHO CAN BE AN ORGAN/TISSUE DONOR? WHAT CAN BE DONATED?

Almost anyone can be a donor. At the time of death, transplant physicians and Legacy of Hope specialists determine the medical suitability of organs and tissues.

| <u>DONATION</u> | <u>THOSE WHO WILL BENEFIT</u>  |
|-----------------|--|
| Heart           | Patients suffering from cardiomyopathy, coronary artery disease, or other life-threatening heart diseases  |
| Lungs           | Patients suffering from emphysema, cystic fibrosis, or other life-threatening lung diseases  |
| Liver           | Patients suffering from cirrhosis, Wilson's disease, or other life-threatening liver diseases  |
| Pancreas        | Insulin-dependent diabetic patients (a transplant eliminates the need for insulin injections and reduces the risk of diabetes related complications such as blindness and amputations) |
| Kidney          | Patients suffering from severe kidney failure caused by conditions such as high blood pressure, polycystic kidney disease, etc. (a transplant eliminates the need for dialysis)        |
| Small Intestine | Patients are generally children who suffer from short bowel syndrome or intestinal malformation  |
| Eyes/corneas    | Patients suffering from corneal blindness caused by disease or injury  |
| Skin            | Surgical reconstruction of soft tissue damaged by illness or trauma, repair of large surgical wounds and final reconstruction for some types of burns                                  |
| Bone            | Patients requiring facial reconstruction, limb salvage, correction of birth defects, cancer treatment, spinal surgery, or oral surgery   |
| Heart Valves    | Patients requiring replacement of a malfunctioning heart valve (in most cases, a donor valve is preferred over a mechanical valve)   |
| Tendons         | Patients requiring reconstruction surgery (commonly used in the treatment of sports injuries)  |
| Veins           | Patients requiring coronary artery by-pass surgery (the donated veins are used to replace the patients blocked arteries) or limb salvage procedures                                    |

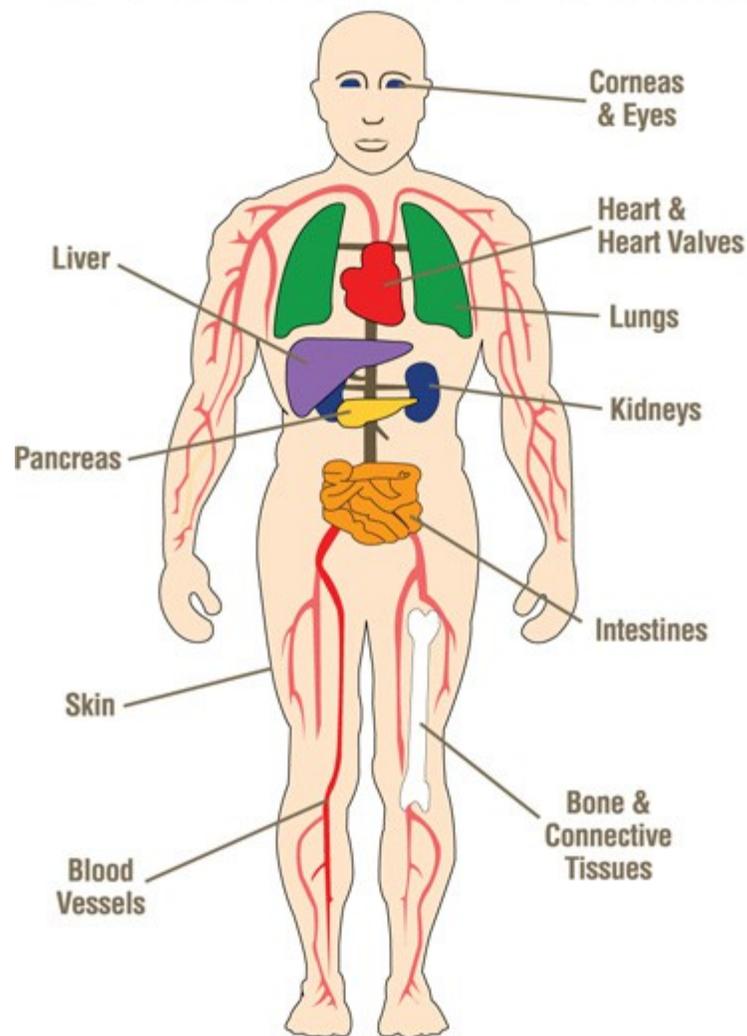


# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## WHAT CAN BE DONATED?

ONE DONOR CAN HELP  
OVER 75 PEOPLE





# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## THE DONATION PROCESS

### An Overview

Legacy of Hope, formerly the Alabama Organ Center (AOC), is one of 58 regional organ procurement organizations (OPOs) that coordinate the recovery of organs and tissues for transplantation. The process is complex and involves medical professionals at many different levels. What enables the process to work successfully is the commitment of the staff at Legacy of Hope, which addresses the needs of organ and tissue donors 24 hours a day, 7 days a week and 365 days a year. Supporting Legacy of Hope are networks of professionals at area tissue and eye banks, tissue and blood typing labs, courier services, air charter firms and more, all providing essential services to ensure the success of the transplant. Most importantly are our partnerships with Alabama hospitals. Here are the specifics on how we work:

- The patient is admitted to the hospital and every attempt is made to save the patient's life.
- A referral is made to evaluate the suitability of the patient for donation. Legacy of Hope coordinators will check for the patient's donor designation.
- The patient is pronounced brain dead after evaluation, testing and documentation by two physicians not affiliated with organ donation or transplantation.
- To proceed, all donations must first be cleared with the medical examiner or coroner, if they are involved.
- If no record is found of the patient's donation decision, the patient's family is offered the opportunity of donation.
- The donor is maintained on a ventilator and stabilized with IV fluids and medications. Many tests are completed to help assess organ function.
- Recipients are identified by accessing the national computerized transplant waiting list at the United Network for Organ Sharing, UNOS.
- Surgical teams are mobilized and coordinators arrive at the donor hospital for the organ recovery surgery.



- The donor is brought to the operating room on the ventilator while the surgical teams are arriving at the donor hospital.
- The organ recovery surgery is performed. The ventilator is discontinued and the heart stops. The organs are cooled and preserved with special solutions. Each team returns to its transplant center to perform the transplant surgery.
- Tissue donation takes place after the organ donation process is completed.
- An autopsy, when requested, is performed by the medical examiner or the hospital, after the donation process is completed.
- The donor is released to the funeral home.
- Legacy of Hope provides the donor family with general information about the recipients of their gifts. Confidentiality is maintained throughout the process.
- All costs related to the procurement of the organs (operating room charges, surgeon's fees, lab fees, transportation, etc.) are billed to Legacy of Hope. The transplant recipient's hospital then reimburses Legacy of Hope for procurement costs. In turn, the hospital is reimbursed by the recipient's insurance company or by Medicare/Medicaid.
- Aftercare Coordinators, specialists in grief and bereavement, follow-up with each donor family after the donation. We provide periodic follow-up for at least a year following the donation.



## **ORGAN AND TISSUE DONATION PROCESS In More Detail**

Organ and tissue donation involves a complex series of events requiring the teamwork and cooperation of the physician/s and nurse/s caring for the potential donor, other hospital staff, the transplant coordinator/s, the donor's family and the transplant surgeon/s. The entire donation process may take anywhere from a few hours to a day or two depending on the individual circumstances.

### **Donor Referral**

At, or near, the time of a patient's death, a physician, nurse or other designated representative from the hospital contacts Legacy of Hope. They provide confidential information to determine if the patient is a potential donor.

### **Medical Evaluation**

A procurement transplant coordinator, or family support services coordinator, travels to the hospital to evaluate each potential donor and to determine the medical suitability of each organ. The coordinator obtains detailed medical information about the patient's current medical condition, as well as any past medical history. After obtaining consent, the coordinator also conducts a detailed interview with the next of kin and completes a medical and social history questionnaire about the donor. Many of these questions are similar to those asked when someone donates blood.

### **Declaration of Death**

#### **Consent for Organ Donation is obtained**

The procurement transplant coordinator, or family support services coordinator, meets with the potential donor's next of kin, or other authorized party, to offer the opportunity for donation. This conversation is carefully timed and only takes place after the next of kin is given time to understand their loved one is dead. Detailed information is provided about the organ donation process including which organs and/or tissues may be donated, how and when the recovery is scheduled to take place, testing that will be required to determine the medical suitability of the donations, and how the organs and/or tissues will be distributed to the patients needing transplants. After making the decision to donate, the next of kin will be asked to sign a consent form documenting which organs and/or tissues they wish to donate.

