

# **Organ and Tissue Donation**

# MANUAL

Donor Alliance 720 S Colorado Blvd · Suite 800-N Denver, CO 80246

# Introduction to Donor Alliance

Donor Alliance is the federally designated organ procurement organization and American Association of Tissue Banks (AATB) accredited tissue bank serving Colorado and most of Wyoming. As a recognized leader in facilitating the donation and recovery of transplantable organs and tissues, Donor Alliance's primary objectives are to save and enhance the lives of others.

### **Mission Statement**

Donor Alliance saves lives through organ and tissue donation and transplantation.

### **Vision Statement**

Donor Alliance will serve all who need transplantation by maximizing the number of available organs and tissues with a commitment to innovations, new technology, and influencing policy.

To achieve these objectives, Donor Alliance employs an effective family approach and recovery programs in over 100 hospitals, and increases the awareness of the need for organ and tissue donation through public awareness and education campaigns in its service area.

### Service Area

Donor Alliance serves 100+ donor hospitals and four transplant centers in Colorado and Wyoming.

The four transplant centers in our service area are:



- > The Children's Hospital
- Porter Adventist Hospital
- > Presbyterian / St. Luke's Medical Center
- University of Colorado Hospital

# "Advocates for Life" Volunteer Program

"Advocates for Life", the official volunteer program for Donor Alliance, offers donor family members, transplant recipients, transplant candidates and others who have been touched by donation or transplantation the opportunity to share their experiences and contribute to ongoing community outreach efforts in Colorado and Wyoming.

Each and every volunteer is a valued member of the Donor Alliance community; as such, it is our commitment that each volunteer feel appreciated and part of a well-structured, worthwhile program. Our goal is to train Donor Alliance volunteers to operate independently while volunteering on behalf of Donor Alliance and the cause of organ and tissue donation.

### Who are 'Advocates'?

'Advocates for Life' are essential partners in raising awareness about organ and tissue donation. As the heart and soul of Donor Alliance's efforts to educate the public and professional health care community, volunteers are people who communicate about donation and transplantation, share the importance of making a personal decision to become an organ and tissue donor, and urge those to share their decision with family members and friends.

#### What are the benefits of being an Advocate?

- An outlet for donor family members, which helps with the transition through grief to healing.
- Volunteering for Donor Alliance is fun and makes you feel good about doing something positive and meaningful in the community!
- Access into community events where Donor Alliance holds a registry drive, including health fairs, concerts, conventions and other local festivities.
- Opportunities to network with other Advocates, Donor Alliance employees, various "donation friendly" businesses and organizations, as well as prominent community figures and role models.
- An outlet for transplant recipients, to express their gratitude and give back to the community after receiving the "gift of life"
- An outlet for transplant candidates, to educate the community and others in their lives about the importance of registering as an organ and tissue donor.
- Staying current and informed regarding what's happening surrounding donation.

Donor Alliance calls upon Advocates to conduct education and outreach through several different outlets.

# **X** Speaker's Bureau (SB)

The goal of the SB is to inspire community members to register their decision to be an organ and tissue donor, as well as to increase education on the registration and donation processes.

# This is accomplished by:

- Answering questions about donation, while dispelling common myths and misconceptions.
- Inspiring people to register their decision on the donor registry AND to discuss their decision with family and friends.
- Provide information on how to update registry status.

# **X** Donor Designation Stations (DDS)

The goal of a DDS is to inspire community members to register their decision to be an organ and tissue donor, as well as to increase education on the registration and donation processes.

# This is accomplished by:

- Providing the public with information regarding organ and tissue donation.
- Answering questions about donation, while dispelling common myths and misconceptions.
- Inspiring people to register their decision on the donor registry.
- Encouraging those registered to discuss their decision with family and friends.
- Informing those registered about updating registry status.

# **X** Behind the Scenes (Administrative Assistance)

The purpose of administrative opportunities is to provide volunteers with additional opportunities to promote organ and tissue donation by offering support to Donor Alliance employees through office and other administrative tasks. These opportunities are especially great for individuals that feel uncomfortable with a presence in the community or that have extra time during the week to devote to office related projects. Some of the administrative projects can even be done from home.

# **X** Media Opportunities (Advocates typically approached)

- To share their story with the media (TV & radio)
- To participate in a viral video for one of our social media campaigns
- To capture their story to be featured on our website

# **&** Community Events

The Donor Dash - Donor Alliance's signature 5K walk/run is held annually at Washington Park in Denver each July to raise awareness about the need for life-saving organs and tissues in Colorado and Wyoming. The event honors the lives of organ and tissue donors, celebrates the lives of organ and tissue recipients and recognizes those who continue to wait for a lifesaving transplant Volunteers help in a variety of areas including registration, water and goodie bag distribution, food & beverage tent, team packet pickup and course marshals.

