

DECEMBER 26, 2005

IDEAS -- VIEWPOINT

By Catherine Arnst

Check A Box And Save A Life

There are 90,000 deathly ill people in the U.S. currently waiting for an organ, and one of them is my friend, Rob Fasano. He is married to Susan Dooha, his partner of 28 years, and is the devoted father of Lily, a lively 6-year-old. And he is dying, for lack of a donor. If you have not checked off the organ donor box on your driver's license, please keep reading.

I first met Rob, who is 53, in 1998 through the agency we used to adopt our daughters. Rob, Susan, and I bonded over our shared quest for a child, and in November, 1999, we also shared the greatest joy of all our lives when we traveled together to China to receive our children. My daughter, Jesse, took an immediate shine to Rob and spent much of the two weeks we were in China grabbing his beard and bubbling over with laughter. As for me, I found his fabulous sense of humor, his patience, and his generosity the perfect antidote to my craziness as a first-time mother.

Our families have remained close since that China trip, and Jesse's love affair with Rob has never ended. We live near each other in Brooklyn, eat together regularly, vacation together, and Lily and Jesse are best friends. Since I am a single mother, Rob plays an important role in Jesse's life -- she often says she thinks of him as a dad. Consequently, I was almost as devastated as Susan and Lily when I learned in August that Rob's liver was failing.

It wasn't a complete surprise. Rob has a genetic condition, alpha-1 antitrypsin deficiency, which causes cirrhosis of the liver in 12% to 15% of adult carriers. The only treatment is a liver transplant. Rob had his first transplant in 1990, after waiting nine months for a donor and nearly dying in the process. That liver started breaking down on Aug. 2, days after our families shared a lovely dinner outdoors.

NOW ROB IS FRAGILE and near death. He had been on the waiting list at Mount Sinai Medical Center in New York until doctors there decided in early December that he had become too sick for them to do the operation. He was transferred to Cleveland Clinic, where doctors think he will recover if he gets a liver soon. "He is a tough guy," Susan says. "I believe in him, and I believe he can get well. If he can get a transplant, he will be restored to us."

Unfortunately, too many lives hinge on the word "if." Last year more than 6,000 people died in the U.S. while waiting for an organ, and 1,500 more were removed from the waiting list because they became too sick to undergo surgery. In recent years the number of people needing an organ has grown five times as fast as the number of donors.

This chasm between supply and demand has spurred some controversial practices. Members of LifeSharers.org, for example, pledge that they will donate their organs on the stipulation that fellow LifeSharers get first access. The nonprofit network has signed on 3,400 members since its inception in 2002. Founder David J. Undis describes LifeSharers as the best free-market approach to organ donation short of financial incentives, which are illegal: "We offer a very good trade. By donating your organs after you can't use them anymore, you could literally save your life."

But do we really want a free-market approach? Do we want patients who sign up with a closed network to get first priority, rather than those most in need of organs? It would be better to instead overhaul the entire donation process.

The U.S. currently uses an "opt-in" approach, which requires potential donors specifically to consent to having their organs harvested at the time of death. But several European nations, including Belgium, France, Spain, and Italy, have switched to an opt-out, or presumed consent, system: It assumes that citizens will donate their organs unless they specifically say no. Austria passed such a presumed consent law in 1982, and by 1990 the number of kidney transplants performed there was nearly equal to the number of people on the waiting list.

Right now, only about 30% of Americans are registered as organ donors. An opt-out system would almost certainly pull that number up significantly, and Congress could save tens of thousands of lives by passing such a law. Until it does, donation will take acts of commitment. So register today. For all the Robs out there.

Catherine Arnst is a senior writer for BusinessWeek covering medicine and science.

JANUARY 23, 2006

READERS REPORT

A Checkup On Organ Donor Options

Catherine Arnst calls LifeSharers, which rewards registered organ donors with preferred access to transplantable organs, a "closed network" ("Check a box and save a life," Viewpoint, Dec. 26/Jan. 2). The exact opposite is true. Membership is free and open to all (lifesharers.org or 1-888-ORGAN88). We welcome everyone, and we turn no one away.

About 70% of the organs transplanted in the U.S. go to people who haven't agreed to donate their own organs when they die. LifeSharers makes the organ allocation system fairer by helping registered organ donors get a fair shake.

David J. Undis
Executive Director
LifeSharers
Nashville

The majority of adults with alpha-1 antitrypsin deficiency get genetically induced emphysema, in addition to other chronic obstructive pulmonary diseases. (I know this because I have alpha-1, too.) I belong to an alpha-1 education group, and several of the people in the group are in desperate need of a lung transplant, just as Arnst's friend is in desperate need of a liver transplant. The Alpha-1 Foundation (<http://www.alphaone.org>) is a wonderful source. Its president, John W. Walsh, is an alpha, too (as we call ourselves).

Alpha-1 is still regarded by many doctors as a textbook illness, and they don't test for it. There are about 5,000 known alphas in the U.S., but it is estimated that 80,000 to 100,000 people in the U.S. have it. It's not curable, but there is therapy for it (a weekly IV infusion) and other things we alphas can do to help ourselves be functional and live longer. For my alpha friends and all alphas who desperately need lung and liver transplants, I thank you so much for writing about this.

Liz Johnson
Winchester, Mass.

Editor's note: Rob Fasano successfully received a liver transplant on Dec. 19.

Catherine Arnst is right on. Medical professionals and families would not face such heart-wrenching decisions if organ donation were mandatory. Our culture is more than ready to define itself a "giving" society. Nothing stands in the way of this gift, except the health of the donor. It should be something on which we can build a consensus. Unfortunately, programs making everyone a donor (with a provisional choice to opt out) seem not to be a priority to lawmakers. It certainly would be a statement for the ages if we all made the choice to opt in.

Dale Gilbert
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