



# PERFECT STRANGERS



In November, the world's largest bone marrow registry—Be The Match—moves into its new headquarters in the North Loop. The nonprofit doesn't typically attract high-profile attention, even though it's credited for helping save the lives of thousands globally by connecting cancer patients with unrelated donors.

*by Elizabeth Foy Larsen*

PHOTOGRAPHS  
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Minneapolis resident Betsy Lucas, above, survived her late-stage leukemia diagnosis, thanks to a donor she didn't know who was living in Germany.

# It

was not until a burning rash spread like mold across her leg that Betsy Lucas realized she might be sick. Sure, she had to drag herself out of bed most mornings, but she was working as a real estate agent in Minneapolis and had two very young daughters—her baby, Molly, was 10 months old, nursing and frequently waking up in the middle of the night. Her older daughter, Julia, was only 3. Who in her situation wouldn't be exhausted?

Lucas called her doctor's office and was advised to take Benadryl. When that didn't work, she went in for an appointment. A blood draw revealed an abnormally high white blood cell count. That was on a Friday in May 2005. By the following Monday, Lucas was back at the doctor's, in an examination room calling her husband, Brian. "I need you to come to the doctor's office," she said, struggling to keep her voice steady. "They're going to run some tests. I need you here."

Lucas didn't tell her husband that her white blood cell counts had doubled over the weekend. Nor did she mention that her doctor had held her hands and tearfully explained that the rash was most likely caused by leukemia. In that panic-stricken moment, Lucas just focused on the fact that she needed Brian to make it to the clinic so she could tell him this terrifying news in person and they could drive together to Abbott Northwestern, where a hematologist and oncologist waited.

A cancer diagnosis can feel like an earthquake ripping apart the foundation of your existence. But for



the Lucases, the aftershocks turned out to be even more devastating than the initial jolt. Lucas had an aggressive form of chronic myelogenous leukemia (CML), a disease in which the bone marrow makes too many white blood cells. The facts and logistics of Lucas's illness and treatment were daunting. She was only 34 years old, but without treatment, her long-term prognosis was grave. Her only real hope was a bone marrow transplant.

"This can't be happening," she thought. "I have young children to raise."

What Lucas didn't know was that the gateway to a cure was just five and a half miles from her home, on 35W, just north of downtown Minneapolis. That's where a nonprofit organization known as Be The Match recruits volunteers to donate bone marrow cells and umbilical cord blood (taken from the cord and placenta after birth) to help patients get life-saving transplants with logistical maneuvers that rival a special ops mission.

That Lucas had never heard of Be The Match—which was called the National Marrow Donor Program (NMDP) when she was diagnosed—is not unusual. Most Twin Citians have no idea that the world's largest registry of stem cell donations is in our backyard. But this month, as the nonprofit moves into a new, seven-story glass and stone building across from Target Field, the public's awareness about the organization is likely to grow. At the same time, Be The Match has had its challenges this year with the global decline in the number of blood transplants, which resulted in the organization's first-ever layoffs this summer.

## TWO OF A KIND

Matching bone marrow is a complex process, far more complicated than matching blood types. While there are only eight different blood types, there are millions, perhaps even an infinite number, of marrow tissue types. Everyone inherits a set of human leukocyte antigen (HLA), which is a marker found on most cells in your body, from their mother and another

set from their father. (Your immune system uses HLA markers to know which cells belong in your body and which do not.) The trick is that each set of HLA has 10 markers and you can have any combination of those 10 markers. The variations can be so diverse that there are some people in the world who don't have a match.

What that means is that 70 percent of patients with a blood cancer don't have a donor in their family and need bone marrow transplants from someone not related to them. The bigger the registry—the Be The Match Registry is the world's largest, with nearly 12.5 million potential marrow donors and blood from more than 209,000 umbilical cords—the more likely you are to find a successful match. Be The Match coordinates with donors, physicians, transplant centers, and hospitals to arrange for the collections to be made after doctors make donor selections from the organization's registry.

"Over two-thirds of people who need a bone marrow cell transplant or cord blood transplant don't have a match in their family," says Dr. Daniel Weisdorf, a hematologist and oncologist and the director of the Adult Blood and Marrow Transplant Program at the University of Minnesota. "They would have no place to turn if Be The Match didn't exist."

