



Connecticut

VOLUNTEER HANDBOOK

Alison Keating
Program Director
Cell: 203.561.5741

P.O. Box 278
Durham, CT 06422
Office: 203.387.1549
www.donatelifect.org
Email: donatelifect@gmail.com

Thank you for Volunteering with Donate Life Connecticut!

Donate Life Connecticut is an all volunteer, non profit coalition of healthcare organizations, passionate individuals and caring professionals working together with one voice to increase donor awareness and assist in registering the wishes of those who decide to donate to save lives.

Donate Life Connecticut is a member of the Donate Life America. Nearly 25 years ago Connecticut donation leaders had the foresight to bring together the state's donation community and unite in our education and legislative efforts to further the donation movement. This group, the Connecticut Coalition of Organ and Tissue Donation (CCOTD) had begun. Over the years, as Donate Life America organized and established tools and materials to be used around the nation, unifying the donation message. To align with the national movement, CCOTD began to do business as Donate Life Connecticut.

The future of transplantation and the ability to save or improve the quality of life for patients depends on more families giving consent to organ donation. Quite simply, organ donation needs to be discussed by family members so those individual wishes with regard to organ and tissue donation are clearly understood. Then and only then will more lives be saved and improved through transplantation.

You can help to achieve this goal!

The Donate Life Connecticut Volunteer Program is designed to educate our communities through the personal stories of our volunteers. Our volunteers come from a variety of backgrounds and experiences, and sharing their message locally brings a great deal of change in the understanding and support of organ and tissue donation.

Donate Life Connecticut Advisory Council Agencies

American Heart Association, Connecticut chapter

American Liver Foundation, Connecticut chapter

American Lung Association, New England chapter

Connecticut Eye Bank & Visual Research Foundation

ESRD Network of New England

Hartford Hospital Transplant Program

LifeChoice Donor Services

National Kidney Foundation serving Connecticut

New England Organ Bank

Yale-New Haven Hospital Transplant Program

Volunteer Program Guidelines

Donate Life Connecticut requires that all volunteers observe the following guidelines:

1. Be supportive of Donate Life Connecticut, it's mission and it's goals.
2. Review and be familiar with commonly asked questions.
3. Have all donor awareness activities pre-approved by Donate Life Connecticut.
4. Demonstrate a positive attitude and event appropriate appearance at all Donate Life Connecticut sponsored activities.
5. Share your personal stories with donation and transplantation.

Please do not approach hospitals. Donate Life Connecticut's member Organ Procurement Organizations (OPO) do all contact with hospitals.

Donate Life Connecticut requests that all volunteers observe the following guidelines:

1. Attend scheduled volunteer meetings/ conference calls. The meetings/calls are a good opportunity to share & exchange ideas.
2. Volunteers are welcome to share their experiences with each other and with Donate Life Connecticut members. Please share photographs of activities you participate in for our annual report, newsletter, etc.

Volunteer Program Q & A's

● **Is it appropriate to share my personal experience with donation in the public?**

Definitely! Please use your personal experience to educate Connecticut about the importance of organ and tissue donation, dispel common myths, and encourage others to join the Donor Registry!

● **Do I need to have a personal experience with donation or transplantation to be a volunteer?**

Donate Life Connecticut welcomes anyone who believes organ and tissue donation is important to help us educate Connecticut!

● **My time is limited, but I would still like to help out. Can I still be considered a volunteer?**

We appreciate any time you can donate to help us promote donation. There are many levels of participation with the Donate Life Connecticut Volunteer Program; working at Donor Designation Stations tables at public events and walks, speaking to civic, educational, etc groups, letter writing, etc. All volunteers are emailed about upcoming volunteer events and programs and can participate as their schedule allows.

● **Are Donate Life Connecticut volunteer meetings also support groups?**

No, volunteer meetings are held to discuss donor awareness events and projects. We can refer people to support groups.

● **Do you share my contact information?**

No, Donate Life Connecticut does not share your personal information with other volunteers or outside organizations without your permission. Your contact information is only shared with Donate Life Connecticut's Board of Directors, if needed.