The Donor Alliance Volunteer and Special Events Coordinator oversee all Advocate opportunities, including and not limited to: training sessions, Speakers Bureau, Donor Designation Stations, media stories and special events.

# **Electronic Communications**

The majority of all Advocate communications are electronic, therefore Advocates who wish to be informed about upcoming volunteer opportunities, must have an e-mail address to receive notification of opportunities or make a point to contact the Volunteer and Special Events Coordinator directly via phone.

# **Bi-Monthly E-mails: Titled "Upcoming News & Opportunities"**

Opportunities are communicated to Advocates through our bi-monthly e-mails which are sent every other Tuesday at 11:30 a.m. MST. The e-mails include:

- A letter from the Volunteer and Special Events Coordinator
- Upcoming volunteer opportunities and special events for Advocates
- 3-4 current events (media stories related to donation and transplantation)
- Birthdays and transplant anniversaries
- The Advocate Orientation and Training Schedule

### How are Advocates Assigned?

Advocates are assigned to opportunities on a first-come, first-serve basis according to the "Advocates for Life" training requirements.

- A confirmation e-mail will be sent out to assigned Advocates 3-4 days prior to each event to confirm all event details and logistics.
- Advocates may be approached directly for volunteer opportunities based on:
  - Donor Alliance staff requests
  - A particular Advocate is the perfect fit for a specific opportunity

# "Be Proactive"

Advocates who are interested in participating in volunteer opportunities are highly encouraged to be proactive and review the bi-monthly e-mails regularly and contact the Volunteer and Special Events Coordinator with their interests and/or ideas. Donor Alliance has roughly 300 active Advocates and therefore we highly encourage Advocates to be proactive in their relationship with the organization and their communication with the Volunteer and Special Events Coordinator.

Donor Alliance Advocates are the heart and soul of our efforts to inspire the public about the importance of registering as organ and tissue donors. We truly value and appreciate the passion, dedication, time and commitment that Advocates devote each and every year to our mission to save lives through organ and tissue donation and transplantation.

### I. Volunteer Records Database

Donor Alliance's volunteer database is managed by the Donor Alliance Volunteer and Special Events Coordinator. A handful of Donor Alliance staff and Advocates have some limited access in order to assist with data entry and records maintenance. Advocates contact information, history regarding relation to donation, training records, dates of service, completed assignments, personal stories and accomplishments are maintained in a confidential database that is password protected.

Advocates relation to donation and personal stories are sometimes shared upon request with Donor Alliance staff and event organizers to determine the best fit for speaking opportunities as part of the Advocates for Life Speakers Bureau and/or to prepare an event organizer with the necessary information to introduce speakers.

### II. Confidentiality

Advocates will be interacting with Donor Alliance staff and might have access to information of a sensitive and confidential nature. All Advocates are required to sign a Privacy and Confidentiality Statement upon the start of their volunteer relationship with Donor Alliance, agreeing to maintain all privileged information confidential.

### **III. Work Environment**

The majority of all Donor Alliance Advocate opportunities take place at various venues and locations within the greater Colorado and Wyoming community.

Some Advocates assist on an administrative level in the office. All Advocates helping with Administrative tasks will be provided with a work space, appropriate equipment and access to necessary resources to accomplish assigned projects. Advocates working in the office are encouraged to take breaks and lunch at their leisure.

# **IV. Appropriate Dress Code**

Advocates are encouraged to wear their "Advocates for Life" name badge for all volunteer opportunities. Below is a list of acceptable attire based on the different volunteer opportunities (unless otherwise noted).

### **Donor Designation Stations**

- Program specific shirts: Donor Alliance polo shirt, Donate Life volunteers t-shirt or Recyclers T-shirt.
- Fall/Winter/Spring Attire: Donor Alliance provided shirt, black or khaki pants, and nice shoes (preferably not sneakers).
- Summer Attire (outdoor and indoor events): Donor Alliance provided shirt, jeans, shorts, skirt and nice shoes. Tennis shoes/sneakers are acceptable.
- Business casual attire

# Speakers Bureau and Administrative Dress Code

a) Business casual or professional attire

# **Advocate Appreciation Event**

The Advocates for Life volunteer recognition ceremony is held in January or February every year. Donor Alliance awards 1, 3 and 5 year pins, recognizes an Advocate of the Year and recognizes Advocates for hours and achievements accomplished on an annual basis.

# American Diabetes Expo

Donor Alliance sets up a Donor Designation Station at this event annually to reach out to the estimated 5,000 attendees. Diabetes is the leading cause of chronic kidney failure and is increasing in the United States at an alarming rate.

