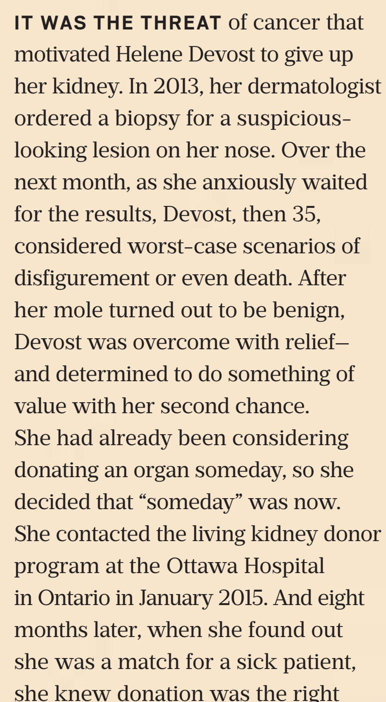
SISTER, CAN YOU *SPARE A KIDNEY?*

If so, you should also spare a few minutes to **educate yourself** about organ donation. BY *Rachel Mabe*



IT WAS THE THREAT of cancer that motivated Helene Devost to give up her kidney. In 2013, her dermatologist ordered a biopsy for a suspicious-looking lesion on her nose. Over the next month, as she anxiously waited for the results, Devost, then 35, considered worst-case scenarios of disfigurement or even death. After her mole turned out to be benign, Devost was overcome with relief—and determined to do something of value with her second chance.
She had already been considering donating an organ someday, so she decided that "someday" was now. She contacted the living kidney donor program at the Ottawa Hospital in Ontario in January 2015. And eight months later, when she found out she was a match for a sick patient, she knew donation was the right

ILLUSTRATIONS BY *Kotryna Zukauskaite*

thing to do: "I'd get six weeks of recovery, maybe discomfort; someone else would get 20 years of life. That sounded like a fair transaction to me."

Upon waking in the hospital after surgery, Devost was surprised to find she wasn't in agony—in fact, she felt better than she had after breaking a rib a few months earlier. And when the nurse informed her that the transplant was a success, she burst into tears—"of utter happiness." Devost never met her recipient, but his thank-you card revealed that he'd suffered from kidney disease since birth; he wrote that he was grateful to Devost for helping him return to work and with any luck see his daughters marry and have children. "As someone who'd battled low self-esteem and depression," Devost says, "I felt like this was the first time in my life that I had done something really worthwhile."

Most donors share Devost's positive response. These comments from a 2014 survey of almost 2,500 kidney donors are typical: "Organ donation was the most meaningful event of my life, after becoming a father." "Being able to help my sister was the high point of my life." "Donation gave me a sense of direction and purpose." A study that followed up with 370 Swedish kidney donors between 1964 and 1995 found that less than 1 percent regretted their decision.

Yet even those who give the most glowing reviews agree that you can never be too prepared. "The better informed the donor, the more likely they will have a better experience," says Jennifer L. Steel, PhD, an independent living-donor advocate in the department of surgery at UPMC in Pittsburgh.

For their protection, potential donors are required to complete an evaluation with a psychologist or a social worker. This 45- to 90-minute session assesses a person's suitability for donation by reviewing their mental health history, social support system, and coping strategies, and by identifying potential medical and psychological risks. Donors learn about the vulnerabilities they may feel as a patient, and they meet with an independent donor advocate who prioritizes their best interests.

Steel notes that even with all the planning and prep work, donors who have never had surgery may find it hard to conceptualize recovery. A UPMC survey found that three to five days after their evaluation, donors on average recall only about 18 percent of the medical, psychosocial, and financial risks explained to them.

Last year, when Diana MacDonald donated a portion of her liver to her father at UPMC, a social worker told her that her history with anxiety and depression put her at a greater risk for emotional issues during recovery. "I didn't *not* believe her—I just didn't care," says MacDonald. "All I could think about was helping my father."

After the surgery, however, MacDonald was dismayed by her profound exhaustion. At first, she couldn't so much as adjust her bed pillows without getting winded. A month later, she still felt exhausted—too tired to socialize, even after she was cleared to drive. "All I wanted to do was sleep," she says. Complicating matters, her self-esteem plummeted when weeks of doctor-mandated inactivity caused her to put on weight. She felt purposeless and sad.