● **When can I get started?**

Now! Every time you share your experiences with donation and transplantation you are inspiring others to save lives by joining the Donor Registry

Volunteer Activities

Donate Life Connecticut is thankful and appreciative of your dedication and desire to help educate Connecticut residents about the importance of organ and tissue donation. By sharing your personal donation stories, dispelling myths and enforcing truths about donation – together we work towards registering all residents as organ and tissue donors. Increasing the number of registered donors will save the lives of the thousands of people waiting for a second chance at life. Numerous opportunities are presented to Donate Life Connecticut volunteers including:

- Public Speaking: Raising awareness at schools, churches, temples, hospitals, civic groups, etc.
- Health & Town Fairs: Staffing information tables at fairs, businesses, blood drives, walks, etc.
- Distribute Materials: Provide your community with Donate Life Connecticut brochures and donor registration cards
- Media: Participating in interviews with local media, writing letters to the editor, and contacting local media outlets to promote use of public service advertising on organ and tissue donation.
- Special Projects: Participating in annual events, such as Donate Life Month, National Donor Awareness Day, National Donor Sabbath and working to decrease racial disparities in the donation community.

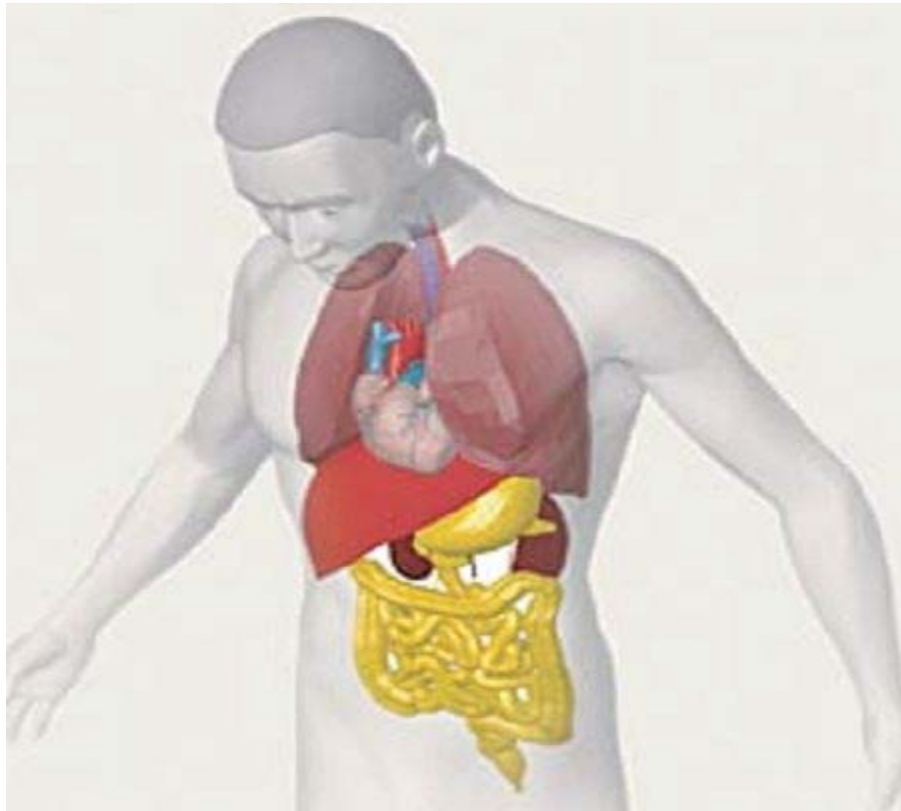
Donate Life Connecticut volunteers are also encouraged to find opportunities in their communities to offer donation information and registration; including, but not limited to High Schools, Colleges, Churches, Civic Organizations. *Please share your ideas and suggestions with the Program Manager.* All ideas are welcome! Donate Life Connecticut provides public education materials such as brochures, donor cards, handouts, and table displays as appropriate for all events.

Donate Life Connecticut History

- 1985** Statewide healthcare agencies and OPOs identified and agreed to establish a statewide coalition to raise public awareness about the need for organ and tissue donation.
- 1986** Partnership with DMV established.
- 1988** First Coalition sponsored poster contest involved three schools in the Milford area. Seventeen posters were entered for judging.
- 1992** CCOTD is incorporated in state of Connecticut as a non-profit corporation and received Federal Employer Tax ID Number.
- 1996** CCOTD received IRS tax-exempt status as a 501(c)(3) corporation.
- 2001** Connecticut Coalition website launched.
- 2001-2003** Donation movie held 57 screenings in Connecticut theaters, donation PSAs shown
- 2004** CCOTD began doing business as Donate Life Connecticut
- 2005** “Thanks for Asking” Campaign kicked-off to recognize the employees of the Department of Motor Vehicles for their assistance in registering organ and tissue donors during driver license, ID card apps or renewals.
- 2005** In addition, organ and tissue donation registration information was incorporated into the DMV driver’s manual (inside cover).
- 2006** April officially declared “Organ and Tissue Donor Awareness Month” in the State of Connecticut, given by Governor M. Jodi Rell and the Connecticut General Assembly. Later in the year, a Dedication Bench engraved stone was installed at the State Capitol building to honor organ and tissue donors and their families.
- 2007** Awarded State of Connecticut grant for funding public education activities and promoting organ and tissue donation awareness.

