Student's bone marrow donation saves boy with leukemia

Denise Brehm, News Office February 13, 2002

The odds were 20,000 to 1, but Stefan Bewley decided to try anyway when he participated in a bone marrow drive for a fellow undergraduate several years ago.

"You get so few chances to really make a difference in someone's life," said Bewley (S.B. 2001), now a graduate student in environmental engineering.

He had no way of guessing that his marrow would later turn out to be a perfect match for an eight-year-old boy in Worcester. Nor would he know until much later that he and the boy, who could have been anywhere in the world, lay in beds in the same hospital during the marrow transplant.

He did know that bone marrow contains stem cells that, when transplanted into people whose immune systems have been defeated, can create a healthy, new immune system for that person. People with diseases such as leukemia often require transplantion of healthy bone marrow, offering them the hope of a renewed immune system similar to that of the healthy donor.

But finding a donor match is difficult, and downright rare for people of Asian and African descent. No match was found for David Li, the undergraduate student whose tragic death, brought on by acute lymphoblastic leukemia, awakened many members of the MIT community to the importance of the National Bone Marrow Registry. The chances of Caucasians finding a match are about 20,000 to 1. The chances of Li, an Asian-American, finding a match may have been as low as 1,000,000 to 1. His friends at MIT organized two donor searches in 1999, but were unable to find a match. Li was 20 years old when he died on August 7, 2000.

The little boy in Worcester was luckier.

Five months after registering his blood sample, Bewley got a call from the Dana Farber Cancer Institute in Boston saying he might be a match for someone in need of his bone marrow.

"I was shocked, because I knew how long the odds were," said Bewley, then a senior in chemical engineering. "It was exciting. I felt like I'd won the lottery."

After further testing, for which Bewley gave another blood sample, the experts at the Dana Farber determined that his bone marrow was a "perfect match" for an anonymous patient. Additional tests determined that Bewley--a member of MIT's swim and water polo teams who won the 2001 Howard Johnson Award as best male senior athlete of the year--was healthy enough to be a donor.

Several weeks later, in November 2000, he was escorted to Brigham and Women's Hospital by a Dana Farber transplant coordinator. Bewley said the Dana Farber provided counseling to help him make his decision ("It took me about 10 minutes," he said) and arranged to take him to and from the hospital for the outpatient procedure. "The doctors and support team were fantastic," he said.

Bone marrow, a soup-like fluid, was extracted from Bewley's hip bone through a needle inserted into his lower back. He opted for general anesthesia, but was alert enough later in the day to write a note on the get-well card he had purchased for his marrow recipient. The confidentiality of both donor and recipient is strongly protected by the marrow registry; Bewley knew only that the recipient of his marrow was a child with no brothers or sisters.

The next day, Bewley sent the get-well card through the Dana Farber to the boy. A month later, he received a card from the child's parents. They said they expected their son to be home by Christmas.

"The full impact of the operation didn't really hit me until I heard back from the parents in a letter that said the boy was doing well," said Bewley. "Before that, it was just me and the doctors, who were certainly caring, but there wasn't any real emotional content for me. But to have a parent write to you and tell you that you saved their child's life is overwhelming, to say the least."

"I think it's a great thing that he did," said Kenny Von Stein, father of Jacob, a fourth-grader who now leads a normal, active life. "If Stefan hadn't signed up at the exact time he did, I don't think it would have turned out so well. Everything just fell into place for Jake."

The child had been diagnosed with acute lymphcytic leukemia in April 2000 when he was only seven. His body was bombarded with chemotherapy. When he didn't respond, he was placed on a bone marrow donor list, where he remained for only two months before a match was found.

WHO WAS THE DONOR?

During Jake's three-month stay at Children's Hospital in Boston, his parents, who had to give up their jobs and income for the period, lived at the Ronald McDonald house. All they knew about the donor was that he was a 21-year-old male living somewhere in the world.

"Every once in a while I'd think, 'Gee, could he be in Boston?' Then I'd think, 'No, what are the chances of that?'" said Von Stein. But one year later, he and his wife, Tami, petitioned the Dana Farber to release the information.

"I had never believed in destiny so much as when I found out he was in Cambridge. They were a few hundred yards away when they were giving, and being given, the marrow. That was unbelievable. His donor could have been anywhere in the world," said Von Stein.

Letters were exchanged. Bewley's mother wrote to Jacob. Jacob's grandmother wrote to Bewley. A meeting was arranged outside the Museum of Science last December.

Von Stein said they knew Bewley would be wearing a maroon sweatshirt. As they scoured the people going in and out of the museum, Jacob asked his father what maroon looked like. "I saw a maroon sweatshirt and I said, 'That's maroon. Right there.' And I knew it was Stefan because his eyes just lit up when he saw Jake," recalled Von Stein of that first meeting.

"I was very nervous standing out there," said Bewley, who comes from Atascadero, Calif. "But from the first visit it's been very comfortable. We've been seeing each other frequently. I'm getting to know them as people and not as a cancer patient and his parents."

Bewley said Jake loves to play Nintendo and hopes to begin playing basketball soon. The boy didn't fall behind in school during his long illness, thanks to some very good tutors. "He made seven As and five Bs on his first report card," his father said. "I was very impressed with it."

The Von Steins and Bewley plan to spend spring break together at Disney World, courtesy of the Make a Wish Foundation. Jake wanted his donor to come along and Bewley wants to make the trip, even though he is fully aware that an MIT student planning to graduate in June would ordinarily be working on his thesis during the break.

Bewley calls the whole experience of donating his marrow and getting to know the Von Steins "a good wake-up call. Being at MIT, it's easy to lose track of your priorities. Something like this makes you step back and remember--or become more aware of--the priorites you had before coming to MIT," he said.

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