# April is Donate Life Month

National Donate Life Month was established in 2003. Every day in April, people across the U.S. make a special effort to celebrate the tremendous generosity of those who have saved lives by becoming organ, tissue, marrow and blood donors and to encourage more Americans to follow their fine example.

# **Donor Dash**

Donor Alliances signature event, the Donor Dash 5K is for runners, walker and the entire family to honor the lives of organ and tissue donors, celebrate the lives of organ and tissue recipients and recognize those waiting for a lifesaving transplant. Advocates are encouraged to participate and/or volunteer.

# Donor Designation Stations include the following materials:

- (1-2) Empowering Testimonial Display Panels
- Donate Life blue tablecloth
- Prize Wheel
- Display Board
- (2-4) Brochure Holders
- Informational literature and publications
  - Donate Life General Market Brochures
  - Donate Life Tissue Brochures
  - Donate Life Hispanic Brochures
  - Donate Life African American Brochures
  - Pope Cards (English and Spanish)
- (3-4) Baskets to hold promotional materials
- Donate Life Magnets
- Donate Life Lip Balm
- Donate Life Green Bracelets
- Donate Life Lapel Pins
- Donate Life Pens
- Prize Wheel Giveaways (quantities limited for each event)



- **ENCOURAGED** to review this manual and current fact sheets prior to arriving at a donor designation station. This preparation helps ensure efficiency and success throughout all of our community outreach efforts ultimately increasing the registered organ and tissue donors in Colorado and Wyoming.
- <u>ENCOURAGED</u> to share your personal experiences with donation and/or transplantation to booth visitors. Please use caution while talking about your experience and remember that some details may be too graphic, emotional or uncomfortable for the general public. It is wise to restrain from details and instead express a broad view of your experience, including how the experience has positively impacted your life.
- <u>**PLEASE**</u> wear appropriate attire, such as Donor Alliance polo shirt with khaki slacks and black shoes. *Attire may vary according to the event.*
- **ENSURE** that every registration form and literature containing a registry form is coded before distribution. Event codes are created and assigned for every event.
- <u>A MINIMUM</u> of one "active" Advocate (volunteer) or Donor Alliance staff member at the booth at all times.
- **MAINTAIN** a neat, tidy and secure booth at all times.
- **<u>BE</u>** cordial and polite to the public at all times, regardless of differing opinions or views on organ and tissue donation.
- **FOLLOW** the Donor Designation Station Checklist.
- <u>TAKE</u> inventory of remaining materials prior to tearing down the booth.



# **FACTS and STATS:**

# About Donation and Transplantation

- In Colorado & Wyoming, more than **2,100** people are currently waiting for a lifesaving organ transplant.
- Of those currently waiting for an organ transplant 71% are waiting for a kidney and 25% are waiting for a liver.
- 14% of current transplant candidates in Colorado have been on the waiting list for 5 years or more.
- Today, more than **112,000** people are waiting for an organ transplant nationally.
- On average, **245** people are added to the nation's organ transplant waiting list *each month*, one every twelve minutes!
- 27% of patients awaiting kidney transplants are African American
- On average of 18 people die each day from the lack of available organs for transplant
- Every year, the lives of about **500,000** Americans are saved and enhanced by organ and tissue donation.
- One donor can <u>save up to eight lives</u> through organ donation, and save and heal up to **100** lives through tissue donation.
- Recoverable organs include: heart, lung, liver, kidney, pancreas and small bowel.
- Tissues that are recoverable include: bone, tendons and corneas as well veins, valves and skin.
- In 2010, Donor Alliance recovered organs for transplant from <u>130</u> donors.
- In 2010, Donor Alliance recovered tissues for transplant from <u>1024</u> donors a record high recovery number for the organization.

Last updated: November 2011



FACT:

Everyone has the power to say "YES" to donation!

# **COMMON MYTHS**

# Regarding Organ and Tissue Donation



**Myth:** "If I am in an accident and the hospital knows I am an organ donor, the doctors won't try to save my life!"

**Reality:** The medical team treating you is separate from the transplant team. Doctors do not know about your wishes to be an organ donor, and the Organ Procurement Organization (OPO) is not notified until all lifesaving efforts have been done and brain death has been declared.

Myth: "My religion does not support donation."

**Reality:** Most religious denominations support organ and tissue donation. In many instances, donation is viewed as an act of charity and a matter of individual conscience.

**Myth:** "Rich and famous people get moved to the top of the waiting list, while 'regular' people have to wait longer for a transplant."

