

# Advocate Support

Ontario Health (Trillium Gift of Life Network)  
Provincial Community Engagement Overview and  
Orientation Package



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## Thank You for Your Time!

### How to use this manual

We greatly appreciate you taking the time and energy to learn more about how to support organ and tissue donation and transplantation across Ontario. This package provides insight and information about the donation process and the many different ways you can get involved in local advocacy. This self-directed orientation covers clinical information, key messages and discussion points you can share with your community in person, online or with the media.

### Key Messages

- On average, there are 1,400 people in Ontario waiting for a life-saving organ transplant.
- Every three days, a person dies waiting for an organ transplant.
- 1 organ and tissue donor can save up to 8 lives and enrich as many as 75.
- Everyone has the potential to be an organ and/or tissue donor, regardless of age or health.
- Paper donor cards are no longer in use. Now your consent to donate is stored in a Ministry of Health database.
- The majority of religions support organ and tissue donation or respect an individual's choice.
- Organ and tissue donation should not affect funeral arrangements.
- Your donation decision is confidential and will not affect your medical care. Your donation decision will only be disclosed at the end of life.
- You can change or withdraw your consent to donate at any time.
- After you've registered, talk to your family about your decision to save lives.

### Where to Begin

How you decide to engage with your community is up to you! Whether you take on an activity as an individual or as part of a group, here are some ways to get started.

### TGLN Support

TGLN staff members are here to help you navigate the steps required to set up your own events or activities. From connecting with advocate groups in your area to ordering materials such as green ribbons, T-shirts, buttons and brochures, we have everything you need to get up and running. Please visit the community support page on our website at [giftoflife.on.ca/en/community.htm](http://giftoflife.on.ca/en/community.htm) for more online resources.

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## **Presentations & Publications**

Sharing your own story is an important part of creating awareness for organ and tissue donation. Personal narratives shared by brave donor families and grateful organ and tissue recipients are compelling and emotional. These touching and inspiring accounts impact audiences in a variety of settings, and inspire engaging and persuasive discussions about donation and transplantation.

TGLN has developed the **Advocate Storytelling Toolkit** specifically for organ and tissue donation advocates. This interactive workbook accompanies this orientation package and will help improve your writing skills for various platforms. We encourage all advocates to incorporate first-person narratives advocating for organ and tissue donation. Every story makes a big impact on increasing registration rates in your community.

## **Cultural Outreach**

Develop or expand relationships with faith and cultural groups in your area to increase awareness of organ and tissue donation. These connections are a great way to promote community dialogue around the importance of donor registration.

## **Youth Outreach & Education**

Connecting with secondary and post-secondary school students is instrumental to ensuring a future culture of donor consent in Ontario. Sharing the vital importance of organ and tissue donation and transplantation brings to life the life-saving and life-enhancing promise of the gift of life.

## **Registration Drives**

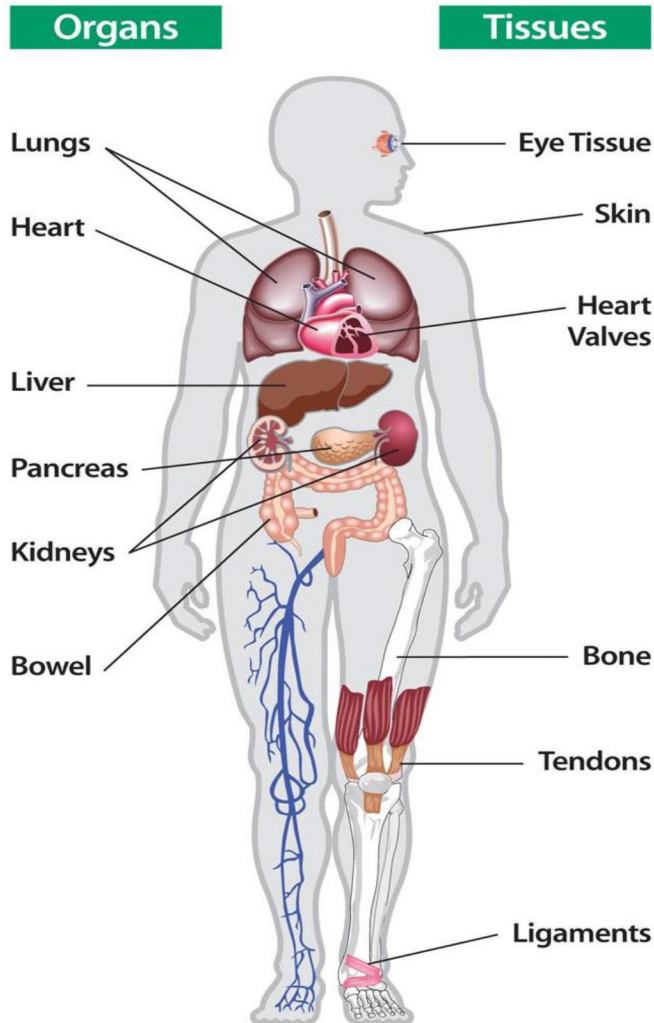
To encourage all Ontarians to register their consent to donate, we need your help! By starting an online registration drive, you can advocate for organ and tissue donation and share why registering is so important. You can either start an individual drive for your family and friends, or an organizational drive on behalf of a company or community group.

Create your own drive here: [beadonor.ca/auth/register](https://beadonor.ca/auth/register).

