



Jennifer Jones Austin desperately needed a bone marrow transplant but even with 8 million possible donors, she couldn't find a match. What brought her back from the brink? Cord blood—a gift any new parent could give.

BY STEPHANIE BOOTH

# "Two Newborn Babies Saved My Life"

ON A FRIDAY AFTERNOON in September 2009, Jennifer Jones Austin came home early from work feeling achy, tired, and feverish. It was unusual for the then-40-year-old to be so wiped out. Even with her packed-full life—mother of two, senior vice president at New York's United Way charify, volunteer at her Baptist church—she rarely came down with so much as a cold. A doctor she consulted the next morning suspected a virus, and told her to rest.

Over the weekend, Jennifer's symptoms didn't improve. "Then on Monday morning when I tried to open my eyes, my vision was so blurred that I couldn't see," says Jennifer. "That's when I knew something was terribly wrong. My mother happened to be visiting, and I remember yelling out for her."

Jennifer was rushed to the emergency room, where doctors began a battery of tests. The next

day, on her daughter Kennedy's 12th birthday, she got a shattering diagnosis: acute myeloid leukemia, a cancer of the bone marrow that floods the body with immature blood cells, gumming up blood vessels and shutting down organs with alarming speed.

Jennifer needed immediate chemotherapy simply to stall those overproducing leukemia cells and survive the week. Then, as soon as possible, she'd need a bone marrow transplant.

"It was such a shock—before that Friday, I hadn't felt any symptoms," Jennifer says. "The last time I'd been in a hospital was when I gave birth to my son, Channing, seven years before."

Shawn, Jennifer's husband of 21 years, was suddenly facing the prospect of losing her. "The doctor explained that if we didn't get Jennifer a transplant, the cancer would come back, and there would be nothing we could do to stop it,"

he says. "The hardest thing I've ever had to do as a parent was sit our kids down in the den and tell them their mom might not make it."

The couple learned that her donor had to be genetically similar—otherwise the new white blood cells produced by the donated bone marrow would attack Jennifer's body as foreign. So her likeliest source was one of her three siblings. Again, awful news: None of them turned out to be a match.

Jennifer's only hope, then, was Be the Match, the largest registry of potential marrow donors in the world, operated by the National Marrow Donor Program (NMDP). But her odds still weren't good. "Patients are most likely to match someone who shares their racial or ethnic heritage, and when it comes to minorities, there aren't enough of them registered," says Dennis Confer, M.D., Be the Match's chief medical officer. "The more complex or unique your ethnic or racial background, the harder it is."

In fact, says Confer, the chances of finding a match are 30%

less for African Americans than for Caucasians. "Those chances were so hard to accept," says Jennifer, and she didn't get lucky. "Over 8 million people were signed up, and I didn't match any of them." When she and Shawn suggested trying to organize a local bone marrow drive, doctors gently cautioned them not to get their hopes up.

"They predicted maybe a hundred or so people would sign up, and our chances of a match would be 'infinitesimal,'" remembers Jennifer. "But Shawn just looked at me and said, 'We're doing it.'"

### **Calling All Donors**

The couple knew they had a powerful advantage in their vast network of caring family, friends, and colleagues. Shawn was a marketer who knew how to run awareness campaigns. Jennifer's father had been a well-known Baptist preacher. And Jennifer, who had decided against a corporate career while in law school, had spent 20 years advocating for at-risk kids—and building connections—in the government and nonprofit world.

From her bed at home in Brooklyn, Jennifer started phoning newspapers, TV stations, and radio shows. Shawn Skyped with relatives and friends, rallying them to start drives at churches, college campuses, and professional organizations for people of color. The family sent endless emails and posted pleas on Facebook.

"We got calls from friends, and then friends of friends," says Jennifer. "'Hey, I'm a member of a sorority in Cleveland. I can do a drive for you.' Or, 'Hi, I live in California. I want to help. What can I do?"

Even as the drive made progress, Jennifer needed two more rounds of chemo to keep her cancer at bay. "I began living in two worlds," she remembers. "One, where I was trying to keep my spirits up, going to as many baseball games and piano recitals as I could. The other, where I was going over my will and talking to my husband about how he would raise our kids after I was gone.

