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*One organ and tissue donor can save or enhances the lives of about 25 people. Still, donation is a morbid topic that many people avoid, but experts say it is vital to express your preferences to loved ones and to formally register for donation, should that be your wish.*

### **Make your wishes known: The discomfoting gift that needs to be discussed**

by GINA MORGANO

Aug 27, 2009

John Lefferts, who grew up near Springfield, made it possible for two people in Missouri to restore their eyesight.

“One military sergeant, he sent us a very nice email saying that he had a knee rebuilt because of John and he could now walk without pain,” said Larry Lefferts, John’s father. The man said he “would always remember John, and that’s pretty comforting.”

Larry and his wife, Vivian, lived their greatest nightmare five years ago.

Their 22-year-old son, John, hadn’t been feeling well for about 24 hours. So, they took him to a doctor that very morning.

Everything seemed fine.

Hours later, John was dead.

He died from an aortic dissecting aneurysm, a very rare condition that describes a tear in the wall of the aorta, the body's main artery.

As soon as the Lefferts, now residents of Normal, received affirmation of John's death, Larry told the nurse that the family wanted to donate all viable parts of John's body. "I'm sure they would have asked us," Vivian said, but Larry didn't give them the chance to ask us. He made the offer as soon as John passed."

The Lefferts were confident that this is what their son would have wanted. "He would do anything for friend," Vivian said. "Anything he could do to help people."

But so many families are less sure of loved ones' wishes. Consequently, they are forced to guess during a time that is overwhelming, exhausting and tragic.

Organ and tissue donation can be a morbid subject, for death is not a topic people enjoy thinking about or discussing. This lack of attention has given donation a cloud of fear, mystery and erroneous assumptions.

John's organs couldn't be used because a torn aorta disrupts blood flow to organs and his heart had been stopped for too long. But his bones and tissue have helped more than 35 people since his death.

Currently, more than 100,000 Americans are waiting for an organ transplant. About 18 people on the list die each day, according to Gift of Hope, the organ and tissue donor network serving most of Illinois and the northeastern corner of Indiana.

Michael Abecassis, chief of transplantation at Northwestern Memorial Hospital, said that, in his experience, 30 to 40 percent of patients die waiting. "There obviously needs to be more of an awareness about the desperate need for organs," he said. "I think one misconception is that there's no organ shortage."

Sixty percent of Illinois adults are registered as organ and tissue donors, according to Donate Life Illinois, a state coalition of donation-related agencies. Nationwide, only 38 percent of adults are registered.

But that still means that plenty of people in Illinois are not registered. For those who have not signed-up, final decisions will be left to loved ones.

Prior to 2007, registration demonstrated the intent to donate, but family members still had the final say. People who signed-up before then must join the new registry to make their wishes legally binding. Those unsure registration status, can simply re-register and the system will check for duplicates, said Joslyn Osten, senior public education coordinator at Gift of Hope.

Experts hope the public will seek education on donation, thinking through preferences and sharing those with family members. This takes the burden of decision away from loved ones and makes an excruciating experience just a little bit easier.

After all, "you never know what will happen," Osten said.

Due to the cause of his death, John wasn't able to be an organ donor, but he was able to be a bone and tissue donor. Under Illinois law, people cannot pick and choose what they would like to donate, they must consent to both organ and tissue donation or choose not to give their consent at all.

John's donation has helped more than 35 people, according to the Lefferts. "We've got a long list, and a lot of it doesn't mean much to me," said Larry. "It doesn't really matter." The Lefferts said they are just happy that people have been helped by their donation.

While people are aware of organ donation, people are often less aware of the importance of tissue donation.

“Skin transplantation is most definitely a life saver for burn victims,” Larry said.

Even if injuries are not explicitly life threatening, Vivian said tissue donation could still be life saving. For instance, she shared the story of a woman who “was near suicidal and got a double ankle transplant. And that really did save her life.”

A single organ and tissue donor typically saves or enhances the lives of about 25 people, according to Gift of Hope. The organization emphasizes that people shouldn't rule themselves out as donors and can let doctors help them make the determination of their suitability.

“We're out on college campuses and they're like 'I drank too much – you wouldn't want my organs,’” said Osten. “Well maybe your liver's not up to par, but what about your pancreas or your heart?” Similarly, she said people frequently think old age or a having a chronic medical condition makes them ineligible. In reality, even people who have received a transplant may be a candidate for donation, so Osten said people should sign-up if interested.

Organ donation is possible in only two instances – brain death or death due to cardiac arrest.

“The most frequent concern is (if) I were to be registered, the doctors won't work as hard to save my life,” Osten said.

Contrary to popular belief, that is not true. “The emergency and trauma doctors are there to save your life,” Osten said. “They don't have time to check your license or anything. There's a completely different team of doctors that do the organ procurement, and they don't even know about the person until the person is declared dead.”

Religion and funeral arrangements are another huge area of concern.

Christopher Floss was a Catholic priest for two years before he left the priesthood to marry. Looking for a new occupation that would utilize his training in ministry and public service, Floss became a Family Support Services Coordinator at Gift of Hope, a position he has now held for about two years. It is Floss's job to discuss the options with families of potential donors.

“Most mainstream religions have no objections to donation, but sometimes individuals' interpretations influence their decision to donate,” he said.

For example, Orthodox Jewish followers are often concerned because of the timeframe. Organ donation typically means that a person will remain in the hospital for an additional 24 to 36 hours, while the Orthodox Jewish religion requires that an individual be buried within 24 hours of death.

“We will do our best to expedite the process if time is an issue,” Floss said. “Even if that means that we are not able to procure as many organs as we normally would if time were not an issue.”