**Reality:** The organ allocation and distribution system is blind to wealth or social status. "The length of time it takes to receive a transplant is governed by many factors, including blood type, length of time on the waiting list, severity of illness and other medical criteria. Factors such as race, gender, age, income, or celebrity status are never considered when determining who receives an organ transplant."—UNOS.

Myth: "My family will be charged large medical bills if I end up donating my organs after my death!"

**Reality:** Costs associated with recovering and processing organs and tissues for transplant are never passed on to the donor's family.

# Tough Questions Regarding Organ and Tissue Donation

Many times, our Advocates will get asked tough questions for which they may not always know the answers. These questions are typically sensitive in nature and should be answered with the same sensitivity kept in mind. The following is a list of common questions with answers:

#### What is Donor Alliance?

Donor Alliance is the federally-designated, non-profit organ procurement organization and an American Association of Tissue Banks (AATB) accredited tissue bank serving Colorado and most of Wyoming. As a recognized leader in facilitating the donation and recovery of transplantable organs and tissues, Donor Alliance's mission is to save lives through organ and tissue donation and transplantation. To achieve this mission, Donor Alliance employs an effective family approach and recovery programs in more than 100 hospitals. Donor Alliance also inspires the public to register as organ and tissue donors through community partnerships, public outreach and education campaigns throughout our donation service area.

Donor Alliance will serve all who need transplantation by maximizing the number of available organs and tissues with a commitment to innovations, new technology and influencing policy.

#### What is organ and tissue donation?

Organ and tissue donation is the process of recovering organs and tissues from a deceased person, and transplanting them into others in order to save the lives of those in need. Up to eight lives can be saved through organ donation and more than one hundred lives can be saved through tissue donation.

#### If I suffer a grave injury, how does the process work?

If a patient arrives at the hospital with a grave brain injury, the hospital contacts the local organ procurement organization (OPO). While the hospital continues aggressive lifesaving efforts, the OPO determines whether the patient is a registered organ and/or tissue donor. This information helps to guide the OPO and the hospital staff regarding how the family should be approached should death be determined imminent for that patient. Only if the patient is medically suitable to donate, and after the family has been informed of the patient's imminent death, is the opportunity to donate discussed with the family. Once the family has been presented with documentation of the patient's donor designation, which legally grants authorization to recover organs and/or tissues, or, in cases where there is no registration present, the family grants authorization allowing the process to move forward.

#### What is the donation process?

Once a patient is declared brain dead, a Donor Alliance family support coordinator works with the family of the deceased to explain the donation process and to ensure that the decision is based on informed consent. A thorough medical and social history of the potential donor is conducted to help determine the suitability of the organs for transplant. After death and upon consent of the family, organs that have been deemed suitable for transplant are recovered. For recovery, the donor is taken to an operating room where a trained surgical team removes the organs and tissue; during which, the same surgical care is taken as in an operation on a live person. The donor is treated with the highest degree of respect and care.

#### What are the benefits of organ and tissue donation?

Each year, the lives of approximately 500,000 people in the United States are saved through organ and tissue donation. One single organ and tissue donor can save the lives of more than 100 people.

#### How many people need donated organs and tissue?

There are currently more than 110,000 people in the U.S. waiting for organ transplants. Each year, approximately 6,000 people die waiting for an organ transplant that would have given them a second chance at life with their families. In addition, each year hundreds of thousands of people benefit from donated tissue that is used for life-saving and reconstructive purposes.

#### Does saying "yes" to becoming a donor affect the medical treatment that I receive?

No. Medical care is not affected in anyway by your status as a registered donor. Every attempt is made to save your life. In fact, patients must receive the most aggressive lifesaving care in order to be potential organs donors. If a patient's heart stops during lifesaving efforts, organs cannot be transplanted. Organ and tissue donation is only considered after a physician has pronounced a person dead and their family has been consulted.

#### What is the difference between brain death and circulatory death in relation to donation?

Organs are most commonly recovered after brain death - when brain function has permanently stopped. Brain death is not the same as being in a coma. No one has ever regained consciousness from or survived brain death. Brian death occurs in about 1 of 100 hospital deaths.

Circulatory death is when the heart stops beating. Though organ recovery is possible after circulatory death, it is a less common form of donation; however, tissues are commonly recovered in both brain and circulatory death circumstances. In no cases are organs or tissues donated until the donor has been declared legally dead.

Heart, kidneys, liver, lung, pancreas and small intestine are the organs which can be transplanted; bone, corneas, heart valves, veins, skin, tendons and ligaments are among tissues.

#### How are donated organs and tissues used?

Donated organs and tissue are transplanted to those on the waiting list. A national system, the United Network for Organ Sharing (UNOS) ensures that organs are equitably distributed. Organs are used in transplantation to replace organs that are severely damaged due to illness, trauma, or birth defects.

