BECAUSE OF ONE

ONE DONOR. MANY LIVES.

NATIONAL ADVOCACY RESOURCES

Effective donation advocacy helps people understand their options and find trustworthy information. This guide explains the roles of national organizations and offers a practical framework for education, storytelling, public participation, and responsible use of statistics. The planning tools are suggestions you can adapt to your community.

Know which organization does what

Donate Life America

➔ Begin here for public education about organ, eye, and tissue donation, registry information, awareness materials, and personal stories. It is a useful starting point for someone learning the subject or planning a community conversation.

OrganDonor.gov and HRSA

➔ OrganDonor.gov offers federal public information about donation, registration, the donation process, and ways to get involved. HRSA also provides national transplant information and OPTN resources. Use federal pages for official explanations rather than relying on unattributed social media summaries.

Organ Procurement and Transplantation Network

➔ The OPTN connects the national donation and transplantation system through policies, data, and other functions. Its patient resources explain subjects such as organ allocation and transplantation. Policy information is different from a general awareness campaign and may require careful reading.

United Network for Organ Sharing

➔ UNOS publishes donation and transplant education, research and system information, and advocacy positions. When using a UNOS policy statement, identify it as that organization's position. An advocacy recommendation is not automatically a current legal requirement or an adopted OPTN policy.

Local organ procurement organizations

➔ An OPO coordinates aspects of deceased donation in its service area and may offer local education and volunteer opportunities. HRSA's OPO directory helps connect national information with a local organization. Ask about the right route for your location and purpose.

Read more: Donate Life America FAQ | OrganDonor.gov | OPTN patient resources | UNOS transplant education | HRSA find an OPO

Choose a useful advocacy goal

Start with a concrete question: What should someone understand or be able to do after this activity? “Understand the difference between living donation and registration” is more useful than an undefined goal to “raise awareness.” A narrow goal makes it easier to choose material and evaluate whether the activity helped.

Public education

Explain donation in plain language, invite questions, and offer appropriate source links. A class discussion, workplace learning session, resource table, or short online post can all work. Match the amount of information to the audience’s time and familiarity.

Family conversations

Offer prompts that help people discuss wishes without requiring an immediate decision. Make room for uncertainty and different beliefs. A useful outcome may be that someone identifies questions to explore with a registry or professional.

Volunteer participation

Use a recognized organization’s current application or inquiry route. Ask about training, time commitments, supervision, accessibility, and boundaries. Do not describe an opening as available until the organization confirms it.

Policy participation

Read the issue, distinguish a proposal from an adopted policy, and use the designated public input process when available. Public education, personal storytelling, and asking for a specific policy change are related but different activities. Be clear about which one you are doing.

Match the resource to the job

For a basic donation question, start with Donate Life America or OrganDonor.gov. For an allocation question, use OPTN patient guidance and policy resources. For training or a presentation, contact an OPO or education organization. For an individual patient’s care, contact the responsible clinical team.

A respectful opening

A useful invitation is: “We are sharing information so people can make informed decisions and talk with their families.” Avoid suggesting that someone must register to participate in an event, share a story, or ask a question. Give visitors a way to take information away and consider it privately.

Read more: Donate Life America involvement | HRSA get involved | HRSA find an OPO

Plan a community activity

Before the activity

- ➔ Define your audience and one learning goal. Choose a format, location, length, and host. Select two or three reliable resources and verify the links. Ask a knowledgeable partner to review technical material or speak. Check permissions for any borrowed photographs, logos, printed materials, or stories.

- ➔ Prepare a short opening, the main explanation, a few common questions, and an honest response for questions you cannot answer. Make a clear plan for referring medical, registry, or policy questions to the appropriate organization. Arrange for large-print or accessible digital material when needed.

During the activity

- ➔ Introduce yourself accurately and explain your connection to the issue. Distinguish personal experience from general guidance. Use everyday examples without presenting invented experiences as real recipient stories. Let people decide whether they want to discuss donation, take a resource, or move on.