### **Medical Examiner/Coroner**

Prior to the recovery of any organs or tissues, the coordinator must also contact the appropriate county Medical Examiner or Coroner if the death is under their jurisdiction.

### **Organ Allocation and Recipient Identification**

Each patient waiting on an organ transplant is listed on a national computerized waiting list that is maintained by the United Network for Organ sharing (UNOS) in Richmond, VA. This



registry contains detailed information about each patient, including their blood type, degree of medical urgency and other data important for matching donors to recipients. This registry changes constantly as new patients are added to the list, and as other patients either receive a transplant, die waiting, or due to a change in medical condition, are removed from the list.

Specific information about each donor, including his/her blood type and body size, are entered into the national computer system. An individualized list is generated for each donor that identifies patients who match for those particular organs. There is a different list generated for each and every donor. Each available organ is allocated according to rules established by UNOS.

The procurement transplant coordinator then contacts the transplant center where each potential recipient is waiting and provides detailed, confidential information about the donor. The transplant surgeon makes the final decision about whether or not the donor and intended recipient is a good match.

### **Organ Recovery Procedure**

The recovery of the organs is performed in an Operating Room (OR) where strict sterile techniques are utilized and standard OR procedures are followed. The procurement transplant coordinator oversees the arrival and departure of the surgical recovery teams. The recovery team consists of surgeons, nurses, the procurement transplant coordinator and an organ preservation technician.

### **Organ Preservation**

Just prior to being removed from the donor, each organ is flushed free of blood with a specially prepared ice-cold preservation solution that contains electrolytes and nutrients. The organs are then placed in sterile containers, packaged in wet ice and transported to the recipient's transplant center.

It is important to transport the organs from the donor to each intended recipient as quickly as possible. Hearts and lungs must be transplanted within approximately 4-6 hours after being recovered from the donor. Livers can be preserved between 12 – 24 hours; the pancreas can be preserved 12 - 24 hours; intestines can be preserved approximately 8 hours and kidneys can be preserved 24-48 hours on ice. Kidneys are often placed on a pump to maintain their viability and evaluate function. This extends preservation time to 72 hours.

### **Donor Family Follow-up**

After the transplants have been completed, a letter is sent to the donor's family that includes information about the outcome of the donations. Care is taken to preserve the identity and location of the recipient(s), but general information is given about how they are doing after receiving their transplant. Similar letters will also be sent to the doctors and nurses who cared for the donor at the hospital.



# LEGACY *of* HOPE

Alabama's Organ & Tissue Donation Alliance

## **Costs**

All costs directly related to the recovery of the organs, including laboratory tests, use of the operating room, surgeons' fees, transportation, etc., are billed to Legacy of Hope. The recipient's transplant hospital then reimburses Legacy of Hope for the recovery costs. In turn, the transplant hospital is reimbursed by the recipient's insurance company or through Medicaid/Medicare. The donor family is not charged for expenses related to the donation. The donor family is responsible for hospital charges until the time of death and funeral expenses.



# LEGACY *of* HOPE

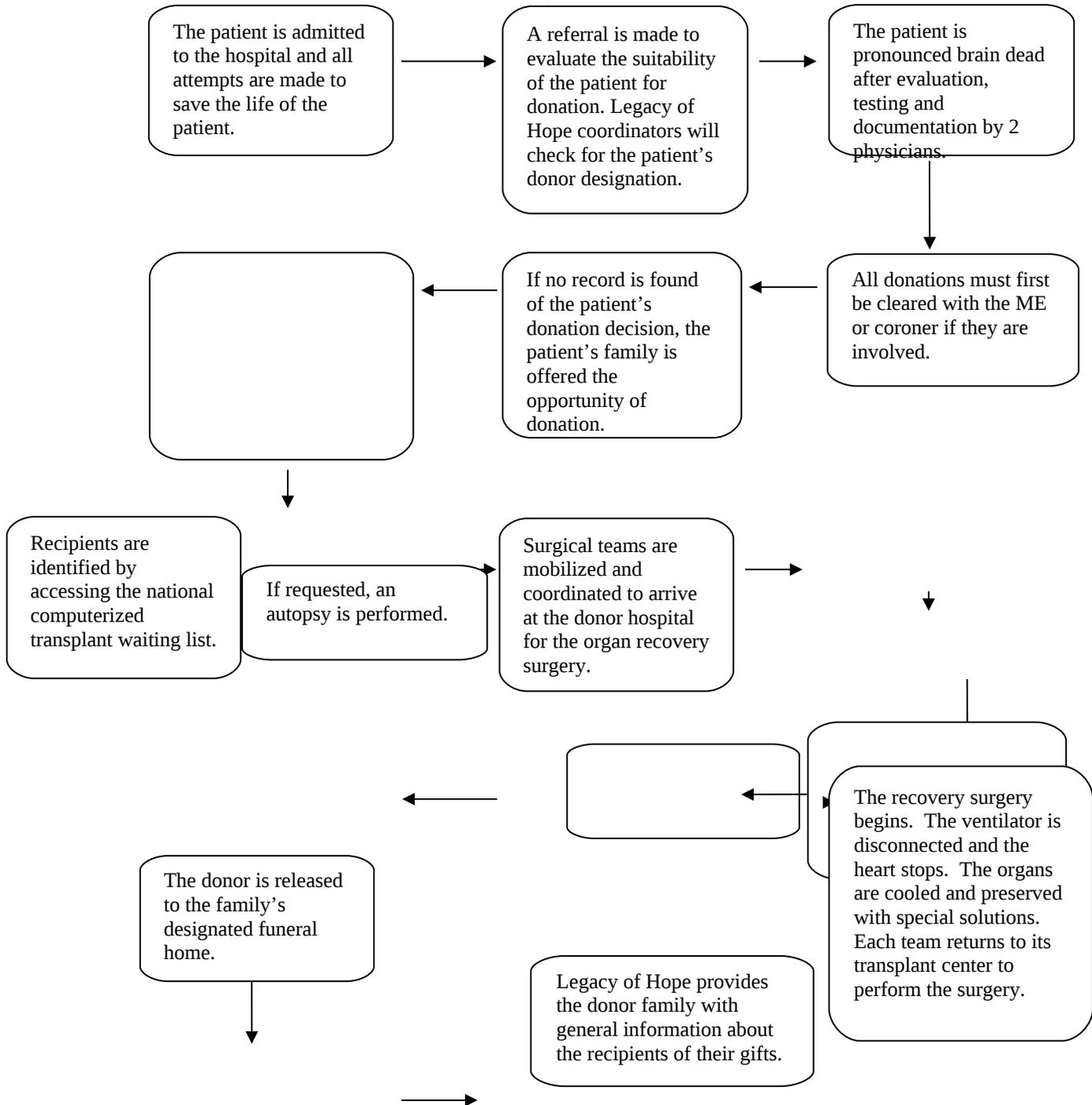
Alabama's Organ & Tissue Donation Alliance

## **FLOW CHART OF KEY ACTIVITIES DURING A DONATION**



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance





# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## **DONOR DESIGNATION ALABAMA'S UNIFORM ANATOMICAL GIFT ACT**

**Donor Designation** is the practice of ensuring that an individual's expressed wishes about organ and tissue donation are fulfilled. Legacy of Hope honors donor designation based on the recognition that every individual has a right to make a personal decision about donation and it is important to respect and honor those wishes to extend the gift of life to others in need.

Legacy of Hope abides by donor designation in a manner which respectfully integrates the philosophy of donor designation, while maintaining a strong commitment to support families in crisis.

Alabama has a computer-based donor registry, Legacy Organ and Tissue Donor Registry. There are three ways to be added to the Registry:

1. The most common way is through the Department of Motor Vehicles (DMV). When an individual obtains a new license, or gets their license renewed, the DMV clerk should ask, "Are you an organ donor?" Individuals who say "yes" will have a red heart printed in the lower right-hand corner of the license. Once a quarter, all new registrants are added to our Registry. Before a family is approached about donation, Legacy of Hope or the Alabama Eye Bank (AEB) checks the registry status of their loved one. This influences how the donation discussion is handled with the surviving family members.
2. Anyone interested in registering to be an organ, eye or tissue donor can register on their own through the Legacy of Hope's website, [www.legacyofhope.org](http://www.legacyofhope.org).
3. People can also register by completing the Registry form that accompanies our general information brochure. The completed forms are sent to Legacy of Hope and the new registrant is added by our staff.