Tissue is commonly used in patients with sports-related injuries (such as knee reconstruction, torn ACLs, etc.), spinal fusions, eye surgery and skin grafts for the severely burned, or those with serious abrasions, and other exposed areas. Recovered bone has many purposes, such as use in orthopedic surgery to facilitate healing of fractures or prevent amputation, as well as in common dental procedures. Heart valves are used to replace defective valves. Tendons are used to repair torn ligaments on knees or other joints. Veins are used in cardiac by-pass surgery. Corneas can restore sight to the blind. Many tissues that cannot be used for transplant can be recovered and used in a variety of research studies to advance medical science.

#### Under what circumstances can a person be an organ/tissue donor?

In almost all cases resulting in organ donation, the patient has suffered a traumatic brain injury and brain death. After all lifesaving efforts have been exhausted and it is determined that the patient's death is imminent, the patient must remain on ventilated support. The reason for this is that the heart and lungs must continue to function after the patient dies so that the transplantable organs continue to receive blood flow. In most cases, if the heart stops beating, the organs die and cannot be transplanted; however, donation after cardiac death is possible and does occur in more rare cases.

On the other hand, virtually all deceased persons, regardless of cause of death, may potentially be tissue donors. Unlike organ donation, it is not necessary for heart and lung function to be maintained on a ventilator. Once a death is reported to the tissue agency, protocols require that the family be contacted within several hours regarding the opportunity to donate.

#### What about factors such as age or pre-existing medical conditions?

Virtually all people of all ages can be potential donors. Organs and tissues are generally not considered for donation if the person has died from cancer or an infectious disease; however, certain cancer patients can donate corneas. There are very few automatic rule-outs, and due to medical advancements, even some of these may change over time. In the event you are in a position to be a donor, medical specialists will evaluate your medical history to determine your suitability to donate. Organs and tissue are tested for infectious diseases, including hepatitis, AIDS and other viral infections before they are actually transplanted.

#### Can a homosexual individual be organ donors or receive a deceased donor transplant?

The homosexual status of a female does not affect the ability to be an organ or tissue donor. Homosexual males who wish to be organ donors also have the opportunity to do so. In this case, however, the organ procurement coordinator on staff would list this donor as a "high risk" donor based on the donor's social history. The decision for donation is then left up to the transplant hospital that would be receiving the "high risk" organ(s). Many transplant hospitals do accept these "high risk" organs on a regular basis. Nonetheless, male homosexuals are not eligible to be tissue donors, simply because of the "high risk" donor status. Homosexual men and women may receive organ and tissue transplants as normal.

#### Do issues such as race or wealth affect the availability of or access to an organ transplant?

No. The United Network for Organ Sharing (UNOS) matches donated organs with critically ill patients on the national waiting list. Medical urgency, length of time on the waiting list, severity of illness, and issues of compatibility such as blood type, tissue match, and body size are considerations in determining who receives a transplant. Factors such as race, gender, age, income, or celebrity status are never considered when determining who receives an organ transplant; additionally, buying or selling organs is against the law. However, organ size (which can be affected by gender) is critical to match a donor heart, lung or liver with a recipient. Genetic makeup can be a factor when matching a kidney or pancreas donor and recipient, because of the importance of tissue matching within those two organs. Optimal tissue matching can happen within the same racial and genetic background. However, cross-racial donations can and do happen with great success when matches are available.

# Can someone who is an organ recipient be a donor? If so, can he or she be a donor with that same organ or part of it?

This depends highly on the circumstance of the patient's cause of death. The type of death must be brain death, or may possibly be circulatory death in which the cause is not related to the recipient organ. Under these circumstances, an organ recipient may be a donor of any eligible organs including a healthy recipient organ. One who has been an organ recipient may not be a tissue donor due to the immunosuppressive drugs that are taken after the transplant and their harmfulness to the body.

#### Does a person have to die to become an organ donor?

No. Living people can donate a kidney or part of the liver or lung; although, Donor Alliance only recovers organs from deceased donors.

#### What steps must I take to become an organ and tissue donor?

Simply register your decision on your state's donor registry:

Colorado residents visit: <u>www.DonateLifeColorado.org</u> Wyoming residents visit: <u>www.DonateLifeWyoming.org</u>

You may also indicate your desire to be an organ and tissue donor on your driver's license or other legal document, and most importantly, discuss the decision with your family so that they know to honor your wish to give the gift of life after your death.

#### What does being registered on a state's organ and tissue registry mean?

When enrolled onto the registry, you have elected to have all organs and tissues made available for transplant at the time of death; unless you specifically declare to only donate certain organs, only tissue, or opt against use towards medical education or research. It is essential that you communicate your wishes to your family, as they will be informed of your decision to be an organ and tissue donor at your time of death, and asked to provide information about your medical and social history.

