

Illinois Donor Consent for Organ/Tissue Donation: The Basics and Background

- On Jan. 1, 2006, Illinois became the 43rd state to honor an individual's legally binding decision to become an organ and tissue donor. This is known as first-person consent for organ and tissue donation, or *donor consent*.
- Today, an individual who registers in the state's new donor consent registry is registering his or her legal decision to becoming an organ and tissue donor after death. Additional witnesses, signatures or decisions from the donor's next-of-kin will not be required to honor those wishes, nor will next-of-kin be able to override the donor's documented decision to become a donor.
- Illinoisans who enrolled in Illinois' former registry (before Jan. 1, 2006) must re-register in the new donor consent registry to make sure their wishes are honored.
- The concept behind donor consent is the same as that of a living will—that an individual who legally documents a personal end-of-life decision will have that decision honored.
- Among those that have worked in support of Donor Consent in Illinois are the Illinois Hospital Association, the Illinois State Medical Society, the Illinois Nurses Association, the Illinois Department of Public Health, Gift of Hope Organ & Tissue Donor Network, Mid-America Transplant Services, the Illinois Eye-Bank, the Musculoskeletal Transplant Foundation and officials from each of Illinois' eight organ transplant centers.
- The more quickly that Illinoisans register in the state's new donor consent registry, the sooner we will be able to save lives as a direct result of this important new law.
- To register to be an organ and tissue donor in Illinois, and learn more about the donation process, go to www.giftofhope.org." You may also register by visiting www.lifegoeson.com, enrolling when you visit any Illinois Secretary of State driver's services facility, or calling 800/210-2106. The new registry is managed by the office of Illinois Secretary of State Jesse White.
- Illinois' donor consent law was passed for two reasons. First, it will help save more lives through organ donation and transplantation. Second, it is a matter of public trust assuring millions of Illinoisans who enroll in the state organ/tissue donor registry that their clearly documented wishes to donate will be honored and will not be overridden.
- Until now, approximately 19% of Illinoisans who enrolled in the state donor registry had their intent to donate overruled by family members. As a result, the individual's wishes to donate were not honored, and opportunities to save lives through transplantation have been lost.
- Based on this data, Illinois new donor consent registry is expected to result in a 10% increase in organ donation, or approximately 100 more organs donated for transplant each year.
- This will make a significant impact in saving lives: Each year, more than 300 people in Illinois die while waiting for a donated organ that never becomes available. Currently, more than 4,700 patients in Illinois and 98,000 across the country are waiting for lifesaving organ transplants.

Illinois Donor Consent for Organ/Tissue Donation: Frequently Asked Questions

- Q: *If I signed up as a donor last year, do I need to re-register in the new donor consent registry?*
Yes. Individuals who are enrolled in Illinois' old donor registry (before Jan. 1, 2006) will not be automatically moved to the new donor consent registry.
- Q: *When I join the new donor registry, will my driver's license look different?*
A: Yes. The word "Donor" will still appear on the front, but there will be no donation information on the back of the driver's license or state ID card.
- Q: *Does Illinois' new law apply to a person who does not enroll in the state registry but has a signed license or another signed document indicating consent to donate?*
A: Yes. However, the document must be signed and dated after Jan. 1, 2006. We also must be able to locate the document in the short timeframe available to coordinate a donation after the donor's death. To ensure your decision to donate is carried out, it is best to register in the Illinois Donor Consent Registry. It is also recommended that you inform family members, so they know what to expect.
- Q: *When I become a donor, how will my family be involved?*
If you are evaluated to be medically eligible to donate at the time of your death, coordinators with Gift of Hope will come to the hospital to talk with your doctors and meet with your family. We will review an affidavit of your donor registration, explain the donation process, answer questions and provide additional support that your family may need. We will ask for current medical information about you, called a medical/social history, which helps us determine which organs and tissues may be transplanted.
During this time, we will also offer to provide your family with follow-up information after the donation, such as general information about the recipients you have helped. Your family can take advantage of our ongoing programs and services for families of donors for as long as they wish. This support that we provide for families has not changed. We are here for families during and after donation regardless of whether consent is given by the donor or by the family.
- Q: *What is an affidavit? What does it say?*
An affidavit is a statement in writing that is sworn to before a notary public or other officer. The affidavit of donor consent in Illinois reads as follows:
Upon review of the records of the Office of the Illinois Secretary of State, it is hereby confirmed that the person identified below has registered as an organ and tissue donor on the Secretary of State's new First-Person Consent Organ and Tissue Donor Registry. Pursuant to Section 5-20(b-1) of the Illinois Anatomical Gift Act, "An individual's consent to have his or her name included in the First-Person Consent Organ/Tissue Donor Registry constitutes full legal authority for the donation of any of his or her organs or tissue." 755 ILCS 50/5-20(b-1).
- Q: *Is the registry a "yes/no registry"?*
A: No. Like a bone marrow donor registry, it is an opt-in registry of those individuals who give their consent to becoming donors. An organ/tissue donor registry by its nature and purpose does not register individuals who are not organ/tissue donors.
- Q: *What if someone joins the registry and later changes his or her mind?*
A: He or she can contact the Illinois Secretary of State's office via phone, the Internet or mail to request removal from the registry.