We encourage everyone to share their donation wishes with their family. This conversation gives the family more confidence and comfort in the donation decision.

We want everyone to register through the Legacy Organ and Tissue Donor Registry. Since Legacy of Hope and Alabama Eye Bank can access the Registry and verify registration, it helps to ensure that your donation wishes will be honored.



## LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

On June 12, 2008, Governor Bob Riley signed the **Revised Uniform Anatomical Gift Act** which was passed in the 2008 Legislative Sessions. The House version was sponsored by the Honorable Robert Bentley and the Senate version was sponsored by the Honorable T. D. Little. The bill facilitates donations and modernizes the Act to reflect changes in federal law and regulations governing organ procurement and allocation as well as changes in organ, tissue and cornea donation practices. The bill's passage is a demonstration of Alabama's commitment to reducing the number of deaths on the organ transplant waiting list, minimizing the number of delayed surgeries due to the lack of available tissue, and honoring a citizen's right to donate. The legislation was promulgated in 2006 by the National Conference of Commissioners on Uniform State Laws (NCCUSL). A committee was formed to review the NCCUSL version and collectively composing language to establish cooperation and protocols between the Medical Examiners and Coroners. The committee included representatives from the Attorney General's Office, the State of Alabama Department of Forensic Sciences, Jefferson County Medical Examiner, Alabama Coroner's Association, Alabama Law Institute, Alabama Hospital Association, Legacy of Hope and the Alabama Eye Bank. The overwhelming commitment, and unparalleled level of cooperation between the representatives, resulted in the presentation to the Alabama Law Institute a bill with universal support. Highlights from the bill include:

- The legal hierarchy respects modern arrangements by identifying and authorizing an "agent" to make a gift on the principal's behalf via power of attorney and healthcare surrogate designations.
- Respects a donor's designation executed at age 16 when applying for a driver's license and the designation of emancipated minors.
- Respects designations or revocations made by any form of communication addressed to two adults as long as one is a disinterested witness.
- Respects designations made in wills effective upon death regardless of whether the will is probated.
- Strengthens designations so that revocation can only be made by the individual whose parts are the subject of the refusal, if physically able, otherwise, the revocation must have been made at the request of the individual or involving two adult witnesses, one of which must be disinterested.
- Strengthens the first person consent designation by firmly stating that a donor's autonomous decision regarding donation is to be honored.
- Adds classes that may make an anatomical gift such as an adult who exhibited special care and concern for the decedent, guardians at the time of death, and any person having the



authority to dispose of the decedent's body. Permits majority rights to making an anatomical gift when there is more than one member of a class rather than rescinding the right when there is one objection.

- Incorporates alternative forms of documents such as e-mail or recorded oral consents when an authorized individual is reasonably available, but not physically present. However, it requires that a member of a prior class be reasonably available to amend or orally revoke an anatomical gift.
- Specifies who may receive gifts from “hospitals” to eye banks, tissue banks, and organ procurement organizations as appropriate.
- Requires law enforcement officers, firefighters, paramedics, or other emergency responders to forward donor documents found during a search to the hospital.
- Rescinds the requirement for hospitals to ask each patient upon admission whether they are an organ or tissue donor.
- Mandates a search for donor designation in the Alabama Legacy Donor Registry.
- Grants the procurement organizations the ability to conduct a reasonable examination to determine medical suitability while preventing the withdrawal of measure until a determination has been made unless there is evidence expressed to the contrary.
- Establishes punishment guidelines (Class C felony) for abuses such as intentional falsification of a document of gift or refusal when done for financial gain.
- Establishes validity and presumption of validity for the document of a gift.
- Specifies that a donor's attending physician and agent shall act to resolve conflict when such exists between an advance health-care directive and an anatomical gift.



## **FINANCIAL ASPECTS OF ORGAN DONATION**

Legacy of Hope is a non-profit, federally designated and certified Organ Procurement Organization (OPO). We are responsible for the coordination of the organ and tissue donation process.

Donor families are not charged for costs associated with donation or transplantation. Recovery agencies absorb the costs of donation, generally beginning at the time brain death is declared.

All organ donation charges and expenses incurred by a recovery agency are regulated and audited by the federal Centers for Medicare-Medicaid Services (CMS). Legacy of Hope is allowed to bill transplant centers an acquisition fee for each organ provided for transplant. This fee includes the medical expenses and transportation costs related to the recovery process. Acquisition fees vary by organ and geographic area.

The acquisition fee becomes a part of the total amount that a transplant hospital will charge the recipient or their insurance carrier.

Medicare generally covers the costs of kidney transplants under the End Stage Renal Disease Program (ESRD).



# APPENDIX

---

## HOW TO BECOME A DONOR

Step 1: Say “yes” to organ donation when you get/renew your driver’s license or obtain a non-driver ID at the DMV or register on-line at [www.legacyofhope.org](http://www.legacyofhope.org) or fill out the Legacy of Hope brochure and mail it to us.

You can also go straight to the registration page on our website via this QR Code



Step 2: Discuss your decision with your family. Although Legacy of Hope adheres to the law as outlined in Alabama’s Uniform Anatomical Gift Act (UAGA), it is important that your family know your donation wishes. This will help our staff abide by your wishes and recover organs and tissue for transplant and research.



## Facts and Explanations

Despite continuing efforts at public education, misconceptions about organ donation persist. It's a tragedy if even one person decides against donation because of inaccurate information. Following is a list of facts about organ and tissue donation designed to help people make an informed decision about donating after they have lived their lives.

**Fact:** Becoming a donor will not affect my medical care if I am in an accident.

**Explanation:** If you are admitted to a hospital, the number one priority is to save your life. Organ donation can only be considered after a physician has declared brain death or the family chooses to withdraw life-sustaining therapies.

**Fact:** Organ and tissue donation is performed respectfully and does not disfigure the body.

**Explanation:** Organs and tissues are removed in an operation with specially trained staff. Your body is treated with respect and an open casket funeral is possible after donation.

**Fact:** Most religions support donation.

**Explanation:** Most religions approve of donation or leave it to personal choice. Donation is considered an act of charity.

**Fact:** If you agree to donate your organs, your family will not be charged.

**Explanation:** There is no financial cost to the donor's family or estate for organ or tissue donation. Funeral costs remain the responsibility of the family.

**Fact:** Even if you have registered to be a donor, it is important to have a family conversation about your decision.

**Explanation:** While organ and tissue donation can legally occur with your donor registration, it is important to discuss your decision with your family to ensure they understand your wishes.

**Fact:** Individuals with health conditions and advanced age can still donate.

**Explanation:** People of all ages and medical histories should consider themselves potential donors. Medical professionals will review your history at the time of death to determine what organs and tissues can be donated.

**Fact:** The organ transplant waiting list is based on medical need, time waiting and compatibility with the donor.

**Explanation:** The organ sharing system is managed by the United Network for Organ Sharing (UNOS) and is based on the severity of the illness, time spent waiting, blood type, and other important medical information.



## **RELIGIOUS VIEWS ON ORGAN/TISSUE DONATION AND TRANSPLANTATION**

### **AME & AME Zion (African Methodist Episcopal)**

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

### **Amish**

The Amish consent to donation if they know it is for the health and welfare of the transplant recipient. They believe that since God created the human body, it is God who heals. However, they are not forbidden from using modern medical services, including surgery, hospitalization, dental work, anesthesia, blood transfusions, or immunization.

### **Assembly of God**

The Church has no official policy regarding donation. The decision to donate is left up to the individual. Donation is highly supported by the denomination.

### **Baptist**

Though Baptists generally believe that organ and tissue donation and transplantation are ultimately matters of personal conscience, the nation's largest Protestant denomination, the Southern Baptist Convention, adopted a resolution in 1988 encouraging physicians to request organ donation in appropriate circumstances and to "...encourage voluntarism regarding organ donations in the spirit of stewardship, compassion for the needs of others and alleviating suffering." Other Baptist groups have supported organ and tissue donation as an act of charity and leave the decision to donate up to the individual.