#### Can I take my name off the registry?

Yes. To remove yourself from the registry you can either fill out the online form located on the registry web sites, or send in your request to be removed in writing to the Colorado or Wyoming Donor Registry at 720 S. Colorado Blvd, Suite 800-N, Denver, CO 80246. Once your decision is received, you will be mailed a notification card, which you are asked to sign and return to confirm your decision. Even though you have been removed from the registry, at your time of death your family will still be contacted by a coordinator and asked if they would like to make the decision to donate on your behalf.

#### How do I cancel my donor registration if I signed up through the DLO?

The red heart will remain on your card until you receive a new driver's license or identification card. Should you desire to have the heart removed from your driver's license or identification card before your renewal period, you must contact your local Drivers License Office (DLO). Specifically, you need to make an appointment to replace your driver license or ID card. Please contact your local DLO or visit their website (http://www.colorado.gov/cs/Satellite/Revenue-MV/RMV/1177024843078) to set up an appointment. It is, however, always important to share your decision about organ donation with your family and friends. If anything does happen to you, your family members will be asked about your wishes.

#### What if my family members are opposed to donation?

Once an individual has made the decision to be an organ and tissue donor, and has joined the registry, that individual's decision is honored, and the donor designation grants authorization for organ and tissue recovery. Should you be in the position to donate, your family members and next of kin will be presented with documentation of your registration that confirms your wish to donate, and walked through the donation process so they will know and understand how the recovery agency will carry out your decision to be a donor; however, family members will not have the power to override your decision. Generally, in the event of a loved one's sudden death, it will ease the family's pain to already

know the wishes of their loved one regarding donation. For this reason we recommend that you share your wishes with your family today.

#### Is my driver's license or ID card enough?

Yes, but you should always share your decision with your family and friends. Individuals can continue to register to be organ and tissue donors at the Drivers License Office (DLO) when acquiring or renewing a driver's license or state identification card. This information from the DLO is downloaded into the registry every 24 hours. So, if you make your designation at the DLO you have been added to the registry. By signing up with the registry, your desire to donate is stored in a secure, confidential database. Should your death result in the opportunity for you to be a donor, an official record of your donor designation will be readily available and your wishes to donate will be respected.

#### If I have an advance directive, should I also register on the registry, or will the advance directive be enough?

Yes. Due to the rapid and emotional nature of events surrounding sudden death, families often do not have time to check legal documents prior to being approached about donation. Without enrolling on the registry, your decision may not be expressed; however, since the registry is viewed in all potential donation cases prior to approaching the family, we are able to share proof of registration with family members at the time donation is discussed, and your wishes will be honored. Keep in mind, each state has its own laws regarding consent for organ donation. In Colorado, your decision is considered the first and only consent needed to pursue donation. Some states have registries while others rely on donor cards or advance directives. If consent is not given through either of these means, all states defer to next-of-kin to make the donation decision on behalf of their loved one.

#### Are there any religious objections to organ and tissue donation?

With the lone exception of Shinto, all major religions throughout the world support or permit organ and tissue donation, with most viewing it as a humanitarian act of giving. Transplantation is consistent with the life-preserving traditions of most faiths, and others consider donation a matter of personal choice. Many religious groups have issued formal statements supporting the idea of organ and tissue donation, which are available online. However, individuals are encouraged to consult their spiritual or religious leader with specific questions.

#### Who can sign up on the Colorado and Wyoming Registries?

The Colorado and Wyoming Registries allow people who are at least 18 years of age to register their authorization to donate specific or all organs and tissues upon their death. Children between the ages of 13 and 17 can join the registry; however, until the designated donor is 18 years old, their parents (or legal guardians) will make the final decision about organ and tissue donation at the appropriate time.

#### Can I sign up my children?

Due to federal privacy laws prohibiting the collection of personal information for individuals under age 13, the registry is unable to accept registrations for children 12 and under. Until registrants and non-registrants alike are 18 years old, their parents (or legal guardians) will make the final decision about organ and tissue donation at the appropriate time.

#### How do you ensure that someone does not sign up another person without his or her knowledge or consent?

Of the 50 state donor registries currently in operation, to date there have been no reported incidences of persons registering people other than themselves. The authenticity of the registrant can be determined using the confirmation email address, the date/time of the registration, and personal information requested during the registration process. Family members are also consulted at the time of donation and will be able to verify the donor's information at that time.