- 2008** Awarded grants from Aetna Foundation and New Alliance Bank to address racial disparities pertaining to donation in CT. Additional funds were donated by Bristol Myers-Squibb to grow the secondary education programs offered by Donate Life Connecticut
- 2009** At request of ABC's Extreme Makeover: Home Edition, Donate Life Connecticut spearheaded onsite and national donation awareness in honor of a Connecticut family chosen to participate on the show.
- 2009** First Annual 'Toast to Life' Wine Event held at Gouveia Vineyards
- 2009** Awarded second State of Connecticut grant to continue and grow public education and outreach about organ and tissue donation

Organs & Tissues for Transplant



Solid Organs:

Heart (1)
Lungs (2)
Liver (2, can be split)
Kidneys (2)
Pancreas (1)
Intestine

Tissues:

Corneas
Bone
Skin
Heart Valves
Saphenous Veins
Tendons/Ligaments

Fast Facts About Organ & Tissue Donation

- Every day in the United States, an average of 18 people die waiting for organ transplants.
- During the past 10 years, the transplant waiting list has more than doubled with more than 100,000 men, women, and children now needing heart, kidney, liver, lung and pancreas transplants.
- More than 1,000 people await transplants in Connecticut
- 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 the heart valves to replace diseased ones.
- One donor has the potential to save and enhance more than 65 lives and take up to eight people off the organ transplant waiting list.
- Studies have shown that over 90% of the population supports organ donation, including strong support from health care professionals and virtually all organized religions, though less than 30% nationally have actually placed the organ donor designation on their drivers license.
- Of all the deaths in the United States, only 1-2% have 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 to repair injured joints or to help save a limb threatened by cancer.
- Help burn victims heal more quickly through donation of skin
- Provide healthy heart valves for someone whose life is threatened by malfunctioning or diseased valves.

Top Ten Myths About Organ & Tissue Donation & Transplantation

If I am in an accident and the doctors or nurses find my donor card, they will not try to save my life.

Doctors, nurses and paramedics will do everything to try to save your life. In fact, an individual needs to be in the hospital, on a ventilator and pronounced brain dead in order to donate organs. Our local organ procurement organizations (OPO's), New England Organ Bank or LifeChoice Donor are not notified until all life-saving efforts have failed. The transplant team is not notified by the OPO's until after the OPO has spoken with the individual's family.

Donation will change the appearance of my body.

Donated organs and tissues are removed surgically in the hospital emergency room. Doctors maintain the utmost dignity and respect for the donor at all times, so much in fact, that all organ and tissue donation does not interfere with open casket funeral arrangements.

My religion does not support donation.

All main stream religions support organ and tissue donation.

Only the wealthy and famous receive transplants.

Most major insurances now cover heart, liver, kidney, and lung transplants. Donors don't pay for donation either. Additionally, organs are matched first according to clinical criteria such as blood type and size, followed by medical urgency and then time accrued on the waiting list.

My organs will be recovered then sold.

The buying and selling of organs and tissues is illegal, as part of The National Organ Transplant Act.

I am too old to be an organ donor.

No set age limit exists for organ donation. 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 sign a donor card and inform their family that they wish to donate.

I have a history of medical illness, you wouldn't want anything.

At the time of death, the OPO staff will review medical and social histories to determine suitability. Any active or spreading cancer and HIV/AIDS are among the few illnesses or conditions that might prevent someone from being a donor.

There are plenty of organ donors out there without me.

There are over 100,000 patients waiting nationally for life-saving organ transplants. In Connecticut alone there are over 1,000. Each year, over 2 million people die nationally... only 1% of that number will be suitable to be an organ donor; but only 50% of those families will say YES.

Only heart, liver and kidneys can be transplanted.

The pancreas, lungs, intestines, stomach and small bowel can all be transplanted, as can corneas, bone, ligaments, tendons, heart valves, saphenous veins and skin.

Transplantation is still experimental.