### **Buddhism**

Buddhists believe organ donation is a matter that should be left to an individual's conscience. Reverend Gyomay Masao Kubose, president and founder of The Buddhist Temple of Chicago and a practicing minister, says, "We honor those people who donate their bodies and organs to the advancement of medical science and to saving lives." The importance of letting loved ones know your wishes is stressed.

### **Catholicism**

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



### **Christian Church (Disciples of Christ)**

The Christian Church encourages organ and tissue donation, stating that we were created for God's glory and for sharing God's love. A 1985 resolution, adopted by the General Assembly, encourages "members of the Christian Church (Disciples of Christ) to enroll as organ donors and prayerfully support those who have received an organ transplant."

### **The Church of Christ, Scientist**

Christian Scientists do not take a specific position on transplants or organ donation. They normally rely on spiritual, rather than medical means for healing. Organ and tissue donation is an issue that is left to the individual church member.

### **Episcopal**

The Episcopal Church recognizes the life-giving benefits of organ, blood, and tissue donation. All Christians are encouraged to become organ, blood, and tissue donors "as part of their ministry to others in the name of Christ, who gave His life that we may have life in its fullness."

### **Greek Orthodox**

According to Reverend Dr. Milton Efthimiou, Director of the Department of Church and Society for the Greek Orthodox Church of North and South America, "The Greek Orthodox Church is not opposed to organ donation as long as the organs and tissue in question are used to better human life, i.e., for transplantation or for research that will lead to improvements in the treatment and prevention of disease."

### **Gypsies**

Gypsies tend to be against organ donation. Although they have no formal resolution, their opposition is associated with their belief in the after-life. Gypsies believe that for one year after a person dies, the soul retraces its steps. All parts of the body must remain intact because the soul maintains a physical shape.

### **Hinduism**

Hindus are not prohibited by religious law from donating their organs, according to the Hindu Temple Society of North America. In fact, Hindu mythology includes stories in which parts of the human body are used for the benefit of other humans and society. The act is an individual decision.

### **Independent Conservative Evangelical**

Generally, Evangelicals have had no opposition to organ and tissue donation. Donation is an individual decision.



## LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

### **Islam**

Muslims believe in the principle of saving human lives, and permit organ transplants as a means of achieving that noble end.

### **Jehovah's Witnesses**

Jehovah's Witnesses believe donation is a matter best left to an individual's conscience. All organs and tissue, however, must be completely drained of blood before transplantation.

### **Judaism**

All four branches of Judaism (Orthodox, Conservative, Reform, and Reconstructionist) support and encourage donation. Said Orthodox Rabbi Moses Tendler, "if one is in the position to donate an organ to save another's life, it's obligatory to do so, even if the donor never knows who the beneficiary will be. The basic principle of Jewish ethics - 'the infinite worth of the human being' - also includes donation of corneas, since eyesight restoration is considered a life-saving operation." In 1991, the Rabbinical Council of America (Orthodox) approved organ donations as permissible, and even required, from brain-dead patients. The reform movement looks upon the transplant program favorably. Rabbi Richard Address, Director of the Union of American Hebrew Congregations Bio-Ethics Committee, stated that, "Judaic Response materials provide a positive approach and by and large the North American Reform Jewish community approves of transplantation."

### **Lutheran**

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

### **Mennonite**

Mennonites have no formal position on donation, but are not opposed to it. They leave the decision to the individual or his/her family.

### **Moravian**

The Moravian Church has made no statement addressing organ and tissue donation or transplantation. Robert E. Sawyer, President, Provincial Elders Conference, Moravian Church of America, Southern Province, states, "There is nothing in our doctrine or policy that would prevent a Moravian pastor from assisting a family in making a decision to donate or not to donate an organ." It is, therefore, a matter of individual choice.

**Mormons**

The Church of Jesus Christ of Latter-Day Saints considers the decision to donate organs a selfless act that often results in great benefit and the decision to donate for medical purposes, or the decision to authorize donation from a deceased family member is made by the individual or deceased member's family. The Church states that the decision should be made after receiving competent medical counsel and confirmation through prayer.

**Pentecostal**

Pentecostals leave the decision to donate up to the individual.

**Presbyterian**

Presbyterians encourage and endorse donation. It's an individual's right to make decisions regarding his or her own body.

**Seventh-Day Adventist**

Donation and transplantation are strongly encouraged. Seventh-Day Adventists have many transplant hospitals, including Loma Linda in California, which specializes in pediatric heart transplantation.

**Shinto**

In Shinto, the dead body is considered impure and dangerous, and thus quite powerful. Injuring a dead body is a serious crime. It is difficult to obtain consent from bereaved families for organ donation or dissection for medical education or pathological anatomy because Shintos relate donation to injuring a dead body. Families are concerned that they not injure the relationship between the dead person and the bereaved people.

**Society of Friends (Quakers)**

Quakers do not have an official position. They believe that organ and tissue donation is an individual decision.

**Unitarian Universalist**

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



## LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

### **United Church of Christ**

Reverend Jay Lintner stated, “United Church of Christ people, churches and agencies are extremely and overwhelmingly supportive of organ sharing. The General Synod has never spoken to this issue because, in general, the Synod speaks on more controversial issues, and there is no controversy about organ sharing, just as there is no controversy about blood donation in the denomination. While the General Synod has never spoken about blood donation, blood donation rooms have been set up at several General Synods. Similarly, any organized effort to get the General Synod delegates or individual churches to sign organ donation cards would meet with generally positive responses.”

### **United Methodist**

The United Methodist Church issued a policy statement regarding organ and tissue donation. In it, they state that, "The United Methodist Church recognizes the life-giving benefits of organ and tissue donation, and thereby encourages all Christians to become organ and tissue donors by signing and carrying cards or driver's licenses, attesting to their commitment of such organs upon their death, to those in need, as a part of their ministry to others in the name of Christ, who gave his life that we might have life in its fullness." A 1992 resolution states, “Donation is to be encouraged, assuming appropriate safeguards against hastening death and determination of death by reliable criteria." The resolution further states, “Pastoral-care persons should be willing to explore these options as a normal part of conversation with patients and their families.”



## **DIVERSITY ISSUES**

The State of Alabama has a very diverse population. With a population of 4.85 million – approximately 2.9% of them are foreign born.

According to the 2017 U.S. Census:

- 69.2% are Caucasian/White
- 26.8% are Black/African-American
- 4.3% are Hispanic or of Latino origin
- 1.5% are Asian
- 1.7% are persons reporting two or more races
- 0.7% are American Indian and Alaska Natives

\* 2017 U.S. Census Bureau



## VOCABULARY RELATING TO ORGAN AND TISSUE DONATION

Language plays an important role in the misconceptions and fears about organ and tissue donation. Please consider how a donor family and the general public may perceive insensitive terminology. Avoiding terminology that causes concern among donor families and the general public will not only help further their understanding, but will also improve their acceptance of the donation process. We request that you support the following changes in terminology.

Please use

|                               |            |              |
|-------------------------------|------------|--------------|
| “recover organs” or           | instead of | “harvest” or |
| “surgical recovery of organs” |            | “harvesting” |

Harvest is a word that has long been accepted by the medical community. However, the public at large associates the word harvest with crops. The word recovery helps people to understand that the removal of a loved one’s organs for transplant is a respectable surgical procedure.

|                     |            |              |
|---------------------|------------|--------------|
| “deceased donor” or | instead of | “cadaver” or |
| “deceased donation” |            | “cadaveric”  |

In the past, the term donor did not require any specificity. Today, as more people choose to become living donors, there is a need to distinguish between living and deceased donors. The term cadaveric depersonalizes the fact that a gift was offered to someone upon an individual’s death. Webster defines cadaver as “dead bodies intended for dissection.” This is not the positive message/image we wish to convey to the public or donor families.

|                         |            |                |
|-------------------------|------------|----------------|
| “mechanical support” or |            |                |
| “ventilated support”    | instead of | “life support” |

There are two ways to determine death: cardiac death (when the heart stops functioning) and brain death (when the brain stops functioning). The term “life support” proves to be a confusing term when used in conjunction with brain death. When death occurs, there is no support that can make the individual live again. In the presence of brain death, an individual may share the gift of life with others through organ donation. “Mechanical” or “ventilated support” are appropriate terms for the support given a deceased person in the event of organ donation.