Having an open casket is another common cause of distress. But organ donation does not interfere with this at all. “You wouldn't know that the person was an organ donor unless you were told that they were an organ donor,” Osten said.

She added that families should share their funeral arrangements and religious concerns with their requester. Religious concerns can almost always be accommodated and alleviated.

Since Floss doesn't claim to be an expert in every religion, he said he is happy to involve the hospital chaplain or outside clergy to help family's better understand their religion's official position.

Floss said he speaks with six or seven families every week throughout the Chicagoland area and estimates that 80 to 90 percent of them eventually consent to donation. Statewide, however, 52 percent of families give consent after conversations with requesters.

“Some people react very positively and are able to think through the tragedy that they’re experiencing,” Floss said. “Others want the thing to be done and don’t want to make another decision.”

So Floss said he tries to emphasize the good that can come from donation. “I realize that their sacrifice of time is a huge sacrifice,” he said. But “Their sacrifice of 24-36 hours could help someone else’s life.”

Floss said he encourages people to sign up in the state registry and to make their wishes known to their loved ones. This takes the pressure off of the next of kin. “If (people) know their loved one wanted to do it, they are most all of the time in support of it,” he said. “Organ and tissue donation is just an outstanding gift, and I think the more we can help people to understand that, the more successful we will be in helping all families consent to donation.”

The Lefferts originally got involved with Gift of Hope because it was an opportunity to talk about their son. “I thought almost immediately, how are people in my life going to know about John?” Vivian said.

Through their involvement with Gift of Hope, John’s legacy survives. “In that way he goes on,” Vivian said. “They won’t forget him. At least we know that he’s out there and he’s still doing some good.”

While some people choose to donate and then maintain their privacy, the Lefferts have found tremendous support in the donor community.

“If it was breast cancer, there’s a structure for that,” said Vivian. “With children, it could be St. Jude’s. But for an aortic aneurysm with young adults, what is there?”

The benefit to a recipient of donation is obvious, but Larry said there is “kind of a hidden benefit to the donor family – you have a gut-wrenching, awful tragedy, but something good came from it.”

While the Lefferts said they will never “heal from this completely,” being involved in the donor community has been their therapy.

“It’s a huge help in getting up in the morning and putting one in front of the other,” Larry said.

The Lefferts knew they made the right decision for John, but they soon discovered tangible evidence. “We cleaned out his apartment,” Vivian said. “There was a Gift of Hope bumper sticker.”

The Lefferts now regularly give presentations on donation to groups, sharing their son’s story and education people as much as possible. They said Gift of Hope has many speakers available to the public, and people should contact the organization if they’re interested in a presentation.

“Talk to other people if that’s possible,” Vivian said. “If you have any questions, seek out the answers to those questions.”

*Gina Morgano/MEDILL*

*Three years ago, Michelle Minkoff received a living-donor kidney transplant from her aunt. Minkoff and her parents said they were incredibly fortunate to have found a donor so quickly.*

## Related Links

[Illinois Donor Registry](#) [Find out how to be a donor in your state](#) [Gift of Hope](#) [Donate Life Illinois](#)

### Kidney donor wanted to help a stranger

Amanda Gedraitis, 25, of Bloomington, donated one of her kidneys.

But it wasn't given to a family member or a close friend. It didn't even go to an acquaintance.

No one Gedraitis knew needed a kidney, but she decided to donate one anyway.

When she was 19 years old, Gedraitis stumbled upon "living donation" online and the idea intrigued her. She started doing research and kept it in the back of her mind as something she might be interested in doing in the future. "When I was 21, I finally figured now was as good a time as any," she said.

Gedraitis had great health benefits and the ability to take time off from her job. She said the timing just felt right.

So she called Northwestern Memorial Hospital's transplantation coordinator and started filling out the necessary paperwork.

"It takes a while," Gedraitis said. They did a family history, chest X-ray, CT scan, blood work, urine analyses, and tissue typing. In addition to meeting with doctors, she was required to meet with a psychiatrist. Then she had to wait two more weeks before she was allowed to schedule the surgery.

"Being as young as I was, even the docs at NU were kind of hesitant to let me go through with an anonymous donation of the kidney," Gedraitis said. While they consented, her parents opposed the whole idea.

"They were 110 percent against it," she said. "For a while they kind of sabotaged every effort I made. They would throw away paperwork. They would cancel appointments. My mom called and threatened my surgeon. Nobody would take me to the hospital on the day of surgery - I had to take the train there. I took the El and walked. They wouldn't talk to me about it."

But when Gedraitis finally woke up from surgery, her family was by her side, "angry and happy at the same time," she said. "As soon as they knew I was okay after surgery, they were okay with what I did."

Gedraitis said she couldn't have had a more positive experience. She felt good as new in a week and was back to work in two.

Recently Gedraitis's brother went through with testing for a possible donation of his own. "My mom was like, 'Oh, God, not another one,'" she said.

Gedraitis has no regrets and said her experience has made her believe in donation even more. Though her donation was supposed to be anonymous, her nurse accidentally mentioned the recipient's name. About five days after surgery, Gedraitis was sitting in a hospital waiting room for her post-operation check-up.

There was one woman who caught Gedraitis's attention. "Did you have surgery on Friday?" Gedraitis asked. "Did you maybe get a kidney? She looked at me with a blank stare, and it occurred to her mom who I was. And she burst into tears - 'It was you, it was you!'"

When people ask her why she did it, she says she couldn't imagine how she would feel if it was one of her family members who was in need of an organ. "I felt like it was the right thing for me to do from the very beginning," she said.