#### Does my registration grant consent for whole body donation?

Registering as an organ and tissue donor does not grant permission for your whole body to be donated to a medical school. Organ and tissue donation for transplant or research is not the same as willed body donation. Willed whole body programs are usually associated with teaching hospitals at major universities, and arrangements must be made in advance directly with the institutions. Please note: should you choose to consent to whole body donation, you may not be able to donate your organs or tissues for transplantation.

#### Is it possible to restrict my donation from prisoners or other groups?

Federal law does not allow you to restrict your donation to or from specific classes of individuals. However, Colorado has never recovered organs or tissues from prisoners who have been put to death. For donation purposes, persons must have been out of incarceration for five or more years to be eligible to be organ and tissue donors, and are considered "high risk" donors.

#### How do people in other states sign up? Is there a national registry?

All of the states in the continental U.S. honor individual state registries; however, there is no national registry. All matters concerning organ and tissue donation are under the jurisdiction of each state's respective laws. Additionally, organs may not be allocated to the registration state. For example, if a Colorado resident on the registry dies in Florida, Florida will recognize the wishes of the donor, but the state will try to allocate the organs to their state first. If the organs do not match out with any patients in that state, they will then be allocated to surrounding states, then nationally, then internationally if need be. For information on how to become a donor in other states, go to http://www.donatelife.net/ and click on the state in question.

#### I don't want to sign up online. Are there other ways to register?

In addition to online registrations, you may sign up through the Department of Motor Vehicles (DMV) when you apply for or renew your driver's license or ID card, which will automatically add your name onto the registry. If you are unable to sign up online or through the DMV, you may fill out a registry form and submit it to your local OPO. However, you should also share your decision with your next of kin in case the donor card is not available at the time you become a candidate to actually donate.

#### If something should happen to me while I am traveling, what role does my registration play?

All matters concerning organ and tissue donation are under the jurisdiction of each state's or country's respective laws. While your donor registration will not serve as legally binding consent for donation outside the state, it will serve as a clear indication of your wish to donate and will be shared with your family when they are approached by the local organ recovery agency.

#### Who is responsible for managing the organ donation process?

The designated, non-profit organ procurement organization (OPO), Donor Alliance, is exclusively responsible for facilitating the process for Colorado residents, and most Wyoming residents. Only OPOs' authorized staffs have access to both the donor and recipient medical information which makes accurate matching possible. Organ recovery and allocation is regulated by the Centers for Medicare and Medicaid Services, a division of the U.S. Department of Health & Human Services.

#### How do you determine who receives the organs?

Organs are allocated nationally based on a complex medical formula that is established by transplant doctors, public representatives, ethicists, and organ recovery agencies. The United Network for Organ Sharing (UNOS) maintains the national list of patients waiting for a transplant. A donor's blood type, tissue type, body weight, and size are matched against patients on the list. If there are multiple matches, priority is given to the sickest patients or, in the case of kidneys, those who have been on the waiting list the longest. Factors such as race, gender, age, income, or celebrity status are never considered when determining who receives an organ.

#### Can I specify which organs and tissues I donate?

You may opt out of donating specific organs and/or tissue or donating for medical research while registering online at:

Colorado residents: <u>www.DonateLifeColorado.org</u> Wyoming residents: visit <u>www.DonateLifeWyoming.org</u>

Simply state your wishes under the "Any Additional Comments" section located at the end of the online registration form. In addition, you can specify that your donated tissue must be used for life-saving or reconstructive purposes only; distributed only to non-profit organizations; or distributed only in the United States.

#### If a family member is in need of an organ at the time of my death, can I specify that he or she is to receive it?

"Directed donation" of an organ to a specific individual is legal, but it must be done at the time of donation (organs may not be directed to a specified group of individuals). Directed donation is best supported by an advance directive or may be granted by next of kin at the time of donation.

# If one has specified in his or her will how long they want to remain on life-support, will this affect the donation process?

Typically, after brain death has been declared and consent gained, it is a short period of time a patient remains on ventilated support, due to the fact that the patient is considered clinically deceased, and the process of donation can begin. Brain death is different than a coma. When a patient is in a coma, there is still brain flow allowing the brain to function. When a patient is brain dead, all function to the brain is lost for good. The longer a patient is on life support after brain death, the more unstable most organs, such as the heart and lungs, become.

#### If I am a donor, what kind of tests do they conduct on my body?

Prior to donation, all potential donors undergo a comprehensive screening that includes a physical examination, and a medical and social history. Once death has been declared and authorization is received through the donor registry (or from the family in lieu of a registration), medical professionals must conduct tests to determine whether the patient is suitable to be a donor. Blood tests and other standard medical procedures determine the patient's blood type, kidney and liver function, exposure to transmittable diseases, and tissue typing for the purpose of matching the kidneys to recipients. These tests are medically necessary in order to save as many lives as possible. Once the organs and tissue are recovered, tests are performed on blood, and organs to screen for disease, bacterial and other infections. Additionally, screens for HIV, Hepatitis B and C, and syphilis are required by the FDA, UNOS and AATB for all donated tissue.