Transplantation has been a successful life-saving process for over 50 years. The success rate for a heart transplant patient is over 80%, and over 85% for a kidney recipient

Public Speaking Events

Introducing Yourself to the Audience

The way you introduce yourself will be the first impression on your audience. Whether you are talking to one person or one hundred people, the more confident you are in your few opening statements will set the tone for a successful conversation about donation.

When you are introduced as the speaker, it's best to make one simple request of your host/ hostess: Introduce you only by name. If you are introduced as "John Smith, a heart transplant recipient" or "Mary Jones, daughter of an organ and tissue donor" most of your story has already been told. Most of the folks in your audience will be aware of your topic prior to the program, but it's best for you to unfold your story, not the host.

The Introduction Basics:

Your Name and who you Volunteer with: First & Last Name. I am a volunteer with Donate Life Connecticut; a non profit organization that strives to educate the public about organ and tissue donation and assist them in registering as a donor.

Where You're From: Sometimes folks will feel an immediate connection to you are from the same or a nearby town.

What You Are Going To Tell Them: "I've been invited by your chapter president, Jim White to speak with you about the opportunity to become an organ and tissue donor and what you need to do to be sure your wishes are carried out."

Why You Are Telling Them This Information:

(Donor Family Member & Living Donors): "I am honored to share with you the story of my husband Bob". <Share your story> Close with something like "I am so proud of my husband, Bob and how he was able to save the lives of four people through organ donation and enhance the lives of many others through his tissue donation. I believe that through Bob's donation, my family and I have been able to heal knowing that others are living because of his decision to say YES to organ and tissue donation. I encourage you to become registered organ and tissue donors and register their wishes (at DMV or online) and tell their family. Thank the audience and host/hostess.

(Recipients):

"I am honored to share my experience of how through the generosity of someone else I am alive today by way of an organ transplant. <Share your story> Close with something like: "I am so thankful to my donor and his decision to save other's lives (like mine) when his/her life was cut short. I hope I can help you to make an educated decision to become a registered organ and tissue donor (through DMV or online registry)...as I am". Thank the audience and host/hostess.

Introducing The Topic of Organ & Tissue Donation

When you're talking about making the decision to become a designated organ and tissue donor, you are asking them to think about an unpleasant topic – death. But by bringing up the topic in a sensitive and appropriate way, the topic doesn't have to be one that makes anyone uncomfortable.

By making a decision (whether it be YES or NO), registering their wishes with their state's online registry and then making their decision known to their family members – if the opportunity to become an organ or tissue donor ever presents itself - their family will be more likely to say YES if they know what their wishes were and it will make the decision much easier on them during a time of great loss.

The key word in bringing up the topic is **OPPORTUNITY**. The opportunity is for someone to save the lives of others in the event a person is not expected to recover from an injury. However, each year over *2 million deaths are reported in the United States; of that number only ½ of 1% go on to be organ donors*. This is an extremely small number of organs available for the growing number of people waiting for a life-saving transplant nationally (over 102,000 on waiting list as of 08/2009).

Positive things we often here are –

- “I won’t need them when I die, why not be a donor.”
- “If I can help someone or many people, of course I’d say yes to being a donor.”

Even though people say those things, talking is different from **taking action** and many of them haven’t taken the steps to become a donor. In fact 29% of Americans polled in 2005 said they didn’t know what they had to do in order to be a donor!

We want to encourage them to take action by telling their family of their wishes and becoming a registered donor either on their state’s online registry or by having the designation put on their driver’s license or state ID card.

In Connecticut: there are two ways to register as an organ and tissue donor.

- Visit www.DonateLifeNewEngland.org and join the new, secure online registry
- At DMV, have their donor designation be put on their license and join the State Registry or fill out (and mail in) the DMV registry forms in our kits

Both registries are accessed by donor professionals at time of death. They are parallel, complimentary registries. It was simply too difficult to coordinate with the DMV to put the existing DMV registry online for access to the public – hence the second – N.E. Registry.

Calling For Questions

After your conversation, most often people won’t have any questions. It’s up to you to phrase questions in a way that will stir people into asking more questions. Use any of the Top 10 Questions about Donation below

If you ask a question, then give the answer – sometimes you’ll see a hand go up with statements about something they saw on television or heard from a friend. Most often, what people have seen on television is incorrect and it’s up to you to set them straight with the correct information. Here is a perfect place to ‘reward’ the audience member who participates with a give-away: Bracelet, key chain, etc.

The top questions & statements often asked are –

● **Can we still have an open casket funeral if my loved one is an organ donor?**

YES. The organ recovery surgery is no different than that of an autopsy, which presents no outward signs that the person even was a donor.

