

the stranger who saved me

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Photographs by
Larsen&Talbert



"I got to meet a person who is part of me—literally. I have her cells inside of me," says Robinson (left), with her donor, Quinn.

Anna Robinson beat back cancer with the help of an anonymous bone marrow donation. Then she began to wonder: Who was the woman who gifted her with a second chance?

Anna Robinson's first clue that something was terribly wrong came just after she had flown home for summer vacation in 2006. She'd finished her junior year at Smith College in Northampton, Massachusetts, and was looking forward to a relaxing summer in Seattle, working at a neighborhood convenience store and hanging out with her boyfriend—a welcome change of pace from the pressures of her engineering major. For Robinson's flight westward, she'd stuffed her things into a rolling duffel bag, which had gently nudged the back of her legs as she walked through the airport. By the time she got home, her thighs and calves were mottled with bruises.

"You should go to the doctor," her father suggested, but Robinson, a slight, freckle-faced 21-year-old, demurred; she was a low-key person who didn't like to make a fuss. "It will go away," she assured her dad. Instead, in the coming weeks, purplish-green bruises bloomed all over her body, standing out against her fair skin. Soon her vision was marred by spots, and the two-block walk to her job became exhausting. She tried not to worry. "I figured there was some simple explanation, like I wasn't getting enough vitamins or I needed to exercise more," she remembers. Finally, by late August, when she couldn't climb stairs without getting dizzy, she agreed to see her family practitioner. That's how Anna Robinson discovered she had leukemia.

Within days, a bone marrow biopsy revealed the grim details. Robinson had an aggressive cancer called acute myeloid leukemia (AML). Normally, the stem cells inside the marrow of our bones produce immature blood cells, which differentiate into red cells, white cells and platelets. But an alarming number of Robinson's immature cells weren't developing properly—they were cancerous and accumulating at a frightening rate. Cancer cells crowded her bloodstream, leaving her with too few red cells to carry oxygen, white cells that were unable to patrol for foreign invaders and not enough platelets to clot injuries. And there was one last cruel complication: Robinson's cancer sported a mutation called FLT3, a sign it was extra resistant to standard treatment.

Her oncology team at the Fred Hutchinson/University of Washington Cancer Consortium in Seattle concluded that chemotherapy alone wouldn't be enough to save her.

For Robinson—lying in a hospital bed with an IV port implanted in her chest to deliver medications and transfusions, her parents and younger sister standing in a worried knot by her bedside—the whole situation felt unreal. "I thought I'd wake up and it would all be a dream," Robinson remembers. Days earlier, she'd been packing to start her senior year of college. Now she was in a fog of chemotherapy, receiving repeated blood transfusions—and facing her own mortality. There was but one ray of hope, she was told: a bone marrow transplant.

Say the words *bone marrow transplant* to anyone and the first reaction is probably a wince. "People imagine drilling through bone and pain and a long recovery," says Katharina Harf, executive vice president and cofounder of the donor-recruitment organization DKMS Americas in New York City. In fact, nearly three quarters of so-called bone marrow donations involve no removal whatsoever of bone marrow—they're done by extracting blood stem cells intravenously from the arm, like giving plasma. (Some doctors now prefer the term "stem cell transplant," because both marrow and blood house these vital cells.) If the transplant takes, with the help of antirejection meds, the recipient's blood-making stem cells are replaced with the donor's, which become new, healthy blood cells for the rest of the patient's life. Meanwhile, the donor's body immediately begins making more cells; within a month or so, her supply is entirely replenished. "You go on with your life as if nothing happened—except you've saved someone else's life," Harf says.

The donation may be relatively simple, but the science behind a bone marrow transplant is rigorous. For the procedure to succeed, donor and recipient each must possess a specific pattern of proteins called HLA (human leukocyte antigens). It's a needle-

in-a-haystack sort of search, because the proteins have 10 billion possible combinations—“more than there are people on earth,” notes Jeffrey Chell, M.D., the CEO of the National Marrow Donor Program (NMDP) in Minneapolis, which runs the nation’s centralized registry. Even with 7 million people on the registry, only 3 out of 10 patients needing a transplant receive one.