- ➔ Provide official registration links. Visitors should enter identifying details directly into the official service using their own device or a registration setup approved by the responsible organization. An awareness event does not need to maintain a separate list of donor identities to be useful.

After the activity

- ➔ Send promised resources through the channel participants agreed to use. Correct any error you discover. Write down unanswered questions for professional follow-up. Ask what was clear, what remained confusing, and whether the format was accessible.

Measure what actually happened

You can count sessions held, materials distributed, questions answered, or people who chose to receive follow-up. Label these as activity measures. A link click is not proof of registration; registration is not proof of eventual donation; an education event is not evidence that a particular transplant occurred because of it.

A simple event worksheet

Record the audience, goal, date, organizer, expert contact, resources, permissions, accessibility arrangements, questions for follow-up, and the measure you will report. Keep personal health information out of an event-planning sheet.

Read more: Donate Life America educational materials | HRSA get involved | HRSA find an OPO

Take part in national policy conversations

OPTN public comment is a route for input on policy and bylaw proposals. The official page explains the process and provides proposal links. Check current opening and closing dates rather than assuming an older opportunity is still active. Public comments may be published.

Prepare a useful comment

1. Identify the exact proposal and read its explanation and questions.
2. Describe your perspective accurately: patient, family member, donor, advocate, or professional.
3. State the issue you want the committee to consider.
4. Separate your personal experience from evidence about the wider system.
5. Explain a possible effect on patients, families, access, clarity, or safety.
6. Offer a specific question or suggested improvement if you have one.
7. Remove identifying health information about other people before submitting.

A clear, specific comment is more useful than repeating a slogan. You do not need to speak for every donor or recipient. If you do not understand a proposal, ask for explanatory material before taking a position.

Read advocacy positions carefully

UNOS publishes advocacy priorities and supporting material. Review the date and whether a page describes a recommendation, proposed legislation, or a completed action. If you share an organization's position, link to its explanation and make clear whose position it is.

OPTN volunteer opportunities are another route for participation. Application periods, vacancies, eligibility, and selection processes can change. Use the current official volunteer page and review the commitment before applying; listing the route does not imply that applications are open at all times.

Safety concerns need the right channel

A public policy comment is not a substitute for immediate clinical communication. Questions about a hospitalized patient's care should go to the treating team. Ask the hospital or relevant organization about its formal concern or complaint process if an issue remains unresolved.

Read more: OPTN public comment | UNOS advocacy | OPTN volunteer information | OPTN patient resources

Use evidence and statistics responsibly

Identify what a figure measures before sharing it. A snapshot of people waiting, the number of transplant procedures in a year, donor registration records, and recipients helped are different measures. Always include the source, geography, and date or reporting period. Avoid mixing numbers from different years to create a single claim.

Read caveats. Counts may reflect people, registrations, procedures, or organs rather than the same unit. A chart about solid organ transplants does not automatically describe tissue transplantation. A potential-impact estimate describes what donation can make possible; it is not a guarantee for every donor.

When sources differ, check their update dates and definitions. Choose the current source that directly supports the claim you need, and explain differences when they matter. Do not average conflicting figures simply to produce a new number.

Tell stories with care

Obtain permission for the text, name, images, and channel of publication. Give the person an opportunity to review what will be shared. Explain whether a story will be edited and how someone can raise a concern later. A person's willingness to speak at one event does not automatically authorize every future use.

National resource directory

Read more: Donate Life America educational materials | Donate Life America involvement | OrganDonor.gov | HRSA national statistics | OPTN patient resources | OPTN public comment | OPTN volunteer information | UNOS transplant education | UNOS advocacy | HRSA find an OPO | National Donate Life Registry

Your next steps

Choose one manageable action: complete an introductory training, ask a local OPO about volunteering, share a sourced educational explanation, or read an OPTN proposal. Record the action and the question it should answer. Build familiarity before expanding your role, and keep a reliable referral route for questions outside your knowledge.

Reviewed October 21, 2026. External organizations have their own programs and requirements; links do not imply affiliation. General education does not replace individual medical guidance.

One donor. Countless lives.