It took six months for her to feel

THE U.S. WAIT LIST FOR ORGANS IN 2017 WAS **499** PERCENT LONGER THAN IN 1991.

like her old self after the surgery—and she says she couldn't have gotten through what she calls her "hibernation" without the care of loved ones. But seeing how much her father's health improved ("He's gained weight and muscle tone, the color has returned to his skin, and he can breathe normally"), MacDonald says she'd "do it all again in a heartbeat."

Without a doubt, unwavering support smooths the bumps in the donation process, but not all donors can count on having it. Devost says the hardest part of her experience was trying to bring skeptical family members and friends on board with her plan to go through a physically demanding operation and recovery for the sake of a stranger. "Few people backed my decision. I have a friend with a very dangerous job in defense, and even he called my idea crazy." (Living people accounted for 37.5 percent of donors last year, but only 4.3 percent of those were "altruistic," or nondirected, donors, who give their organ without a specific recipient in mind. It's possible that this breed of donor is genuinely special: A Georgetown University study suggests they have more volume and enhanced responsiveness in the right side of the amygdala—a brain area that processes emotion—possibly making them extra sensitive to other people's distress.)

In organ donations, recipients' identities are protected, so they decide whether to share personal details. That means altruistic donors must be prepared for the possibility of never meeting or hearing from the person who benefited from their gift.

And all donors should brace themselves for potential problems. Thirty-eight percent of liver donors experience complications, about half of them serious. And research suggests that even kidney transplants, though they've become relatively standard, have about a 17 percent risk of donor complications; 7 percent of donors have issues requiring invasive intervention.

When Cindy Beyer decided in 2016 to donate a kidney to a friend's ailing sister, she thought she was well prepared; she never expected to become one of the unlucky donors to run into serious trouble. But during the kidney removal, a part of Beyer's small intestine became stuck in her stitches. Two days after the surgery, she was rushed back into the OR for an emergency procedure. She spent eight more days in recovery and was readmitted for another eight days the next month.

Last winter, Beyer was still feeling unsettled about what had happened. On one hand, extended time in the hospital had given her an opportunity to bond with the recipient's family: They're now so close that she spent the past two New Year's Eves and a summer beach vacation with them. On the other hand, Beyer felt traumatized by the surgical mistake. "I wanted to see how my experience compared to other people's," she says, so she joined a Facebook group for living donors. This, she realized, was what she'd needed: a place to work out her complex feelings about donation.

The group also propelled her to act. Beyer signed up to be a donor buddy and now offers peer support, shares her experience, and answers questions on everything from emotional after-effects to scar remedies.

Donors may not think to ask about finances, but even though transplants are often covered by a recipient's health insurance, they have hidden costs: One study found that 78 percent of kidney donors paid for some of their own medical or nonmedical (mostly travel) expenses. And a 2016 study in the *American Journal of Transplantation* (*AJT*) found that when lost wages are factored in, the majority of kidney donors experience a net financial loss in the 12 months after donating. While it's illegal to pay someone for an organ in the U.S., recipients are allowed to replace lost wages and help donors with medical and travel costs related to donation. Experts say this is uncommon, though, because a recipient with a faulty organ has likely been too sick to work (and, therefore, to reimburse the donor). In the *AJT* study, 18.6 percent of kidney donors were helped by nonprofit organizations, transplant centers, or the National Living Donor Assistance Center, a federally funded program that provides income-based financial assistance for donors who can't get reimbursed from insurance, state programs, or the recipient.

In 1999, the Organ Donor Leave Act allocated 30 days of paid leave for donors who are federal employees, and most state governments have passed similar laws. For those in the private sector, only eight states and the District of Columbia have any kind of donor leave law (ranging from one week paid to up to four months unpaid), and only 19 states offer tax incentives like deductions (usually up to $10,000 for lost wages, lodging, and travel). The Living Donor Protection Act, introduced in 2017 by representatives Jerrold Nadler from New York and Jaime Herrera Beutler from Washington, would add organ donation to the Family and Medical Leave Act, which guarantees job protection and unpaid time off with benefits at large companies. The act would also safeguard organ donation from being labeled a preexisting condition; it's yet to make it to a full House vote.

Although organ donors think it's important to be fully aware of all the risks and repercussions, they also return, again and again, to the unique fulfillment, satisfaction, and joy they've gained from the experience. Three years after giving away her kidney, Helene Devost still raves about being an altruistic donor. "I haven't felt a whisper of depression since making this decision, and I figured out the key to my happiness," she says. "All that for the price of one spare organ."

IN 2017, THERE WERE **34,770 ORGAN** TRANSPLANTS IN THE U.S.

THAT LEFT **115,759 PEOPLE** STILL WAITING FOR A MATCH.