Recruitment organizations have sprung into action by holding drives for specific patients—especially for African-American and Hispanic patients, whose need for donors is particularly urgent. However, recruitment efforts face major hurdles: not only a lack of public awareness but also a chronic lack of money. The genetic testing is so complex, recruitment groups spend \$100 to process each potential donor; the 450,000 donors who registered in 2008 bore a price tag of \$45 million.

Umbilical cord blood donations—which contain stem cells that are less mature and thus more adaptable and easier to match—cost even more. Because the registry must spend \$1,500 to process and freeze each donation, most new moms aren’t even given the option to help. (A list of the 200 participating U.S. hospitals is available at www.bethematch.org/cord.) In 2005, Congress pledged \$79 million to increase cord-blood donations by 2010, but it has provided only about half the promised money.

To make up for the shortfall, the NMDP and other organizations raise money in communities and are appealing to Congress to make good on its pledge. In the meantime, the lives of an untold number of people are left to the charity of anonymous strangers.

Katie Quinn was feeling dejected as she headed out of the annual Greek Week blood drive at the University of Missouri at Columbia in the spring of 2007. She had been all set to represent her sorority, Kappa Alpha Theta, by giving a pint. But a finger prick revealed that her iron was too low to qualify. The

red-haired 20-year-old nursing student was genuinely disappointed as she slung her book bag over her shoulder and started off to class. So when she heard a young woman at a booth call out, “Hi, would you like to sign up?” she stopped walking.

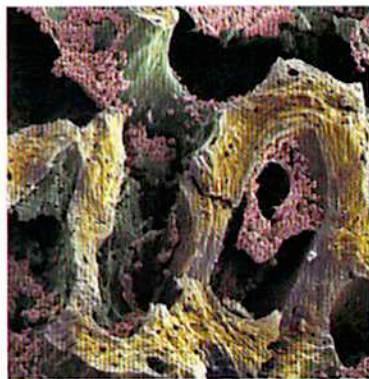
“Sure. What is it?” asked Quinn, athletic and vivacious, with smiling brown eyes. She filled out a form to become a bone marrow donor, brushed the inside of her cheeks with a cotton swab to give her DNA sample and, less than 10 minutes later, continued on her way. “I had no idea what I was getting myself into,” Quinn says now, laughing. She forgot all about it—until six months later, when she got a call from the donor center DKMS saying she was a potential match for a leukemia patient.

Quinn was taken aback. Despite studying nursing, she knew little about bone marrow donation. Nonetheless, she agreed to have two vials of blood drawn at a nearby lab for more precise genetic testing and infectious-disease screening. “I knew the chances of having a match were pretty slim,” she reflects. But before long, her phone rang again; the DKMS donor request manager was on the line. “You are a match,” she said.

Quinn listened in shock as she was briefed about “her” patient: a desperately ill 22-year-old woman in Seattle. “This is an urgent patient,” Quinn was told; she’d need to decide quickly whether she was willing to donate. She was crying by the time she hung up, overwhelmed by the awesome responsibility she’d been handed. “It was up to me. Some other person’s fate rested on me,” she remembers. She spent that evening tearfully talking it over with her three housemates. She happened to be in the middle of her most challenging semester of school and intensely strapped for time. But most of all, she felt surprisingly uncertain about giving a piece of herself to a complete stranger.

“That was definitely the most surreal thing to me: Who is this person?” Quinn recalls. “I’m a perfect match for her, but I don’t know who she is or anything about her. It’s all unknown.”

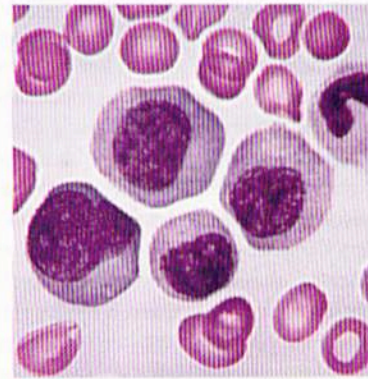
How Katie Quinn’s cells helped Anna Robinson heal



1 Kick-starting marrow
First, Quinn took a drug that spurred her marrow, the spongy tissue in bones, to release extra stem cells into her bloodstream.



