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The gift of life

Impulse to help gives a stranger chance to live

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What shocked Casey L. Caruso was how unsupportive some people were when she donated blood stem cells for a leukemia patient she did not know.

"They asked me, 'Why did you do it?' " she recalled.

For Ms. Caruso, the mother of two young children, providing life-saving help seemed like the only thing to do. She had received an e-mail about a boy less than a year old who had leukemia and needed a donor. She immediately went to the mother's Web site; up came a picture of the child.

Casey L. Caruso is shown with her family, husband Christopher A. Caruso, and their children, Griffin, 4, front, and Riley, 3.

"He reminded me of my son — the big blue eyes," Ms. Caruso said. "It made me think of my own children and that this mother would do anything to save her child's life."

Ms. Caruso knew that it was not likely her tissue would be a match for that little boy. But she might be able to help save someone else's life. "I knew there was a mother out there praying for a miracle," she said.

That April day, Ms. Caruso went on www.marrow.org and took the first steps to add her name to the National Marrow Donor Registry. Within two weeks, she received a kit containing Q-tips to swab the inside of her cheek in four different directions. She returned the kit to the National Marrow Donor Program in Minneapolis, thereby joining nearly 6.7 million people on the registry.

Ms. Caruso had no idea when or if she would be contacted, so she was surprised and pleased when she got a call in July from a regional donor center in Oradell, N.J., which is affiliated with the national registry, informing her that she was a potential match for a young adult with leukemia. She headed to MetroWest Medical Center in Framingham, where eight vials of blood were taken for more refined testing.

A couple of weeks later, Ms. Caruso was told she was a match. Five of six human leukocyte antigens — proteins that help identify tissue type — matched those of the patient. She cried. Her 10-year-old golden retriever, Bailey, had died of cancer the day before.

“I told them, ‘I’m not normally so emotional. You must think I’m a little off,’ ” she said. “But it seems like such a connection. My dog dies of cancer, and the next day I’m given the opportunity to save someone’s life.”

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> Casey L. Caruso,
> ON DONATING BLOOD STEM CELLS FOR A LEUKEMIA PATIENT

She quickly agreed to go ahead with a donation of peripheral blood stem cells, even though the donor specialist assigned to her urged her to think it over. Ms. Caruso had been told that the patient’s status was “urgent.” While searching the Web, she also had learned that it was not unusual for someone listed on the registry to back away from donating when the time came.

In fact, of those deemed potential matches, 64 percent proceed and 36 percent can’t be located, have changed their minds, have become medically ineligible or are temporarily unavailable — often due to pregnancy, according to Linda Abress, director of donor resources at the NMDP. Ms. Abress said that one in eight who proceed to the second stage of testing will be asked to donate.

Ms. Caruso knew that she would not change her mind.

She told the donor specialist: “I don’t need to think about it. I know what I want to do.”

At her spacious, airy home in Upton on a recent morning, Ms. Caruso, 35, said that she was asked to wait a year before talking to the Telegram & Gazette about being a donor to protect her identity and that of the patient. She said she was not concerned about herself and wanted to proceed because she is hoping to encourage others to add their names to the registry, increasing the chances for each patient to find a match. Donating stem cells, whether taken from pelvic bone marrow or from blood, involves physical discomfort and a commitment to the process.

“It’s definitely a worthwhile cause, but it’s more than a notion,” said Lee Hayes, an NMDP spokeswoman. “It’s more than just signing up. You have to follow through, as well. It involves testing and all of that. Some people are afraid.”

Ms. Caruso was given several pieces of specific information about the recipient of her donation. At the request of the NMDP, the Telegram & Gazette has agreed not to provide that information or the date of the donation. The recipient could live in the immediate area or anywhere in the world.

Along with thoughts of the beautiful blue-eyed boy with leukemia, Ms. Caruso had another reason to proceed: She has a strong history of breast cancer in her family.

“As I go through life, there’s a pretty good chance I or my sister will get it,” Ms. Caruso said. “I was raised to help other people out. My mind-set is, ‘You have the ability. It’s not going to kill you. Why don’t you do it?’ ”

At first, her husband, Chris, was hesitant.

“There was just concern about what risks it might be to her health,” Mr. Caruso said. “I bought into the whole concept of doing something nice like that. My only concern was her health and the kids.”

Ms. Caruso was given a date that the patient’s physician was requesting for the donation. She had planned a vacation and asked if it could be done at another time. She was told the donation could be scheduled later.

“I didn’t want any part of that,” Ms. Caruso said. “I wanted to make sure I wasn’t part of the stalling process. I didn’t want to delay it. My vacation could wait. It was a life-and-death situation. We put off our vacation. It wasn’t a big deal.”

She was sent to Massachusetts General Hospital in Boston for a thorough physical examination to make certain she had no infections or other health problems that would endanger her or the recipient. “They made it clear, ‘You’re our patient, and our concern is whether you’re OK to do this,’ ” she said.

She was cleared the following week, and arrangements were made for her to commence injections of a drug called filgrastim, which increases the number of stem cells in the bloodstream. The typical side effects are headaches and bone aches.

Ms. Caruso got her first injection in the hospital. As she started her preparation process, the recipient’s immune system was shutting down. She was told that backing out now could be a death sentence for the recipient. The only alternative would be to find a cord blood donation, in which four of six antigens must match.

“We would be scrambling,” Ms. Abress said. “Donors are told they need to be very certain of their decision because the consequences for the patient could be fatal.”

For the following three days, a visiting nurse gave Ms. Caruso the injections in her home. She suffered from headaches and insomnia. By the last day, she felt achy all over.

“One afternoon I was driving my kids home from the movie theater and I felt as if I would fall asleep,” Ms. Caruso remembered. “I called my husband and said, ‘You have to come home. I am so tired I can’t think straight.’ ”

On the day of the donation, Ms. Caruso and her husband were driven to Massachusetts General Hospital by a limo that had been arranged by the donor center. She had more blood tests. At 8:45 a.m., she was hooked up to an apheresis machine, which takes blood from one arm, separates the stem cells and returns the remaining blood through the other arm. Her face felt numb, indicating she was suffering from calcium depletion. She was given Tums and additional calcium intravenously.

Ms. Caruso, who is 5 feet 6 inches tall and weighs 120 pounds, has small veins. In order to keep the blood flowing, she had to continuously pump a ball. She was on the machine for seven hours.

“I lost complete feeling in my hand,” she said. “At the very end, I started getting cramps in my hand and arm. A nurse started massaging my hand and put heat packs on my arm for the last hour and a half, so I didn't have to pump as much. At the end, they joked and said, 'You want to take the ball home?' I said, 'No. I never want to see it again in my life.' "

Dr. Thomas R. Spitzer, medical director of the Center for Bone Marrow Transplant at Massachusetts General Hospital, said that Ms. Caruso's experience was uneventful, and the time it took to make the donation was "pretty typical."

"The length of collection is determined by the recipient's transplant center," Dr. Spitzer said. "That is based on the size of the patient and how many cells they want. The average is five to six hours for an adult collection."

Ms. Caruso and her husband were back home 12 hours after they had departed. She was fully recovered in a day or two. In a year, if they both agree, Ms. Caruso and the recipient can contact one another.

"She definitely did something important," Dr. Spitzer said. "It's a gift of life that precious few people can give."