“ Love and compassion are necessities, not luxuries. Without them, humanity cannot survive. ”

- DALAI LAMA

## What can be donated?



### Organ Donation

#### Neurological Death (NDD)

- Heart
- Lungs
- Liver
- Pancreas/Islets
- Kidneys
- Small bowel

### Organ Donation

#### Donation after Cardiac Death (DCD)

- Kidneys
- Lungs
- Liver
- Pancreas

### Tissue Donation

#### In situations of organ donation with NDD, DCD as well as most deaths

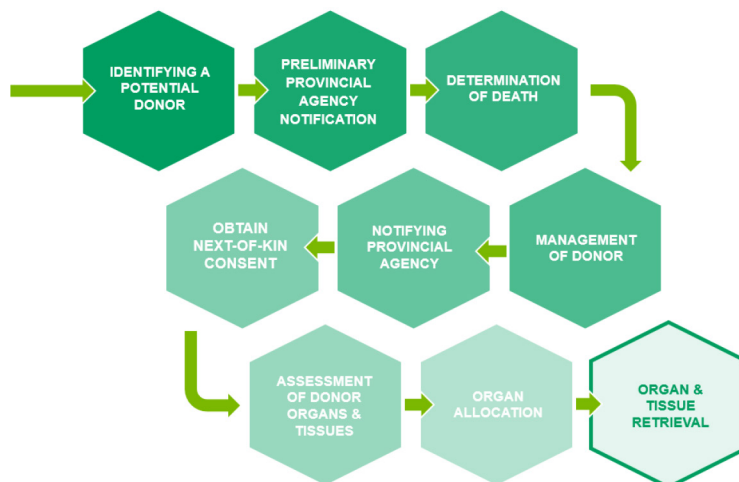
- Bone and tendons
- Eyes and Corneas
- Heart for valve recovery
- Skin

## Organ vs Tissue Donation

### Organ Donation is Rare

It is more likely that you or someone you know will actually need a transplant rather than become an organ donor. This is because only 2% - 3% of people who die in a hospital become eligible donors. Death must occur while the potential donor is on life support because ventilation of organs is crucial to their vitality.

## The Organ Donation Pathway



### How are Donations Allocated?

- ✓ Compatible blood type
  - ✓ Size match
  - ✓ Sickest patient
  - ✓ Longest waiting time
- ~~Race~~  
~~Gender~~  
~~Income~~  
~~Social Status~~

### Myths & Misconceptions

**Doctors won't work hard enough to save me.** A physician's first responsibility is to their patient's care. Donation does not become a medical option until all life-saving therapy has been exhausted. In the case of organ donation, two doctors are required to make a determination of death and the medical care team involved in donation is distinct from the team involved in your medical care.

**No one would want my organs - I'm too old. I'm too sick.** Everyone has the potential to be an organ and/or tissue donor, regardless of age or health. There are very few illnesses that rule out both organ and tissue donation.

**Asking a devastated family is cruel.** Although it's a decision that comes at a difficult time, most donor families take comfort in knowing something positive has come out of the loss of a loved one. This has helped them through their grieving process. Also, make sure to talk to your family after you've registered, about your decision to save lives.

**Transplants don't work.** Since 2003 over 22,000 Ontarians have received a life-saving transplant.

**I won't be able to have an open casket at my funeral.** We work closely with funeral directors who, through great skill and care, ensure an open casket is possible for families who request it.

**My religion is against organ donation.** Most religious groups support organ donation and/or respect the individual's choice. Beliefs about tissue donation vary as some groups may consider tissue donation life enhancing, separating it from organ donation which saves lives.

## Make it count!

### Why is registration important?

When not registered, only 50% of families consent to organ and tissue donation. That's why registering your decision is so important.

**Currently, only 35% of Ontarians have registered their donation decision.**

### Did you know?

**You can register online, in person at any ServiceOntario center or by mail even if you've signed a paper donor card!**

Paper donor cards are no longer used because the information is not recorded and may not be readily available when needed. When you formally register, your decision is captured and stored in a Ministry of Health database.

## Three Ways to Register!

Registering through one of the following channels is the only secure and guaranteed way to make your decision known.

### [beadonor.ca](http://beadonor.ca)

Web portal to online donor registry that is maintained by ServiceOntario.

### ServiceOntario

Public interface for provincial government transactions, i.e. health card and driver's license. You can register at both public and private ServiceOntario centres.

### Canada Post

Registrants can download and mail in a "Gift of Life Consent Form" [here](#).

“ Being an advocate has really given my life meaning since I am no longer able to work full time at a conventional job. I enjoy helping others through their transplant journeys, it gives me a sense of purpose and makes me really happy to be able to help others. ”

**Shillane Labbett, Kingston ON  
Double Lung Recipient  
Advocates in Action Award Winner, 2017**



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## Effective Platforms

### April is BeADonor Month

BeADonor Month occurs each April across Ontario. Every advocate, whether an individual or part of a group, has access to campaign materials to support TGLN's call to action to register. This is an exciting month with big results!

### Elected Officials

Encourage your Mayor, MPPs and MPs to get involved by sharing campaign information on social media, delivering advocate recognition in Members' Statement in the House of Commons or the Ontario Legislature, and participating in local flag raisings and making BeADonor Month proclamations.

### Local Businesses

Share organ and tissue donor registration information with your co-workers, vendors, customers, and other businesses. Encourage your team to host a workplace registration drive, or create a campaign page to share on your website, in newsletters and email signatures.

### Health Centres

Healthcare professionals play an important and unique role in organ and tissue donation. Invite a hospital representative to an event to share inspiring patient success stories and the impact on both donor and recipient families or arrange to visit a hospital to share your transplant story with the staff.

### Requesting Event Materials

Contact TGLN to order materials to support and enhance your events, such as green ribbons, pens, buttons, pins, T-shirts and signage. These items will be delivered straight to your door. To order TGLN materials download and complete the [Community Event Form](#). Once you have answered all of the questions on the form, please email it to Gracinda Varghese who will confirm your details and arrange for delivery of materials. If your event is public, we will post it on the Calendar of Events page on the TGLN website [here](#).