2 Isolating critical cells
Quinn gave blood, and a centrifuge drew out stem cells. Meanwhile, chemotherapy killed nearly all of Robinson’s blood cells.



3 Adapting to a new home
Quinn’s blood stem cells took up residence in Robinson’s marrow and matured into healthy red and white blood cells and platelets.

Save a life!

Adding your DNA to the Be The Match Registry is painless and private and takes 10 minutes or fewer—and if you match, donating cells could be as simple as a needle prick. Join SELF’s drive at DKMSAmericas.org. You’ll get a cheek-swabbing kit that will put you on the registry. Donations to pay for processing your sample are appreciated but in no way required.

This decision is the pivotal moment in any bone marrow donation—because when called upon, nearly half of potential donors ultimately don't go through with the transplant. Reasons include a pregnancy or an illness, a change of address that renders people impossible to track down or a simple change of heart for fear of all the unknowns. Says Harf, "The patient's doctor tells them we have a perfect match, but then we have to tell them the donor is unavailable. It's heartbreaking for everyone."

Quinn called her parents in Chillicothe, Missouri, that night. "I don't know what to do," she agonized, and they told her exactly what she needed to hear. "This isn't about you, Katie. It's about this other girl," her father said. "You can make a difference in her life and in the life of her family, if she has one." That did it. "Afterward, I realized there was no way I could have said no," Quinn admits. "I don't know why I was even weighing the pros and cons. This was the only choice."

The moment Quinn made her decision, her inner tumult lifted. She was dry-eyed and confident as she dialed the DKMS office the next morning. "Sign me up!" she exclaimed, surprised at her own excitement. "What do I do next?"

The 15 months since Robinson's diagnosis had been brutal. Her initial round of chemotherapy had landed her in the intensive care unit twice, first for an infection, then for a 104-degree fever and fluid that had seeped into her lungs. Those ailments were on top of chemo's usual miseries: Robinson was hairless and nauseated, her throat and mouth lined with sores. Ever practical, she asked her family not to discuss her chances of survival. "Knowing those odds wasn't going to help me get through it," Robinson explains in her hushed, unsentimental voice. "You try not to look at the big picture and just focus on the day-to-day stuff, and if you feel better that day, it's a good thing." She tried to stay upbeat by spending her hospital days watching DVDs of *Arrested Development* and listening to her mother read aloud from David Sedaris books. But after the chemo was complete, Robinson learned it hadn't worked: Her bloodstream was still littered with leukemia. A second punishing round of chemo and radiation had been necessary before the disease was temporarily beaten back.

The next step was a bone marrow transplant, and the family rejoiced when Robinson's 18-year-old sister, Becky, tested as a match. Then, eight months after the transplant, Robinson relapsed. The match may have been *too* perfect: Becky's white blood cells were so similar to her sister's that it's possible they didn't recognize the cancer cells, with the tricky FLT3 mutation. When Robinson's doctors submitted an urgent request for a new donor, the odds seemed poor. Yet the registry located someone with unexpected swiftness. "They told me, 'We have a donor who is a 20-year-old female,'" she remembers. "I was very lucky."

She was lucky—and in more ways than one. Not only had Robinson been matched with a willing donor, but she also had health insurance that covered her transplants, each of which cost upwards of a half million dollars. Robinson also lives near a world-class transplant center. "There are so many barriers to treatment," Dr. Chell explains. "You may have great insurance, but if you live away from a major metropolitan area that has a transplant

center, you have to figure out how to pay for transportation and housing." On top of it all, Robinson had a supportive family to advocate for her, help her make medical decisions and, not least, nurse her through the transplant hell she was about to face.

