

CASE 9

Every day, 110 people join the list of people in the United States waiting for organs. They increasingly seek live donors for livers and kidneys, as there are not nearly enough donations from deceased donors to meet the skyrocketing demand for organs. To the relief of individuals waiting for organs, many are finding donors among the living. Nearly half of those who donated organs in the United States in 2004 were living donors.

When her niece Patty needed a liver transplant, Brigid Higgins figured that she was the right person to volunteer to be a live donor: she was 32, healthy, childless, and had the summer free from teaching duties to recover. Patty's sister, Molly, also offered to be a donor, but because Molly was still a teen-ager, everyone agreed that Brigid's maturity made her a more appropriate choice.

Brigid wasn't released from the hospital when expected, however, as she continued to experience complications following surgery. Nearly a month after donating part of her liver to Patty, Brigid was feverish, vomiting, in intense pain, and suffering from multiple infections. Her liver, lungs, and kidneys no longer worked properly.

Only after the donation did Brigid realize that she had not been fully informed of the risks of live donation, primarily because that information is just not available. Every transplant recipient is tracked over the long-term. People waiting for organs can find a myriad of data on complications, survival rates, and morbidity and mortality risks. This is not the case for donors. In contrast to the situation for organ recipients, no money is included in the federal health budget to track outcomes for all donors. The medical community doesn't know how big a risk living donors face, and appears to have little interest in longitudinal studies of organ donors. Because of the resulting lack of information, no one knows how many donors have suffered complications or have died because of their donation.

"I felt prepared," said Brigid. "I asked so many questions, except the ones I should have asked: 'What evidence is there of long-term consequences and adverse outcomes for living donors, and how reliable and extensive are these data?'"

More distressing to Brigid than the impossibility of informed consent – the desire to help Patty was so strong that, even knowing the risks, she would have accepted them to save her niece's life – was learning that there is no uniform process for deciding who is an appropriate donor. The elderly, minors, and even the psychologically fragile, may act as living organ donors, and because they may be overly trusting, not able to appreciate fully the potential risks, not know what questions to ask, be easily coerced, or think it is impossible for anything to go wrong, they are particularly vulnerable. It deeply troubled Brigid every time she reflected that it might have been Molly going through the medical nightmare she was now experiencing. Brigid also felt isolated, unable to discuss her medical problems with her family. The last thing she wanted was to diminish their joy over Patty's successful transplant by giving anyone the impression that she regretted her donation.

The National Organ Act of 1984 does not address specifics of living donation. Many transplant surgeons oppose instituting formalized guidelines on the grounds that organ transplantation is still a developing field where progress is made by doing the seemingly impossible, and imposing formalized standards would impede progress and cost lives. Although the Health Resources and Services Administration (the federal agency charged with organ transplants oversight) could regulate the system, it often defers to the recommendations of institutions and professional groups.

Advocates for living donors are concerned that the transplant system revolves around recipients to the detriment of live donors. Because patients waiting for organs are very ill, often near death, the transplant team gets to know them better, and invests more in their care. The success rates of transplant surgeons reflect outcomes of organ recipients; the rates don't consider donor outcomes. Consequently, advocates fear that the doctor-recipient relationship takes precedence over the doctor-donor relationship. This imbalance may be exacerbated as the recipients' insurance pays the bills. All of this may lead some doctors to advocate, unaware, for the welfare of the recipient over that of the donor.