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## PREFERRED TERMINOLOGY

“Donation after Cardiac Death”      instead of      “non-heart beating donation”

Donation after cardiac death (DCD) occurs when a ventilated patient with a non-survivable injury or illness does not deteriorate to brain death. If the heart stops beating within one hour after the ventilator is removed, the patient is transported to the operating room where the donation process proceeds. The liver and kidneys (and sometimes the pancreas) can be recovered from a DCD patient, as well as bone and tissue.

“donor designation”      instead of      “first person consent”

There are three ways an individual can make their organ and tissue donation wishes known:

1. Fill out a donor registration card and mail it to Legacy of Hope
2. Go online to [www.legacyofhope.org](http://www.legacyofhope.org) and fill out a donor registration form
3. Say “yes” when asked by the clerk at the local driver’s license department.

By registering to be an organ donor, an individual has legally indicated his or her wish to be an organ and tissue donor.

“deteriorating to brain death”      instead of      “progressing to brain death”

Progressing indicates a positive change or event. Deteriorating to brain death better describes a negative change in the patient’s condition.



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## GLOSSARY OF TERMS

### **A**

#### **ABO Blood Type**

The classification of human blood into four groups: A, B, AB, and O.

#### **Allocation**

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

#### **Allograft**

Organ and tissue transplants between genetically different humans of the same species. See **Bone Allograft**.

#### **Antibody**

A protein substance made by the body's immune system in response to a foreign substance, for example, a transplanted organ, blood transfusion, virus, or pregnancy. Because the antibodies attack the transplanted organ, transplant patients must take powerful anti-rejection (immunosuppressive) drugs.

#### **Antigen**

A foreign substance, such as a transplanted organ, that triggers the body to try to destroy it. This response may be the production of antibodies, which try to destroy the antigen (the transplanted organ).

#### **Anti-Rejection Drugs (immunosuppressive drugs)**

Drugs that are taken to help the body accept the transplanted organ.

#### **Apnea Test**

The apnea test is completed as part of the evaluation for brain death. It demonstrates the absence of respiration (breathing) and lack of function of the brain stem. Brain dead patients do not breathe on their own.

### **B**

#### **Bone**

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

#### **Bone Allograft**

Bone transplant between genetically different humans of the same species.

#### **Brain Death**

Brain death is a diagnosis of death that is both medically and legally recognized. Brain death occurs when blood flow the brain stops for an extended period of time. Without blood, the brain has no source of oxygen and without oxygen, the brain begins to die.

Brain death may be caused by any condition that stops blood flow to the brain. Examples include acute injuries such as automobile accidents or when a blood vessel bursts in the brain. These conditions cause the brain to swell. If this swelling is not controlled, blood flow to the brain will stop, permanently resulting in brain death.

For more information about Brain Death, log onto [www.braindeath.org](http://www.braindeath.org). This site,



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

while it may be helpful in further explaining Brain Death, is not in any way related to the Alabama Organ Center, and the AOC is not responsible for its content.

## **Brain Stem**

A stem-like extension of the brain that controls heart-beat and respiration.

## **C**

### **Cadaveric**

Term no longer used by organ and tissue donor families. See **Deceased Donor** or **Non-living Donor**.

### **Cardiac Death**

The cessation of all respiratory and cardiac functions.

### **Cartilage**

A translucent elastic tissue that composes most of the skeleton; cartilage bone, formed by ossification of cartilage.

### **Centers for Medicare & Medicaid Services (CMS)**

CMS is an agency of the United States Department of Health and Human Services. CMS administers the Medicare and Medicaid programs, which provide health care to America's aged and indigent populations, (about one in every four Americans, including nearly 18 million children), and nursing home coverage for low-income elderly.

### **Cold Ischemia Time**

The time interval beginning when an organ is cooled with a perfusion solution at the organ procurement surgery and

ending when the organ is re-perfused at implantation.

### **Connective Tissue**

Forms the supportive and connective structures of the body.

### **Cornea**

The outer curved transparent tissue covering the iris and pupils on the outside of the eye. Only the cornea is removed for corneal transplants.

### **Cross-matching**

A blood test done before the transplant to see if the potential recipient will react to the donor organ. If the cross-match is "positive," then the donor and patient are incompatible. If the cross-match is "negative," then the transplant may proceed. Cross-matching is routinely performed for kidney and pancreas transplants.

### **Cyropreserved**

The process of cooling and storing cells, tissues, or organs at very low temperatures to maintain viability. For example, the technology of cooling and storing cells at a temperature below the freezing point (-196°C) permits high rates of survivability upon thawing. In Greek "kryos" = cold. Cryopreservation is cold storage for the purpose of preservation.

## **D**

### **Deceased Donor**

A deceased organ or tissue donor who is usually unrelated to the recipient.



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## **Declaration of Death**

Declaration of death is performed by the donor's physician and is the official time of death. Death of a patient is determined when there is an absence of cardiovascular (heart beat) and respiratory functions or when there is an absence of all brain function, including lack of function of the brain stem. Physicians make the determination of death based on standard medical practice.

## **Directed Donation**

Donors, or donor families, can specify transplant recipients under a procedure known as "directed donation." It is specifically permitted under most state laws governing anatomical gifts. To receive a directed donation, the recipient would have to be formally accepted for a transplant by a transplant center and would have to be medically compatible (blood type, size, etc.) with the donor.

## **Donation**

Is the act of giving one's organs or tissue to another person(s).

## **Donation After Cardiac Death (DCD)**

Donation after cardiac death allows for the recovery of liver, kidneys, pancreas and tissues from patients who have suffered a devastating, non-recoverable illness or injury and are ventilator dependent, but do not meet the criteria to be declared brain dead. This type of donation is offered to families only after the decision has been made to remove the patient from life supporting therapies. The recovery of organs takes place after the patient has been declared dead based on the absence

of all cardiovascular and respiratory function (no heart beat or breathing).

## **Donor**

A deceased or living donor who provides cells and/or tissue for transplantation in accordance with established medical criteria and procedures.

## **E**

## **End-State Organ Disease**

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

## **G**

## **Graft**

An organ or tissue transplanted from one individual to another of the same species

## **H**

## **Harvest or Harvesting**

Term no longer used by organ and tissue donor families. See **Recover**.

## **Health Resources and Services Administration (HRSA)**

HRSA, an agency of the U.S. Department of Health and Human Services, is the primary Federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable.



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

Comprising six bureaus and nine offices, HRSA provides leadership and financial support to health care providers in every state and U.S. territory.

HRSA oversees organ, bone marrow and cord blood donation. It supports programs that prepare against bioterrorism, compensates individuals harmed by vaccination, and maintains databases that protect against health care malpractice and health care waste, fraud and abuse.

HRSA was created in 1982, when the Health Resources Administration and the Health Services Administration were merged. Its mission is to improve health and achieve health equity through access to quality services, a skilled health workforce and innovative programs.

## **Heart**

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

## **Heart Valve**

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

## **Histocompatibility (HLA System)**

The examination of human leukocyte antigens (HLA) in a patient is often referred to as “tissue typing” or “genetic matching.” Tissue typing is routinely performed for all donors and recipients in kidney and pancreas transplantations to help match the donor with the most suitable recipients to help decrease the likelihood of rejecting the transplanted organ.

## **I**

### **Immunosuppressive Drugs**

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

### **Intestines**

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

### **Islet Cells Transplants**

Islet cells are found in the pancreas and produce insulin that the body needs to use glucose for energy.

## **K**

### **Kidneys**

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

## **L**

### **Life Support**

When a person has been declared brain dead, it is incorrect to say that the person



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

is removed from “life support.” See **Ventilator**

## **Liver**

A large reddish-brown organ that secretes bile and is active in the formation of certain blood proteins and in the metabolism of carbohydrates, fats, and proteins. The liver can be donated and transplanted.

## **Living Donor**

A person who donates a kidney, part of a lung or part of a liver, while they are still alive.

## **Lungs**

A pair of two spongy organs that remove carbon dioxide from the blood and provide it with oxygen. The lungs can be donated and transplanted.

## **M**

## **Match**

The compatibility between the donor and the recipient. The more appropriate the match, the greater the chance of a successful transplant.

## **Multiple Listing**

Being on the **waiting list** at more than one **transplant center**.