The history of Be The Match dates back to 1979, when a 10-year-old Colorado girl with leukemia named Laura Graves was the first patient to receive a bone marrow transplant from an unrelated donor. Although the transplant was a success, she died two years later. Her parents worked to establish a national registry in Laura's memory where people could voluntarily give blood samples that were then categorized and logged into a database that could be searched by doctors for their patients in need of bone marrow transplants.

The Graves family's advocacy culminated in 1986, when a group of medical experts from transplant centers on both coasts, the Red Cross, and research hospitals—including the University of Minnesota—agreed there was a need for a national registry to bring together all the separate registries around the country.

According to Be The Match CEO Dr. Jeffrey W. Chell, the Twin Cities was



chosen as the headquarters for what was then called the National Bone Marrow Donor Program because, in addition to being conveniently located in the center of the country, the region is a leader in medical technology. The new registry was housed in a tiny office in the headquarters of the St. Paul Red Cross, which, along with the University of Minnesota, provided its first computer and paid the salary for its initial four employees. The organization grew as the science of transplants advanced. Today, more than 70 different diseases can be managed with a bone marrow transplant. The age of patients who can be successfully treated has also increased.

Chell acknowledges that Be The Match hasn't had the public attention typical of such a large nonprofit. "For years we didn't do much to promote ourselves because we were focused on our mission, which is to help transplant centers save the lives of their patients," he says.

**ABOVE:** Betsy Lucas with her husband, Brian, and their children Molly, 11, and Julia, 13. **OPPOSITE: (Top)** Lucas's donor Tobias Hofmann of Germany. **(Bottom)** Hofmann and Lucas met for the first time in 2008 when Hofmann traveled to Minneapolis.

But spreading the word about the organization's mission is imperative now to help diversify the donor base so that people who are more difficult to match—such as people of mixed races—have higher odds of finding that match.

Since its founding in 1986, the nonprofit has coordinated more than 68,000 marrow and cord blood transplants—roughly 520 every month—and is affiliated with more than 40 registries in other countries.

## RACE AGAINST TIME

When Lucas got sick, she hoped her sister would be a match, but she wasn't. Lucas's doctors at the University of Minnesota, where she'd been referred to the transplant unit, were optimistic they'd find a donor because her western European heritage and tissue types are more widely represented in the millions of samples in the

## BE THE MATCH BY THE NUMBERS

**68,000**

■ Bone marrow transplants since 1987

**6,300**

■ Marrow transplants a year

**12,500,000**

■ Bone marrow donors in the database

**209,000**

■ Umbilical cord blood units

**1,000-2,000**

■ Donor sample kits processed daily

**784**

■ Employees

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registry. She was taking Gleevec, a form of targeted chemotherapy that was new to the market, to lower her white blood counts and put her leukemia into remission so that she could have a transplant.

The hope was to identify a donor by July. The waiting game had begun.

In the meantime, Brian and Betsy and two friends organized a bone marrow drive in the basement of Blake School's Minneapolis campus, where Brian and the friend funding the drive had gone to school. "We knew it was highly unlikely that we'd find a donor in our hometown," Lucas says. "But it was something positive we could do that would also raise awareness about the need for donors."

Lucas knew that the reason her doctors wanted a bone marrow donor identified by July was because they didn't know how long she would stay in remission from the Gleevec. "I'm thinking, 'I've got to find a donor really fast,'" she remembers. "I would call the search coordinator at NMDP every couple of weeks." When she finally got the call, her doctors moved quickly to get her into the hospital for an aggressive seven-day pre-transplant regimen of intense chemotherapy and radiation—she'd be in the hospital another five weeks after the transplant. The doctors explained that they'd be bringing her blood cell counts down to zero on the day of the transplant so that her body would be able to accept the new marrow.

By late August Lucas's body was ready and a donor was in place. What she wouldn't know until two years later—the amount of time required to have contact with an international donor—is that the bag of pale pink stem cells that would eventually make their way into her body belonged to a 19-year-old German man named Tobias Hofmann. At the same moment that Lucas's doctors were readying her for her new bone marrow, Hofmann was taking the train with his mother from their small town two hours north of Frankfurt to a transplant center in Dresden.