"I've done this before; I can do this again," Robinson told her mother. To prepare, she was given two more rounds of chemo to push her leukemia into temporary remission, so her new immune system would have a fighting chance. Although

Quinn was overwhelmed by the responsibility she'd been handed. "It was up to me," she remembers. "Some other person's fate rested on me."

chemo failed once again to wipe out the cancer, her doctors had little choice but to plunge ahead anyway. Three days before the transplant, Robinson was dosed with yet another IV of toxic chemicals—her "conditioning" chemotherapy, which killed off the contents of her bone marrow. Bereft of an immune system, Robinson was left utterly vulnerable to illness; even a run-of-the-mill cold could have been enough to kill her. Her doctors administered antibiotics, in case a wayward germ entered her hospital room. By November 8, 2007, Robinson lay bald and listless in her hospital gown, kept alive with infusions of other people's donated blood and platelets, while her parents sat vigil. All they could do was wait.

Two thousand miles away, Quinn put on her own blue gown and followed a nurse into the donation room of St. Louis University Hospital. As she settled into bed, her mother, Judy Quinn, pulled up a chair beside her. "I was a little nervous, so I was glad to have my mom with me," Quinn says. The nurse inserted an IV into the back of her left hand, then a second one into the crook of her right arm. Quinn looked away as the needle pierced her skin. "I'm a nurse, and I deal with needles all the time," she says sheepishly. "I just don't want to see one in me!"

It had been a busy week. For the previous five days, Quinn had received injections of Neupogen, a drug that supercharged her production of white blood cells. By day two, the marrow of her pelvic bones ached from the increased effort. "My back and thighs felt sore, like I'd worked out really hard," she says. A predonation physical exam at St. Louis University Hospital had meant a four-hour round-trip drive from campus. And there'd been one more wrinkle: her 21st birthday. Quinn had decided to hold off on the festivities; alcohol inhibits bone marrow production, and she wanted to be in tip-top shape.

To begin the donation, a nurse plugged the ends of the IV tubes into the centrifuge by the bed. Blood flowed out of Quinn's right arm and into the machine, which looked a bit like a tan kitchen stove. The machine whirred as it spun the blood, separating out her stem cells and white blood cells, which dripped as a creamy orange mixture into a clear (continued on page 140)



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(continued from page 125) plastic bag. The rest of her blood returned to her body through the tube in her left hand. Over the course of the procedure, every drop of blood in Quinn's body passed through the machine three times. "It didn't hurt. I didn't feel a thing," she says.

This mode of donation, called peripheral blood stem cell donation, has been in use for the past decade and accounts for 74 percent of so-called bone marrow donations today. The rest are done surgically: The donor is put under anesthesia, and the liquid marrow is extracted from her pelvic bone via a hollow needle. This needle aspiration may cause lower-back pain or stiffness, but it usually subsides within days, according to Robinson's doctor, Eli Estey, M.D., an AML specialist at the Fred Hutchinson Cancer Research Center and a professor of hematology at the University of Washington. About 1 percent have a serious complication, such as a reaction to anesthesia or nerve damage in the hip.

Given the choice of collecting cells from the arm, why would a transplant physician ask someone to give surgically? "The most common reason for a doctor to request it is if the recipient is a child," Dr. Chell explains; scientists aren't sure why, but stem cells taken directly from marrow provide better outcomes for kids. Conversely, clinical trials have found that adult recipients recover quicker with peripheral stem cells. Ultimately, studies have found little difference in outcomes for adult cancer patients.

For Quinn, the toughest part of donating was holding perfectly still for five hours. Still, before she knew it, the nurse came in and sloshed the bag of cells Quinn had produced. "This is what the patient's going to get, probably later tonight," the nurse told her, and Quinn was struck anew by the urgency of it all. She felt a little light-headed but otherwise fine. In fact, because her mom was wary of city driving, Quinn drove them home.