**Illinois Donor Consent for Organ/Tissue Donation:
Frequently Asked Questions (*cont'd*)**



- Q: *Can someone from outside Illinois, such as a college student from another state, sign up in our donor consent registry?*
- A: Only if they have an Illinois driver's license or state ID. Most other states—including Indiana and Iowa—also have donor registries, so out-of-state residents are strongly encouraged to register in their states. If an out-of-state resident dies in Illinois, we will check to see whether the patient is registered as a donor in his or her own state. If so, we will honor that donor consent decision in Illinois.
- Q: *When I register, can I designate which organs and tissue I want to donate?*
- A: When you register in the Illinois donor consent registry, you register to donate all eligible organs and tissues. Organs that can be donated are the liver, heart, lungs, kidneys, pancreas and small intestine. Corneas, bone, saphenous veins, heart valves and skin are tissues that can be donated. The organs and tissues that you are medically eligible to donate cannot be determined until the time of your death. Individuals who wish to donate only specific organs or tissues must inform family members of those wishes, and Gift of Hope will carry out donation through the family consent process rather than donor consent registry. Whether your donation takes place upon your consent through the registry or through your family's consent, we will confirm with family members the organs and tissues that you are eligible to donate. We will provide your family with information on the people who have been helped through your donation, unless your family asks not to receive this information.
- Q: *What happens if my family is opposed to my decision to donate?*
- A: Donor consent laws are established to honor your legal end-of-life decision, and to clearly document an individual's wishes when family members may be unaware or have differing opinions. We encourage you to inform family members of your decision to donate, so that it is not a surprise to them at the time of your death. Our coordinators are carefully trained to work with families experiencing a wide range of emotions at the time of a loved one's loss, and will delicately work through any questions and concerns your family may have. It is never our intent to compound a family's grief or cause additional stress at such a difficult time. In the end, however, we are bound by the law and the decision you have made. The experience of the many other states that honor donor consent shows that over the years, only a small handful of families have opposed donation after learning of their loved one's decision and having their questions and concerns answered.
- Q: *Where can I find out more about organ and tissue donation, and how it works?*
- A: Contact Gift of Hope Organ & Tissue Donor Network at 888/307-3668 or visit www.giftofhope.org. Gift of Hope is the federally designated not-for-profit organ procurement organization that coordinates organ and tissue donation in the northern three-quarters of Illinois and northwest Indiana. Our role is to coordinate the donation process, educate medical professionals on all aspects of donation, and provide support for families of donors.
- Q: *I've heard about donating for research. When I register as an organ and tissue donor, does this mean I will donate for research, too?*
- A: No, unless your family gives consent in the event that organs and tissues recovered for transplant cannot be transplanted, after all. When you register as an organ and tissue donor, you are registering your consent to donate only for transplant. Only organs and tissue that are medically eligible for transplant are recovered. Occasionally, however, these donations cannot be transplanted due to unforeseen circumstances that arise. For example, the intended recipient may be suddenly unable to undergo surgery, or further medical testing reveals a condition that prevents safe transplantation. We will ask your family whether they wish to provide these donated organs and tissues for medical research purposes should this situation take place.
- Q: *If a durable power of attorney or living will states a decision to not donate, will donation be pursued?*
- A: No, unless the individual registered consent to donate in the Illinois donor consent registry at a later date.