In most cases, stem cells are extracted from a needle in the donor's arm and passed through a machine that separates the blood-forming cells. The remaining blood is returned through the donor's other arm.

In Dresden, a volunteer courier from Minneapolis was waiting to pick up Hofmann's marrow donation and fly it

back to Minnesota. "I felt so vulnerable," Lucas remembers of that day. "I didn't have an immune system, so I felt like I had no backup. I couldn't help myself from thinking, 'What if the plane goes down?'"

Because it's optimal if bone marrow is delivered within 24 hours of being harvested, Be The Match has five full-time travel agents and an entire logistics team to monitor each retrieval and delivery. The trained couriers must always keep what they refer to as "the product" in view. Special coolers are designed to fit underneath an airplane seat. They also need to be able to keep track of the extensive paperwork needed to carry liquids through TSA.

When a flight has a mechanical problem or a weather delay, the courier calls Be The Match and the logistics team swings into action to strategize a new route. "You have to be really flexible," says Rodney Soderberg, a volunteer courier from St. Paul. "But it's so rewarding when you deliver the product to the transplant center and they sign off on it. You think, 'Someone really needs this.' It's such a good feeling."

During the week of 9/11, Be The Match had 35 scheduled transplants. Volunteers from the organization's donor center, who jumped in their cars and took turns driving through the night so they could deliver the bone marrow on time, delivered the domestic donations. For international donations, Be The Match relied on its longstanding relationship with the Department of Defense, which allowed them to charter private planes to make the deliveries. All 35 patients got their transplants.

"We've had to use all kinds of innovative approaches to make sure these products get delivered," says Chell. "We've had TV news helicopters help out when roads are flooded. We've had police escorts."

### NEW CHALLENGES

A special history wall at the new Be The Match headquarters will be filled with stories of hope and survival, but the organization also is dealing with its own challenges. New blood cancer treatments mean that some patients don't need bone marrow transplants. That's good news, but it means there was a slight dip in the number of transplants Be The Match

coordinated in 2014. Numbers are projected to remain flat this year and next, too. Complications from implementing the Affordable Care Act (ACA) might also be creating a lag, although Chell is quick to point out the ACA should eventually make expensive treatments like bone marrow transplants available to up to 400 more people a year.

Chell insists that there's still a tremendous need for donors and the work done by Be The Match. "We know that the need for transplants is three times more than what we are meeting today," he says. "We aren't competing with these new therapies. We are a complement to them."

Fees from transplants account for the majority of Be The Match's \$390 million annual revenue. As a result of the flattening demand, the organization had to lay off 50 employees, mostly middle managers, last June. That news made some people question whether the new state-of-the-art glass building is a prudent investment, a criticism Chell says is unwarranted because it would have cost more to revamp its current location. In addition to the North Loop being a vibrant neighborhood that will appeal to talented potential employees, the organization hopes that the building's prime real estate, with a sign that will be visible from Target Field, will make it more widely known in the community.

In the meantime, Be The Match is focused on growing its cord blood registry and expanding the diversity of its bone marrow registry to include more options for patients who are hard to match. Age also plays a part—people between 18 and 44 are most urgently needed since transplant doctors request them most of the time and there's a greater chance for transplant success. Donors in this age group can donate free of charge. Be The Match charges \$100 for anyone older than that, up to the age of 61.

Once on the donor registry, there is a commitment with Be The Match until the age of 61. That means donors are expected to make a donation if called unless a medical or life circumstance prevents the person from donating. Currently 50 percent of people who sign up can't or don't follow through when called. "We need to do more education upfront to help potential donors know what their commitment means

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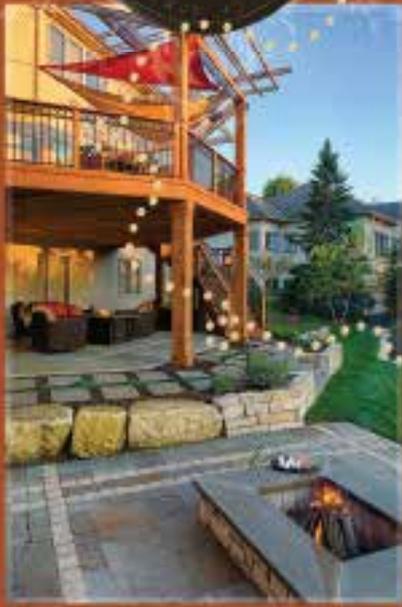
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and what it means to a patient if they choose to not follow through," Chell says.