A transporter whisked the bag of cells away in a cooler and boarded a commercial flight heading west. Nine hours after Quinn donated them, her cells were delivered to the University of Washington hospital, much to the relief of Robinson's parents, who'd been imagining worst-case scenarios. "I had a vision of them carrying this incredibly precious cargo, and I thought about plane crashes and car accidents," says Anna's mother, Diane

Robinson. Anna herself was half asleep from her meds. At 1:38 A.M., with no fanfare, a bag containing 3 billion or so of Quinn's cells was hung from an IV pole and plugged into the portal in Robinson's chest. By 4 A.M., the bag was drained.

Robinson didn't need to wait long to find out the results. Within three weeks, her blood counts began rising, indicating her marrow was producing its own blood cells—producing Quinn's cells, actually. After one more round of chemo and immunotherapy using Quinn's white blood cells, she was cancer-free.

Now that she had the luxury of thinking beyond her day-to-day survival, Robinson began to wonder about the young woman whose blood pumped through her body. "All along, I've been receiving red blood cells and platelets from God knows who, so I wasn't a stranger to the idea. But this was different," she says. "You know how people cut their palms and put them together? It's like we're blood sisters. We have the same blood, that kind of special bond."

It got her thinking: She'd really like to meet this person.

And so one recent morning, Anna Robinson and Katie Quinn found themselves converging on a New York City photo studio for a meeting arranged by SELF and DKMS. "I'm very excited and, at the same time, very nervous," said Quinn, bursting with energy as she sat on a love seat waiting for Robinson to arrive. For more than a year, she had wondered how her anonymous patient was faring; she'd even periodically called the DKMS office to try to wheedle information. So Quinn was thrilled when, at last, DKMS informed her that the recipient had been in remission for one year—and that she wanted to introduce herself.

Robinson emerged tentatively from the elevator, pale and frail. "I don't know what I'm going to say to Katie yet," she said softly. "It's hard to say, 'Thank you for being so selfless.' There really are no words to thank her for what she's done."

From across the room, the women spotted each other and uncertainly approached. They smiled shyly and then wrapped their arms around each other, Quinn towering over Robinson. "I can't believe I'm meeting you," Robinson said, looking her donor up and down.

"It's so nice to meet you," Quinn responded. She couldn't stop grinning.

After 20 months in remission, Robinson is out of immediate danger, but the specter of leukemia still looms large. The day she met Quinn, she had an upset stomach, a skin rash and dry eyes, all mild symptoms of "graft versus host disease"—in some ways a welcome sign, because it indicates that the new white blood cells are working. "It means Katie's cells are looking at every organ in my body," Robinson explains. "They're sort of cleaning out any cancer cells. And in the process, they're attacking all my cells, as they get to know the difference." During this get-to-know-you phase, which can last five years or longer, Robinson is protecting her new immune system by avoiding sick people, thoroughly cooking food and washing her hands a lot; she is rebuilding stamina and muscle tone through yoga and resistance training. And she is experimentally taking a cancer drug called sorafenib, typically used for kidney cancer patients, which Dr. Estey credits as playing a major role in her recovery.

"Anna is courageous—a remarkable person, to say the least," Dr. Estey says. "You can't underestimate the ordeal she's still going through. But she has done a great job in dealing with it." Her health forecast is uncertain. Anna still refuses to ask about her five-year survival odds but knows relapse is always a possibility. ("I'm hesitant to say I *had* leukemia," she says.) She runs the risk of developing secondary cancers later in life, due to her chemotherapy and radiation. But she remains as optimistic as ever. A few weeks after meeting Quinn, she vacationed in Australia with her boyfriend—a trip they started planning a year ago, when her immediate survival was a question mark—then returned to Smith for her senior year, finally ready to pick up where she had left off three years ago.

In the studio, Anna Robinson presented Katie Quinn with a black velvet box wrapped in white ribbon. "I have your cells to remember you by," she said. "I wanted to give you something to remember me by." She looked on bashfully as Quinn pulled off the ribbon and opened the box. Inside was a round silver pendant bearing an inscription that summed up everything she wanted to say: *The things that matter the most in the world can never be held in our hand.* ■