

Medill



Tiffany Sharples/Medill

Debbie DeVito admires a picture of her son, Marco. At age 13 he was killed while riding his bicycle, and she chose to donate his organs.

Part 3 of 4: Organ donation brings solace in times of tragedy

by [Tiffany Sharples](#)

May 23, 2007

When the ringing phone woke Julie Bieneman and her husband Ed in the wee hours of the morning on their 16th anniversary, she was convinced it was a crank caller. Three times the person called, yet twice she could hear no one on the end of the line.

The third time, she recognized the voice. It belonged to her transplant coordinator. “How would you like to come to the hospital in the morning?” Julie remembered her asking.

Suffering from diabetes and already on dialysis for six months, Julie was on a waiting list for a kidney. She understood what the phone call could mean. Still, she had to ask the obvious: “What for?”

“We have a donor,” the coordinator said.

Julie turned to her husband. “You don’t have to buy me an anniversary gift now,” she said. “I don’t think you could outdo this one.”

In Illinois in 2006, there were more than 1,300 transplants of donated organs, nearly 400 more than just 10 years ago. Yet there are currently 4,700 Illinois residents waiting for transplants, and more than 96,000 nationwide, according to data from the Organ Procurement and Transplantation Network. And last year alone, 327 people died in Illinois, and 6,805 died nationally while waiting for transplants.

A meager 2 percent of all registered donors are ultimately eligible to give their organs. (To be eligible donors have to die in a controlled environment to sustain their organs long enough for transplant.) And due to disease and other factors, including family members’ disapproval, of that 2 percent only one quarter actually go through with the donations.

The small numbers prompted Illinois legislators to change the law to ensure individuals’ wishes aren’t overturned by loved ones in their moment of strife.

The third in a four-part series, this article considers organ donation and the lives it affects. The series began with an analysis of the use of cadavers in anatomy classrooms, followed by a story on full body donation, and will continue tomorrow with an examination of the stances taken by major religions on the practice of donating your body to science.

As of January 2006, the decision to donate organs no longer has to rest upon the shoulders of grieving family members. That’s what the “I am. Are you?” posters dotted throughout Chicago are about — getting people to re-register for donation.

Illinoisans ages 18 and older can sign up by visiting the state registry's Web site, clicking on "register today" and filling out their driver's license numbers and other contact information. Alternatively, they can call the secretary of state's office to register. Right now 40 percent of adults in Illinois are not registered donors.

"Many Illinoisans still do not realize that signing the back of your license is no longer adequate, and you need to re-register... to ensure your decision to be a donor will be carried out," said Scott Meis, a spokesman for Donate Life Illinois, which is running the ad campaign.

The transition to first-person consent was made because in 20 percent of cases loved ones overrode the intention of the deceased because they were grieving and in shock.

That's the exact situation that Debbie DeVito faced in 1992. "My father died suddenly and I didn't know about donation then," she said. "I was hysterical and I said no."

Thirteen years later, DeVito found herself facing the question again. On February 21, 2005, the older of her two sons, Marco, was riding his bike to a friend's house when he was hit by a car in a dangerous intersection and fatally injured. DeVito remembers receiving the call from the chaplain at Lutheran General Hospital in Park Ridge.

"I fell to my knees," she said. Marco was 13-years-old.

"We were told that Marco would no longer be with us, and then we were approached by Gift of Hope to see if we would consider donating his organs, and we decided to do so," she said. "Marco would have wanted that."

Gift of Hope Organ and Tissue Donor Network is one of the nation's 58 organ procurement agencies, which work with donor families and recipients. These groups communicate with one another, matching donors and recipients across the country. Because so few people die in conditions that would make them eligible to donate, these agencies are informed of all deaths in controlled environments.

Asked to explain the controlled environment in layman's terms, Dave Bosch, a spokesman for Gift of Hope, said, "We need someone to be brain dead and on a ventilator."

Upon learning of a death that meets this requirement, representatives of Gift of Hope communicate with hospital staff to determine if the person is medically eligible to donate — free from certain communicable diseases, for example.

If the donor is eligible, a representative of Gift of Hope will then approach the family. For those who are registered, this is to offer support and explain the process, as well as review the donor's affidavit.

“If a person’s not in the registry, we will ask the family and they can consent to donation,” said Bosch.

Once people decide to donate, a thorough medical history is requested from the family and the physicians, before the match-finding process begins. Organs each have a limit to how long they can survive — the heart’s is the shortest at just six hours — so this process takes place very quickly.

Debbie DeVito still remembers the compassion she saw in the eyes of the representative who approached her after her son’s death. “It takes a special person,” she said. “You have to be there for them.”

Wanting to participate however she could, DeVito offered to volunteer for Gift of Hope following her son’s death. In January of this year she began working for the organization full time.