## BEHIND THE SCENES

The outside of Be The Match's repository in New Brighton—one of the world's largest tissue sample storage facilities for medical research—looks like any other suburban office park. Inside, it's more than 40,000 square feet of high-tech science, with technicians in white coats titrating blood samples and cryogenic storage vats leaking clouds of liquid nitrogen. This is the hub for the organization's donor intake.

Each day, lab workers process between 1,000 and 2,000 donor sample kits from around the United States—basically cheek swabs taken using customized kits that consist of four buckle swabs and a consent form. The kits are free, unless you are between the ages of 45 to 61 (people older than 61 are not eligible to make bone marrow donations), in which case you make a \$100 tax-deductible donation. People usually request kits when they know someone who is sick, have been to a bone marrow drive, or hear a celebrity talk about the need for donors. In 2012, Be The Match mailed a record 2,549 kits on the day that *Good Morning America* host Robin Roberts announced on ABC that she had a bone marrow disease and mentioned the organization.

The repository is a sterile environment, with white walls and mammoth stainless steel freezer doors. But there's a palpable human side to this clinical backdrop. One workstation is decorated with a thank-you note from a 5-year-old recipient. On a corkboard, employees post letters that arrive with the mail-in donation kits. "This is for my daddy," says one. "He never got to have his transplant. I couldn't save his life. I hope I can save someone else's."

## BLOOD TIES

A year after her successful transplant, Lucas heard from Andrew Mullin, a close childhood friend who had registered with Be The Match at the Blake School drive. He'd gotten a call, and after a follow-up exam and blood work, it was determined he was a match for a patient who needed his bone marrow.

"Having watched Betsy and witnessing her strength, I had no reservations," says Mullin, who is on the Wayzata city council. "I knew Betsy's bone marrow transplant was her last shot. There was no way I couldn't do it."

A few weeks later, Lucas called Mullin. "As soon as you get your donation settled I want you to call me," she said. "I'm coming with you."

Mullin was concerned. Lucas was still very ill from an almost fatal case of graft-versus-host disease, which occurs when the transplanted cells think the recipient's body is foreign. A little graft-versus-host can actually kill a person's remaining cancer cells, but a lot of graft-versus-host can also kill the patient.

"At first I said no because I was too worried that she could get sick," says Mullin. "But my wife reminded me that this had nothing to do with me. Betsy needed to be there." So the old friends sat together for eight hours at a donation center while Mullin had his stem cells extracted through an IV. (Most donations are done this way. In some cases, the marrow needs to be taken from the hip bone, in which case the donor is put under general anesthesia.) It had been a little more than a year since a stranger's cells had taken the reverse journey into Lucas's body, a sensation she describes as feeling like an explosion of heat and life. Now, her friend was giving someone else a chance to live.

The tears came fast for both of them. Lucas ran behind the face mask she had to wear to protect herself from infection.

Two more volunteers were matched from that same bone marrow drive at Blake School. Thanks to them, a woman in Spain has bone marrow from a woman in Minnesota and a man in Miami is enjoying life with his grandchildren.

Lucas, who just this summer celebrated 10 years in remission, contacted Hofmann two years after her transplant. It was an experience her husband, Brian, tenderly portrays in his book, *Here Comes the Sun: A Young Family's Journey Through Cancer*. In 2008, Hofmann and his fiancée visited Minnesota to spend time with Lucas and her family. And Betsy and Brian traveled to Germany to celebrate his wedding. It's a genuine lifelong connection. "He feels like a brother to me," says Lucas. "It's amazing that a perfect stranger has become a part of my life simply because he said, 'I will do this.'"