● **Does my religion support donation?**

YES. All major organized faiths support donation.

● **If I’m in an accident and they know I’m an organ donor, no one will try to save me.”**

This is not true. First of all, if you are in an accident the first people on the scene are the police. If you have the designation on your license, paramedics or EMS wouldn’t know as your identification would

be taken by the police in order to fill out the police report. Then your personal items are bagged and locked at the hospital. Secondly, the medical personnel are there to save your life at all cost – in fact, many patients cannot go on to be donors because the efforts to save their life were so intense, organs were damaged and not able to be used. Thirdly, the EMT/paramedics, the Emergency Department staff and the Transplant surgery staff are not related in any way, and Transplant staff would never be notified until it was ruled that your injury was non-recoverable. And finally, no doctor/surgeon in the world would risk your health in the *hopes* you could be a donor...not exactly the resume builder.

● **Will my family have to pay for me to be a donor?**

No. There is no cost to the donor or donor family.

By having the clear answers to questions or statements like these, you will be able to educate your audiences and therefore create awareness about the facts about organ and tissue donation. It is helpful to review your notes and educational tools prior to a presentation, so you are well prepared. And remember, if a question arises you do not know the answer. It is ok. Offer to learn the answer and pass along to them (via phone or email) or encourage them to contact Donate Life Connecticut for the answer.

Conclusions

Now that you've talked with your audience about the opportunity of becoming a donor, you now have to finish up and drive the message of taking action home.

Finishing up strong is really important! If you've kept your audience interested in the topic, you have to finish up with passion and purpose.

"What do you want the audience to take away from your presentation?"

You want the audience to be inspired by your words so that they will start a ripple effect. You've shared the information, now it's up to them to not only make a decision, but to also tell their family their wishes and become a designated donor but also to share this information with others.

You tell two friends.
Then they tell two friends.
Who then tell two friends.

By encouraging your listeners to talk with others – you're educating a lot of people through your conversation with just one or two people at a time.

Remember: VOCABULARY LESSON:

We use the word "RECOVER" **not** "HARVEST" when talking about organs and tissues.

We use the term "Mechanical or Artificial Support" **instead of** "LIFE SUPPORT".

More Public Speaking Tips

Did you know that the #1 fear of Americans is public speaking? It's true. By being prepared and confident you'll become more relaxed with each presentation that you do!

Some helpful tips:

- Keep in mind that your audience wants you to be successful. They are there to listen and learn.
- If you don't know an answer, be honest. You can't know absolutely everything. The best thing to do is to offer to find out the answer and get it back to them or provide them the phone/email of Donate Life Connecticut to have a professional answer their questions.
- Remember that you are there to share information, not to get into a debate. If you and someone in your audience don't quite see eye to eye, merely stick with the facts and move on to avoid any further disruption.
- Don't worry – if you leave something out, they'll never know. After all, you are the presenter. If there's something you forget to tell them, do it another time.

Use educational materials as a supplement to your presentation; *not* as the center of your speech. Donate Life Connecticut will provide you these materials and give-aways prior to your event. At table events, we encourage you to put out a guarded amount of smaller give-aways...and replenish your supply as the event goes on. Sometimes people get excited about getting something 'free' and forget to listen to the message we are trying to share with them. In a lecture setting, it is effective to 'reward' audience participation...toss a (soft) giveaway, like a bracelet, to an audience member who asks questions, answers your questions, shares a personal connection, etc. This too will encourage other more passive audience members to contribute – for a freebie!

Your audience wants you to be successful in your endeavors, and by firmly asking them to take action – they are more likely going to follow through.

Be educated. Be confident. Be successful.

About The Waiting List – What Statistics To Use and When...

The rule of thumb when it comes to statistics is to use **four or less**, mainly because people won't remember that stats you give them. The most important statistics to include in any conversation are –

National Waiting List
Local Waiting List
Number of Names Added Each Day
Number of Patients Who Die Each Day Waiting...

National Waiting List – The total number of people waiting in the USA: **MORE THAN 102,000**
(To provide a visual representation: the National Waiting List is LARGER than packing BOTH the Red Sox's Fenway Stadium AND the Yankee's New Stadium

Local Waiting List – The number of people waiting in Connecticut : **MORE THAN 1,000**

Each Day, **13 patients** are added to the National Waiting List

Each day **18 patients die** because the life-saving organ they need to survive is not available due to the organ shortage.