"I had to find my lesson in this," she said. "It’s to help other people." She believes that donating her son’s organs, and saving the lives of five recipients, enabled her to find some solace in this tragedy.

“It was part of my healing to know that my son did not leave without making his profound impact upon this world,” she said.

DeVito said she never had any concerns that her son would not get the best treatment if they decided to donate.

Bosch said for some people those concerns come up, but that there is no legal basis for them. “The medical team that attends to you when you go into a hospital, by law, cannot be the same people who ultimately recover organs for transplant. A transplant doctor cannot declare you dead.”

“The simpler explanation?” he said. “There’s no logic [to the idea that] a physician is not going to save the life of a patient to save the life of another patient they don’t even know.” In fact, Bosch suggested that if anything, physicians struggle, as families do, to take solace in the positive outcome of donating organs from a patient who didn’t survive.

Debbie DeVito said she now understands both sides of the issue. "Some people are very frightened about organ donation, but if their loved one is waiting for an organ, their attitude will change."

When Anne Gulotta’s two children were getting old enough for driver’s licenses, she and her husband Jay had a conversation with them about signing up for organ donation. The whole family agreed that they wanted to donate, if and when the moment came.

On May 8, 2002, it did. Anne wasn’t home when her two children heard a loud noise.

“My son ran up to the attic, he yelled to his dad, but he didn’t answer,” she said. “When he got close, he saw that he had shot himself.”

They lived less than a mile from the Good Shepherd Hospital in Barrington, so her husband was quickly taken in for care. When Gulotta arrived, she was ushered into the chapel.

“If you’re brought there, you know the news isn’t good,” she said. They informed her and her children that her husband would not survive.

When later she was approached by a representative of Gift of Hope, she was grateful that they’d already made the decision as a family.

“When you’re in the middle of a trauma and people are approaching you, asking you questions, if you’re not prepared the chance is you’re going to say no,” she said. “We were prepared.”

Once someone has donated organs, Gift of Hope then gives both the recipient and the person’s loved ones the option to request more information about each other. Either party has the right to decline, if they choose. Shortly after her husband’s death, Gulotta was told that his organs had gone to several people, including a 55-year-old man, a 42-year-old woman and a 16-year-old girl.

“A couple of months after Jay’s passing I received, through the Gift of Hope, information about the recipients. A few months later I got a thank you note and a condolence card,” Gulotta said.

The card and thank you note were from the woman who had been given Jay’s left kidney. Her name was Julie Bieneman, and she lived in the small town of Havana, Illinois.

Bieneman remembers the first time that Anne Gulotta called her. “I think I was in shock for the first few minutes,” she said. “I thought, here I am, a living example of her husband, yet her husband died for me to live.”

Months later, the two women met in person for the first time. “It was truly a homecoming in some senses,” Gulotta said. “I just remember running from the car and hugging her. She showed me the scar and she put her hand over her left side, her left kidney.”

Julie remembers that moment too. “That was the best thing at that point that I thought I could do for her,” she said. “That gave her a sense that a part of Jay is still alive.”

Now, Anne Gulotta speaks publicly about organ donation. Last year she and Julie Bieneman planted a tree in honor of her husband.

“Nothing is closer to my heart than meeting Julie. She is a testimony that Jay lives on,” she said.

“I may never know why Jay took his own life, but knowing that others live gives me great comfort,” she said. “I think [my kids] look at their dad now not as someone who took his life, but gave his life to others.”

**Tomorrow: Each religion has unique rituals to usher the deceased into whatever lies beyond. Yet some religions believe that those donating bodily remains deserve exemptions from traditional death rites.*



Courtesy of Anne Gulotta

Anne Gulotta, with her husband Jay. He died in 2002. She later became friends with the recipient of his left kidney.

To learn more about organ donation:

Gift of Hope, <http://www.giftofhope.org/>, 888/307-3668

United Network for Organ Sharing, <http://www.unos.org/>, 888/894-6361

To sign up for the Illinois donor registry:

Illinois Organ/Tissue Donor Registry, <http://www.giftofhope.org/donatelife/>

Illinois Secretary of State, 800/210-2106

To follow the series on body and organ donation:

May 18: The vast majority of medical schools employ cadaver dissection as a crucial teaching tool for first year medical students. Experts argue that the practice has a

profound impact on the students, the medical profession, and ultimately the patients of future doctors.

May 22: Full body donation is an essential part of medical science, yet most of us know very little about how this process works. It is less creepy than we might think, and considered noble in the eyes of those who benefit from these donations.

Today: Only a fraction of 1 percent of people who sign up to be organ donors will actually be able to donate, making it all the more important in advocates eyes to register for donation and discuss the issue with loved ones.

Tomorrow: Each religion has unique rituals to usher the deceased into whatever lies beyond. Yet some religions believe that those donating bodily remains deserve exemptions from traditional death rites.

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