"I felt I had to prepare my family. I never wore a wig, because I thought they should see me in the realest way," she says. "Over and over, I'd ask Kennedy and Channing, 'If I die,

## WHY AREN'T WE BANKING MORE CORD BLOOD?

Until 1988, when the first successful cord blood transplant saved the life of a 5-year-old French boy, a baby's cut umbilical cord was simply thrown out as medical waste. Today, we know that its replenishing stem cells can save the lives of people with about 80 diseases, including leukemia, lymphoma, sickle cell, and cerebral palsy. "In some countries, like Italy, umbilical cord blood is donated by default, unless parents opt out," says Karen Ballen, M.D., of the Leukemia Program at Massachusetts General Hospital. "The U.S. isn't there yet." Only some 230 U.S. hospitals can readily accept donations (though others may be willing to be part of a mail-in program). Congress could expand donation programs: Urge your Representative to advocate for more cord blood banking using the easy email template at BetheMatch.org (look under "Advocacy").

# **How It Works**

Most future parents don't know that donation is an option, or how easy it is:

- At birth, after the umbilical cord is clamped, blood is collected from the cord—not, as is typically misunderstood, from the baby.
- The blood is tested, tissue typed, frozen, and sent to a cord blood bank, where it's stored until a patient requests it. The process is free and anonymous. See ParentsGuideCordBlood.org for more info, and spread the word: Cord blood can save lives.

what do you do?' And I'd have them say, 'I keep going.'"

By mid-January 2010, after 13 weeks of campaigns, a staggering 13,000 people had added their genetic information to the registry. Eighty percent were from ethnic minorities, possibly the largest group of minority donors added to NMDP in a single year. This influx almost immediately resulted in two or three matches for waiting patients—but none for Jennifer. "I'm a woman of great faith, but I began to falter," she says.

Then, later that month, her doctors surprised her. Two possibilities had been found—from an entirely different donor source.

### Newborn Promise

"My doctors said they'd found a match in a cord blood bank," says Jennifer. "I hadn't even known that was an option."

Cord blood is nutrient-rich blood that's left in the umbilical cord after a baby is delivered. Like bone marrow, it contains valuable blood stem cells. A small number of parents pay to bank their babies' cord blood privately, solely for their family to use in a medical emergency. An even tinier group—less than 5% of those who donate—choose to give it to a public bank, where it's

available, anonymously, to anyone who needs it. (See "How It Works," at left.)

Cord blood transplants are particularly promising because the match between patient and donor doesn't have to be as precise. "The white blood cells of a newborn have a higher tolerance for a mismatch," explains Andromachi Scaradavou, M.D., a pediatric hematologist at Memorial Sloan Kettering Cancer Center in New York City and medical director of the National Cord Blood Program at the New York Blood Center. And unlike bone marrow, which still has to be collected from the donor after the match is found, cord blood is already stored and ready to use.

There are drawbacks: For starters, the process is fairly new—fewer than 30,000 cord blood transplants have been performed. And because cord blood comes in a limited amount—about a half cup from each umbilical cord—it



"My doctors said they'd found a match in a cord blood bank," says Jennifer. "I hadn't even known that was an option." contains just a small number of stem cells. This meant Jennifer would need two donors instead of one, and her body would take longer to accept the transplant. She'd have a longer hospital stay and, potentially, more complications.

"It very much felt like an experimental procedure," says Shawn, "but we didn't hesitate. Jennifer had no other option."

In February 2010, Jennifer endured her fourth round of aggressive chemotherapy and radiation to knock out any remaining cancer cells. Then, she was hooked up to an IV that delivered the cord blood's healthy stem cells into her body. Afterward, she was in isolation for more than a month to protect her nearly nonexistent immune system from germs. Shawn and Kennedy had to dress in gowns, masks, and gloves when they visited. Hospital rules prohibited Channing from even entering her room. But after 41 days of painful isolation, Jennifer was sent home with her familyfor good this time.

This year, she hit a big milestone: five years cancer-free. She thinks often about the gift she was given. "I didn't donate cord blood when I had my kids—I didn't

know I could," she says. "Now I send out holiday cards every Christmas and, without fail, I write on the back, 'Help save a life,' and list websites for bone marrow and umbilical cord donation. I talk about it with every pregnant woman I can. Cord blood saved my life, but we're still throwing it away every day. That just kills me."

She comforts herself knowing that the bone marrow donors who stepped up for her are still saving others. Three to four dozen matches have resulted from her drive. "Just today I got an email from a former colleague who's donating," she says. "That's the power of community."

Jennifer will never know her donors, but she understands, deeply, the significance of receiving cord blood from two newborn African American boys. "I spent so many years helping kids who needed a lifeline," she says. "Then, two little babies saved me." •