## **O**

## **Organ Donation After Cardiac Death**

Generally, organ donation takes place after a patient has been declared brain dead. It allows the recovery of livers, kidneys and

tissues from patients who have suffered a devastating non-recoverable illness or injury and are ventilator dependent, but do not meet the criteria to be declared brain dead. This type of donation is offered to families only after the decision has been made to remove the patient from life sustaining therapies.

## **Organ Donor**

A person who wishes to donate organs and indicates so on their driver's license, through Alabama's Legacy Organ & Tissue Donor Registry or on an organ donor card.

## **Organ Preservation**

Donated organs require special methods of preservation to keep them viable between procurement and transplantation. Without preservation, the organ will deteriorate. The length of time organs and tissues can be kept outside the body vary depending on the organ, the type of preservation fluid, and the preservation method (pump or cold storage). Common preservation times vary from 2-4 hours for lungs to 48-72 hours for kidneys.

## **Organ Procurement and Transplantation Network (OPTN)**

In 1987, Congress passed the National Organ Transplant Act that mandated the establishment of the OPTN and Scientific Registry of Transplant Recipients. The purpose of the OPTN is to improve the effectiveness of the nation's organ procurement, donation and transplantation system by increasing the availability of and access to donor organs for patients with end-stage organ failure. Members of



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

the OPTN include transplant centers, Organ Procurement Organizations (OPOs), histocompatibility laboratories, voluntary healthcare organizations and the general public. The United Network for Organ Sharing (UNOS) operates the OPTN under contract with the Federal government.

## **Organ Procurement Organization (OPO)**

An organization designated by the Centers for Medicare and Medicaid Services (CMS) and is responsible for the procurement of organs and tissues for transplantation and research and the promotion of organ and tissue donation. Fifty eight OPOs currently operate in the United States.

## **Organs**

Human organs available for transplantation include the heart, liver, kidney, pancreas, intestines and lungs.

## **P**

### **Pancreas**

Long, irregularly shaped gland, which lies behind the stomach, and secretes pancreatic juice into the lower end of the stomach that aids in the digestion of proteins, carbohydrates, and fats. The pancreas can be donated and transplanted. Also see **Islet Cells transplants**.

### **PELD**

Candidates under the age of 18 who are waiting for livers are placed in categories according to the Pediatric End-stage Liver Disease (PELD) scoring system. The

measures used are as follows: 1) Bilirubin, which measures how effectively the liver excretes the bile; (2) INR (prothrombin time), which measures the liver's ability to make blood clotting factors; (3) Albumin, which measures the liver's ability to maintain nutrients; (4) growth failure; and (5) whether the child is less than one year old when listed for a transplant. (Source: United Network for Organ Sharing – UNOS.)

### **Perfusion**

The passage of fluid through empty spaces to preserve the viability of recovered organs.

### **Procurement**

See **Recover**.

## **R**

### **Recipient**

An individual who receives transplanted organs or tissues. Federal and State legislation requires hospitals to have in place written policies and protocols for referring potential organ and tissue donors and/or requesting donation from families of potential donors. Factors such as race, gender, age, income or celebrity status are not considered when determining who receives organs or tissues.

### **Recover**

A term used to describe the process of recovering life-saving and life-enhancing organs and tissues for recipients on the waiting list. Donated organs are removed surgically; donation neither disfigures the



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

body nor eliminates the possibility for an open casket funeral.

## **Rejection**

- (1) The body's attempt to destroy the transplanted organ; usually occurs in the first year after transplant.
- (2) Rejection occurs when the body tries to attack a transplanted organ because it reacts to the organ or tissue as a foreign object and produces antibodies to destroy it. Anti-rejection (immunosuppressive) drugs help prevent rejection.

## **Routine Referral**

Hospitals are required, on or before each death, to call the **Organ Procurement Organization (OPO)** in order to determine suitability for organ, eye and tissue donation. The OPO, in consultation with the patient's attending physician, or his or her designee, will determine the suitability for donation. If the patient is a candidate for organ or tissue donation, only personnel from the OPO or a trained designated requestor from the hospital, can request donation from the next of kin.

## **Sclera**

The white part of the eye.

## **Sclera Patches**

These are used when the sclera (white part of the eye) has thinned or has been punctured. When the sclera breaks, vision is lost completely. A sclera patch restores the eye to its proper shape so that it may function normally.

## **Soft Tissues**

Tissues that connect, support or surround other structures and organs of the body. These include muscle, fat, tendons, ligaments, cartilage, fibrous tissue, blood vessels, or other supporting tissues of the body.

## **Suitability Assessment**

This is an evaluation, using existing information about a potential donor, to determine whether the donor meets specific qualifications for suitable transplantation.

## **T**

### **Tendons**

Tissue that connects bone to muscle.

### **Tissue Bank**

An organization that provides or engages in one or more services involving cells and/or tissue from living or deceased individuals for human transplantation purposes.

### **Tissues**

Tissues available for transplantation include corneas, skin, bone, heart valves, arteries, veins, tendons, etc.

### **Transplant Center**

A hospital that performs transplant surgery.

### **Transplantation**



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

A surgical procedure whereby life-saving and life-enhancing organs and tissues are implanted into a living human recipient.

## U

### **Uniform Anatomical Gift Act (UAGA)**

A model set of laws, adopted by many states, regarding a person's gift of his or her body parts after death. Legislation that provides guidelines for the voluntary donation of organs and tissues. The law outlines authorization for making this gift, describes the manner in which it may be done, and prohibits the sale of organs and tissues for profit.

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

The transplant community is joined under a nation-wide umbrella: The United Network for Organ Sharing is a non-profit charitable organization, administers and maintains the nation's organ transplant waiting list under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Located in Richmond, Virginia, UNOS brings together, under that contract and on behalf of the Organ Procurement and Transplantation Network (OPTN), medical professionals, transplant recipients and donor families to develop organ transplantation policy. The U.S. OPTN helps ensure the success and efficiency of the U.S. organ transplant system.

## V

### **Vascular**

Related to or containing blood vessels.

### **Ventilator**

A machine that "breathes" for a person when he or she is not able to breathe properly. In the case of **brain death**, when the person is clinically dead, the person is sometimes incorrectly referred to as being **on life support**. In this case, saying **that the person is brain dead and that his or her body function is being maintained by a ventilator** is more accurate.

## W

### **Waiting List**

After evaluation by a team of healthcare professionals, a patient is added to the national waiting list by the **transplant center**. Lists are specific to both geographic area and organ type (heart, lung, kidney, liver, pancreas, intestine, heart-lung, or kidney-pancreas). Each time a donor organ becomes available, the **United Network for Organ Sharing (UNOS)** computer generates a list of potential recipients based on factors that include genetic similarity, blood type, organ size, medical urgency and time on the waiting list. Through this process, a "new" list is generated each time an organ becomes available that best "matches" a patient to a donated organ.

## X

### **Xenograft**



# LEGACY *of* HOPE

Alabama's Organ & Tissue Donation Alliance

An organ or tissue procured from a different species for transplantation into a human.

## **Xenotransplantation**

Transplantation of an animal organ into a human. Although xenotransplantation is highly experimental, many scientists view it as an eventual solution to the shortage of human organs.



## LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

### **FAST FACTS ABOUT ORGAN AND TISSUE DONATION\*** **THE NATIONAL DONOR REGISTRY IS 101.4 MILLION STRONG**

**THE NEED** More than 125,000 men, women and children in the United States need life-saving organ transplants. Of these patients, more than 2,100 are waiting in Alabama. They are in desperate need of the following organs: heart, kidneys, pancreas, lungs, liver and intestines.

#### **ORGAN DONORS AND TRANSPLANTS**

Every day in the United States, an average of 20 people die waiting for organ transplants.

Tens of thousands of others need corneas to restore sight, bone and other tissues to repair injured or diseased bones and joints, skin to heal burns and heart valves to replace diseased ones.

One donor has the potential to save eight people and enhance more than 75 lives.

Though the majority of Alabamians support organ donation, including strong support from healthcare professionals and virtually all organized religions, only 35% have actually registered to be an organ and tissue donor or discussed their decision with family.

Of all the deaths in the United States, only 1-2% has the potential to result in organ donation. Unfortunately, only about 50% of those individuals actually donate. If everyone who could donate said "yes," the waiting list for transplants would be greatly reduced.