#### Does donation affect funeral arrangements?

The body is treated with great respect and dignity throughout the process, and the donor's appearance following donation still allows for an open-casket funeral. Once the organ and/or tissue recovery process is completed, the body is

released to the donor's family. From the time the donation process begins, the entire process is usually completed within 24 to 36 hours, and the family may then proceed with funeral arrangements.

#### Is my family or estate charged for donation?

No. There is no cost to the donor's family for organ and tissue donation. Donor Alliance, a non-profit organization, assumes all costs associated with recovering and processing organs and tissues for transplant once death has been declared and authorization is confirmed through the donor registry, or from the family in lieu of registration; these costs are never passed on to the donor family. Our business model, culture and values are all built on respecting and appreciating the gift of donation. We find this is a comfort to both donor families and recipients. Eventually, these costs are then reimbursed by transplant centers, once a transplant is completed, who in turn bill private and public insurance plans. Hospital expenses incurred before the donation of organs or tissue in attempt to save the donor's life and funeral expenses remain the responsibility of the donor's family.

#### I think I may need an organ transplant. How do I get added to the list?

The process of joining the UNOS National Organ Transplant Waiting List begins with your physician referring you to a transplant center for evaluation. A committee of doctors, transplant surgeons, and other hospital staff make the decision as to whether a patient is a suitable candidate, and whether to be placed on the waiting list for an organ transplant. This decision is based on the status of the patient's health, his or her medical and social history, and the expectation for their stability after the transplant takes place.

#### What is the likelihood a recipient rejects their transplanted organ or tissue?

Each person's immune system reacts differently to transplanted organs, so there is no set formula to determine whether or not an organ will be rejected. However, new medications are continually being developed to reduce the risk of transplant rejection in patients. With these new medications, rejection rates are as low as 10-15 percent of patients and one-year transplanted organ survival has improved to 95 percent. Rejection of tissue is uncommon.

#### Do the donor and recipient families meet?

The identity of all parties is kept confidential. The donor family and the transplant recipient may receive such information as age, gender, occupation and state of residence. Individually, the recipient may be told the circumstances of the donor's death. The donor family may be informed of the transplants that were performed and receive information on improvements to the health of the recipients. The donation agencies facilitate anonymous correspondence and meetings initiated by either the donor family or recipient as agreed to by both parties.

#### How can I be sure my information is kept confidential?

As a state-authorized public service, Donor Alliance adheres to the strictest and most up-to-date guidelines to keep all personal information confidential. It is absolutely vital that we identify individual registrants with 100% certainty if they should ever be in a position to be an actual organ or tissue donor. We would never want to confuse a patient who is not registered, with someone who is. We assure you that every precaution is in place to protect the information from identity thieves. Of the 40+ state donor registries now in operation, there are no reported problems with unauthorized access to personal information.

#### Can organs be sold?

Buying and selling organs for the purpose of transplantation is illegal in the United States. Under the Uniform Anatomical Gift Act of 1984, human organs cannot be bought or sold, and violators are subject to fines and imprisonment. This strict regulation prevents any type of ""black market"" for organs in the United States. Medically

speaking, illegal sales are impossible because recovered organs must be appropriately matched to recipients and distributed according to national policy established by United Network for Organ Sharing (UNOS).

### Where can people go to find more information about organ and tissue donation?

- Donor Alliance: <u>www.DonorAlliance.org</u>, (303) 329-4747 or (888) 868-4747 (toll free)
- Donate Life America: <u>www.donatelife.net</u>
- United Network for Organ Sharing: <u>www.unos.org</u>
- AlloSource: <u>www.allosource.org</u>
- Their local driver's license office

# What Can Be Donated? *Transplantable Organs and Tissues*





To learn more about organ and tissue donation, please visit www.DonorAlliance.org or call 303-329-4747.

YOU can join the Donor Registry by visiting: www.DonateLifeColorado.org or www.DonateLifeWyoming.org



Heidi Schaiberger – Advocates for Life (Volunteer Inquiries)

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Jennifer Moe – Media Inquires Director of Communications / PR (303) 329-4747 (Donor Alliance) JMoe@donoralliance.org

# For questions about organ or tissue donation, please call or write to:

Donor Alliance, Inc. 720 South Colorado Blvd. Suite 800-N Denver, CO 80246 (303) 329-4747 or (888) 868-4747 You may also visit us on the Web at: <u>www.DonorAlliance.org</u>