#### **ONE DONOR CAN:**

- Donate kidneys to free two people from dialysis treatments needed to sustain life.
- Save the lives of patients awaiting heart, liver, lung or pancreas transplants.
- Give sight to two people through the donation of corneas.
- Donate bone and help repair injured joints or to help save an arm or leg threatened by cancer.
- Help burn victims heal more quickly through donation of skin, and provide healthy heart valves for someone whose life is threatened by malfunctioning or diseased valves.

\*HRSA / OPTN / Donor Alliance



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## COMMONLY ASKED QUESTIONS ABOUT ORGAN & TISSUE DONATION

### **Who can become a donor?**

Anyone can decide to be a donor. If you are under the age of 18, however, you'll need a parent or guardian's consent to be an organ or tissue donor. You may still indicate your wishes to donate through the Registry or where you receive your driver's permit or license.

### **How do I become an organ/tissue donor?**

You can either say "yes" to donation when you get/renew your driver's permit or license at your county's DMV; or, you can register on-line at [www.legacyofhope.org](http://www.legacyofhope.org); or, you can complete a registration form and mail it to us. We will then input your information and register you as a donor. Call us and we can mail you a form, or you can download it from our website.

### **Is there a need for organ and tissue donors?**

There is a desperate need. Approximately 2,100 people in Alabama and over 122,000 nationwide are waiting for a life-saving or life-enhancing transplant. Each day, 20 people die while waiting for an organ transplant. A new name is added to the waiting list every 10 minutes. Thousands more await bone, corneal, and other tissue transplants.

### **How do I discuss organ and tissue donation with my family?**

Many people are uncomfortable talking about death. Explain to your loved ones how your decision to donate at the time of your death will offer hope to others whose lives can be saved or enhanced through transplantation.

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

A growing number of minorities are awaiting transplants throughout the United States. Certain diseases of the kidney, heart, lung, liver and pancreas are prevalent in minority communities. Many of these diseases can be treated through transplantation. For example, African-Americans are affected with kidney problems three times more than persons of other ethnicities.

### **Can I sell my organs?**

The buying and selling of organs and tissues is illegal in the United States, as part of the National Organ Transplant Act (Public law 98-507).

### **Can I change my mind once I register with the Legacy Organ & Tissue Donor Registry?**

You can call 1-800-252-3677 to have your name removed from Alabama's Legacy Organ & Tissue Donor Registry.



**Can I be an organ and tissue donor and also donate my whole body to medical science?**

Usually an individual can do one or the other. Most medical schools do not accept bodies that have been organ and tissue donors. You can either donate organs and tissues or donate your body to medical science.

**What is brain death?**

Brain death is death. It is the total, irreversible cessation of all functions of the entire brain, including the brain stem, which controls respiration (breathing). If artificial respiration (ventilator) and other mechanical and chemical support are given, it is possible to maintain organs, including the heart, artificially for a short period of time in order to keep organs viable for transplantation.

**What organs and tissues can I donate?**

Organs that can be donated include the heart, kidneys, pancreas, lungs, liver and intestines. Tissues that can be donated include eyes, skin, bone, heart valves, tendons, veins and blood vessels.

**Can I donate organs to a friend or loved one awaiting a transplant?**

Directed donation is a request made by a donor, or a donor family, to transplant a specific recipient. The practice is legally recognized in the Uniform Anatomical Gift Act (UAGA). The request is made to Legacy of Hope and then we verify that the intended recipient is actively waiting for a transplant and is compatible with the donor. This donation request takes priority over the traditional organ sharing system. If the organ is not compatible with the requested recipient, most families will allow the organ to be shared through the traditional system.

Living donation is also an option. If you are interested in donating an organ to a friend or loved one awaiting a transplant, please call the transplant hospital where your family member or friend is waiting. If they are waiting at University Hospital, please call 1-888-822-7892 or 1-205-975-9200.

**Will donation change the appearance of my body?**

No. Donation neither disfigures the body nor interferes with funeral arrangements.

**Does it cost anything to donate organs and tissues?**

No. There is no financial cost to the donor's family or estate.

**Is there an age limit for donating organs?**

No set age limit exists for organ donation. We have had organ donors who were 92 years old. At the time of death, the potential donor's organs are evaluated to determine their suitability for donation. Therefore, people of any age wishing to become organ and tissue donors should



indicate it on their driver's license or register with Legacy at [www.legacyofhope.org](http://www.legacyofhope.org). Again, it is important to tell your family your donation wishes.

**Who is responsible for the cost of transplant surgery?**

Most transplants are covered by individual health insurance, Medicare or Medicaid programs. Patients should contact their physicians or health insurance company for more information.

**What medical conditions exclude a person from donating organs?**

HIV and actively spreading cancer normally exclude people from donating organs. Otherwise, the organs are evaluated at the time of death. Therefore, those with other pre-existing medical conditions such as diabetes or hypertension may be able to donate and should share their decision with their family.

**Does my religion approve of donation?**

Most of the major religions in this country approve of organ and tissue donation or at least leave it to personal choice. Donation is considered a gift – an act of charity. If you have questions, contact your faith advisor. Please see the Religious Views on Donation on page 32 of this Handbook.

**What are the steps involved in organ and tissue donation?**

Hospitals are required by CMS and the Joint Commission to notify the Alabama Organ Center of the impending death of a patient. The AOC staff will then consider possible medical disqualifications for organ and tissue donation. If none are readily apparent, a trained coordinator will visit the hospital to further evaluate the patient. If the patient is medically suitable, the option for donation is offered to the next of kin. Once the family consents, the coordinators work with the national computerized waiting list at the United Network for Organ Sharing (UNOS) to match the donated organs with the most appropriate recipients and arrange for the recovery surgery. They also stay with the donor's family and provide support as long as the family wishes. Immediately after the organs are surgically removed from the donor, the AOC staff transports the organs to the transplant hospitals.

**How is the potential recipient identified?**

The United Network for Organ Sharing (UNOS) maintains a national computerized list of candidates for transplant. Recipients are identified through a comprehensive evaluation of medical compatibility, including size and blood type, medical urgency and location. The financial background of the patient does not determine who receives a transplant.

**How are recipients matched to donors?**

Individuals waiting for transplants are listed by the transplant center in their area (in Alabama, the University of Alabama Hospital). Their name then goes into a national



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

computerized waiting list of potential transplant patients in the U.S. that is maintained by UNOS. UNOS heads a 24-hour telephone service to aid in matching donor organs with patients on the national waiting list and to coordinate efforts with transplant centers.

When donor organs become available, Legacy of Hope provides UNOS with information about the medical characteristics of the donor. Each organ is then matched with a recipient based on height, blood type, weight, and age, as well as the recipients' urgency of need and length of time spent on the waiting list. Also, preference is generally given to recipients from the same geographic area as the donor, because timing is a critical element in the success of transplants.

## **How successful are transplants?**

Success rates for vital organs average 80-90 percent; the success rate for various types of tissue transplants is more than 90 percent.

## **I've heard a lot of people have to wait a long time for an organ. How did celebrities like Mickey Mantle and Steve Jobs get their transplants so quickly?**

Organs are allocated based on a number of medical criteria, including blood type, how sick the patient is, how long that individual has been on the waiting list, and in the case of kidneys, how closely the donor's antigens (genetic factors) match the recipient's antigens. Both Mickey Mantle and Steve Jobs received their transplants quickly because they were the sickest patients on the list at that particular time. Other patients had been waiting longer, but without receiving a transplant when they did, neither Mantle nor Jobs would have lived more than a week or two.



## IMPORTANT WEBSITES

### GENERAL INFORMATION

Donate Life America  
[www.donatelife.net](http://www.donatelife.net)

Alabama Kidney Foundation  
<http://www.alkidney.org/>

American Liver Foundation  
<http://www.liverfoundation.org/>

AOPO – Association of Organ Procurement Organizations  
<http://www.aopo.org/>

Camp BRIDGES  
<http://www.campbridges.org/>

Donor Memorial Website  
<http://www.donormemorial.org/>

Gift of a Lifetime, Organ & Tissue Transplantation of America  
<http://www.organtransplants.org/>

JCAHO – Joint Commission and Health Care Organizations  
<http://www.jointcommission.org/>

MOTTEP – Minority Organ Tissue Transplant Education Program  
<http://www.natlmottep.org/>

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

National Kidney Foundation Serving Georgia and Alabama  
<http://www.kidneyga.org/>

RENALNET – Kidney Information Clearinghouse  
<http://www.therenalnetwork.org/>



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

Tom Golden (Crisis, Grief & Healing)

<http://www.webhealing.com/>

Transplant Living

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

Transplantes Y Vida

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

TransWeb: Organ and Tissue Donation Issues and Answers

<http://www.transweb.org/index.shtml>

United Network for Organ Sharing

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

U.S. Government Information on Organ and Tissue Donation and Transplantation

<http://www.organdonor.gov/>

## **SCHOOL PROGRAMS**

Students for Organ Donation

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

Gift of a Lifetime, Organ & Tissue Transplantation in America

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



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## FORMS & IDENTIFICATION

---

### FORMS & IDENTIFICATION

Legacy of hope has created a series of forms to gather information and organize the Ambassador Volunteer Program. Copies of these forms are available in this Appendix. These forms include:

#### **Volunteer Interest Form**

Every volunteer must fill out the Volunteer Interest Form with hours available, emergency contact information, address, phone number, etc. Please call or e-mail us at 205-731-9200 or 1-800-252-3677 to ensure our office is updated with the latest contact information. We do understand many lifestyle changes may be required for our volunteers, so even if your participation in our activities is limited, we're happy to keep you involved through our newsletters and our Facebook page.

#### **Emergency Information**

Please complete this form with contact information in case something happens to you while you are volunteering for Legacy of Hope.

#### **Please Share your Personal Story or Interest as it Relates to Donation**

#### **Confidentiality Statement and Agreement Form**

All volunteers must sign a confidentiality form. This form alerts our volunteers about our responsibility to safe-guard confidential information including any information regarding laboratory, medical, surgical, social, employee or business operations.

#### **Permission for use of Picture/Personal Information and Consent for Use of Name and Likeness of Donor**

This form gives permission for the media (both internal and external) to use your likeness or feature products created by you (stories, photos, artwork, etc., developed within the course of your work as volunteer) in a publication, news story or other medium.

#### **Volunteer Hours**

This form provides a record of service of your volunteer time and experience for Legacy of Hope.



### **Materials Request**

This in-house form is used to keep track of materials requested, find out which materials work, what inventory items are popular. Please request materials at least 2 weeks prior to your event.

### **In-House Volunteer Request Form**

We created this form to find out about events, to advertise the events to most volunteers in advance and to gather information about all volunteer hours.

### **Event Evaluation Forms**

This form was created so that all events can be evaluated by the volunteer, Legacy of Hope staff and hospital service employees. We can then make decisions on whether we can or should continue to be involved with these events.

### **Handbook Receipt**

This form is completed by a volunteer after receiving this Handbook. It is used to assure that a volunteer has attended a training session and has received the information regarding organ and tissue donation.

### **Volunteer Travel/Expense Form**

While you are volunteering for Legacy of Hope, you may be entitled to reimbursement for meals and gas.

### **Volunteer IDs**

For identification purposes, Legacy of Hope will create IDs for you to wear when coming to the office or when representing the organization at an event.



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## VOLUNTEER APPLICATION FORM

Please complete this form if you would like to give the gift of time to promote organ and tissue donation. We will send you additional information via e-mail or the US Postal Service.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP: \_\_\_\_\_  
\_\_\_\_\_

Preferred Telephone: \_\_\_\_\_ Evening Telephone: \_\_\_\_\_  
\_\_\_\_\_

E-Mail Address: \_\_\_\_\_  
\_\_\_\_\_

Date of birth: \_\_\_\_\_ Gender: \_\_\_\_\_ T-shirt size: \_\_\_\_\_

Please check the time(s) you are available to help:

weekdays  weekends  evenings  anytime  depends on schedule

How far can you drive round-trip to an event?

less than 20 miles  20-30 miles  more than 50 miles

Please share your special connection to organ & tissue donation and transplantation:

- transplant recipient
- registered on the Waiting List for a transplant
- donor family member
- recipient family member
- healthcare professional
- friend or relative of someone touched by transplantation
- other \_\_\_\_\_

Date of transplant or date your loved one became a donor: \_\_\_\_\_



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

Please check the activities that interest you:

- community events
- health & wellness fairs
- office work (mailings, filing, etc.)
- Legacy of Hope Celebration of Life Picnic (set-up, serve food, monitor games, clean-up)
- in-service presentations for nursing staff (with AOC staff member)
- share your story with others (civic groups, church groups)
- sporting events (distribute materials at football, baseball, basketball games)
- I give Legacy of Hope permission to use my picture, likeness, name, city, type and date of transplant for education purposes, including publications or give to the media.

---

Signature

Date

THANK YOU so much for your interest in volunteering with Legacy of Hope.

Please return this form to:

Ashley Anderson  
Legacy of Hope  
421 Richard Arrington Jr. Blvd, S  
Birmingham, AL 35233



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## VOLUNTEER EMERGENCY INFORMATION

Volunteer Name: \_\_\_\_\_

In case of emergency, notify: \_\_\_\_\_

Relationship \_\_\_\_\_

Telephone: \_\_\_\_\_ Cell Phone: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

\_\_\_\_\_  
Volunteer Signature

\_\_\_\_\_  
Date





# LEGACY *of* HOPE

Alabama's Organ & Tissue Donation Alliance

---

---

---

---

---

---



## CONFIDENTIALITY AGREEMENT

Confidential information is defined as, but not limited to, all donor information, recipient information, including the names of donors, recipients and/or their families, medical information, staff information, organizational plans, research and development or marketing plans concerning the Legacy of Hope operations. All information including medical, financial, donor, recipient and family information is considered strictly confidential and is not to be discussed with non-Legacy of Hope personnel.

As a volunteer, I understand that I may be exposed to personal information about other volunteers and/or staff. I will protect the privacy of other individuals. It is important that I keep information on donors, recipients, staff and all other program operations confidential and allow them only to be used for Legacy of Hope activities.

I hereby affirm that I will treat as confidential any information learned in the course of my volunteer work with the Legacy of Hope relating to donor or recipient information or other sensitive business information. I agree that I will not copy, or remove any donor or recipient information from the facility or otherwise use my role as a volunteer to attempt to obtain information about any donor or recipient. I will not disclose any such information to third parties unless explicitly authorized in writing by Legacy of Hope.

I understand that in the case of my failure to adhere to this Confidentiality Agreement, Legacy of Hope shall have the right to pursue all available legal remedies, including damages for breach of contract and such other relief as appropriate.

---

Volunteer Signature

---

Date



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## **MEDIA AGREEMENT**

I authorize Legacy of Hope to use materials created by Legacy of Hope or provided by myself, including but not limited to photographs, audio/videos, and writings, of me and/or my family for promotional and educational purposes. I understand that Legacy of Hope may edit the materials. I understand that Legacy of Hope owns all copyright to the materials created by Legacy of Hope.

My consent is freely given as a public service to Legacy of Hope without expecting payment and I release Legacy of Hope from any and all liability which might arise from the use of such materials.

\_\_\_\_\_  
Volunteer

\_\_\_\_\_  
Date



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## VOLUNTEER HOURS

This form provides a record of service of your volunteer time and experience for  
Legacy of Hope

| DATE | CITY | EVENT | ARRIVE | DEPART |
|------|------|-------|--------|--------|
|      |      |       |        |        |
|      |      |       |        |        |
|      |      |       |        |        |
|      |      |       |        |        |
|      |      |       |        |        |
|      |      |       |        |        |
|      |      |       |        |        |

COMMENTS

---

---

---



# LEGACY of HOPE

Alabama's Organ & Tissue Donation Alliance

## EVENT EVALUATION FORM

Please complete Form after each activity in which you participate.

Your Name:

---

Name of Event:

---

Date/Place of the Event:

---

—

Overall Attendance (approximate):

---

—

Number Approaching Booth (approximate):

---

—

Do you think we should participate in this event again in the future?

Please circle YES NO

Overall, I would rate this activity (please circle):

10 9 8 7 6 5 4 3 2 1  
Best Worst

My comments and/or suggestions about this community event:

---

---

---

Is Email Volunteer Sign up form included?

Please circle YES NO



# LEGACY *of* HOPE

Alabama's Organ & Tissue Donation Alliance

Please email this form and email sign up form to [ashleyanderson@legacyofhope.org](mailto:ashleyanderson@legacyofhope.org) or mail to: Legacy of Hope, ATTN: Ashley Anderson, 421 Richard Arrington Jr. Blvd, S Birmingham, AL 35233.