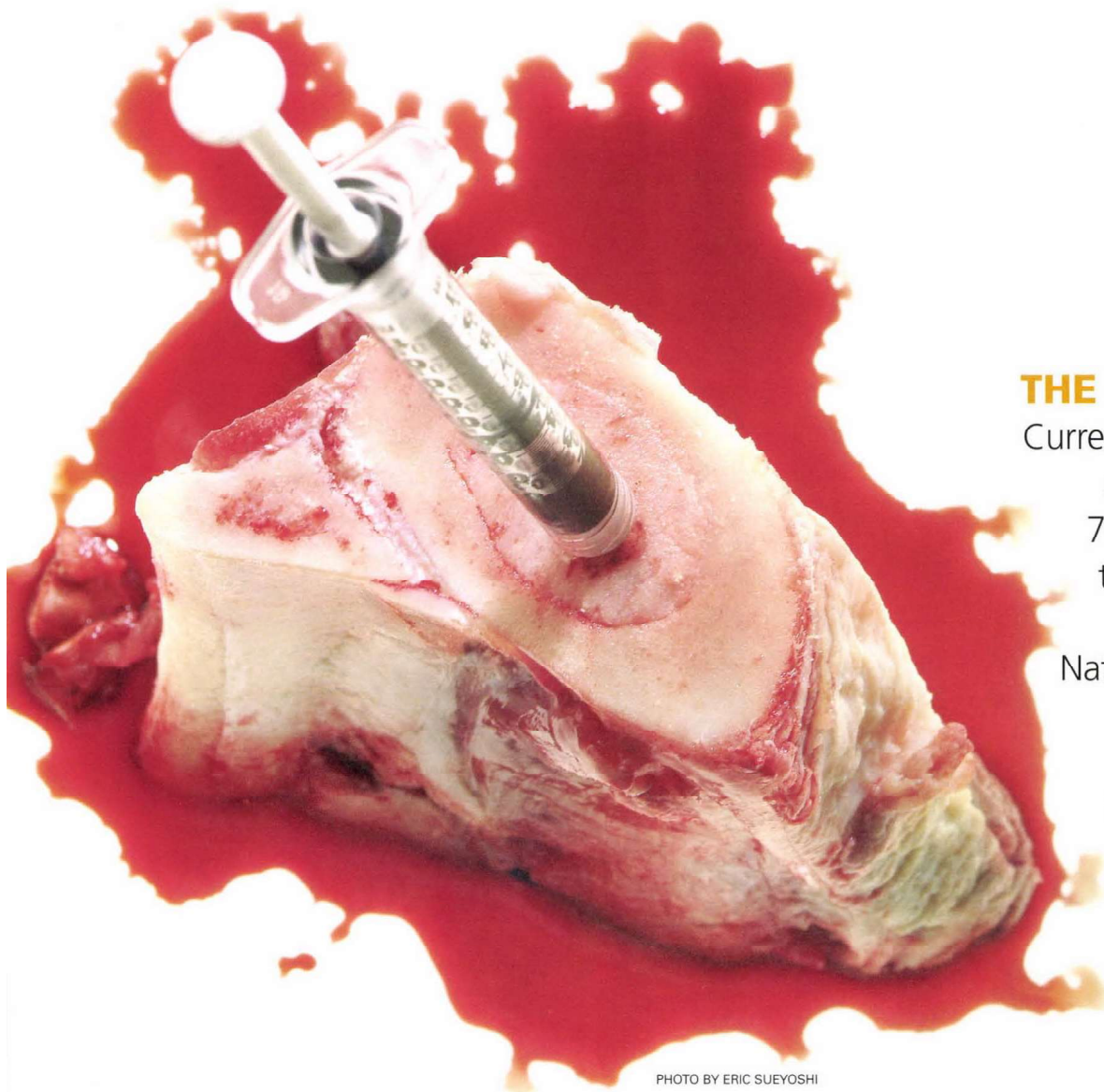


Could your bone marrow save someone from a life-threatening blood disease? Probably.

BONDED by **BLOOD**

STORY Teena Apeles



THE GORY DETAILS

Currently Asian Americans account for less than 7 percent of the more than 5 million people registered with the National Marrow Donor Program, leaving hundreds suffering from life-threatening blood diseases with little hope of finding a match within their own race.

PHOTO BY ERIC SUEYOSHI

Southern California native Valerie Sun, who is of Chinese and Caucasian descent, was 11 years old when she was diagnosed with aplastic anemia, a rare condition wherein a person's bone marrow fails to produce enough blood cells, leading to severe fatigue, inability to fight infection and potentially more serious health problems. In Colorado, an uncontrollable nosebleed signaled that 9-year-old Thai adoptee Zak Rossbach had the same condition, which destroyed 95 percent of his bone marrow.

More than 30,000 people of all ages, races, ethnic communities and socioeconomic backgrounds are diagnosed with life-threatening blood diseases each year. Though this is a daunting number, more than 70 of these blood diseases — including certain acute and chronic leukemias, stem cell disorders, and inherited immune system and genetic disorders — can be treated with healthy bone marrow or stem cells from a living donor.

For Valerie and Zak, there was a chance for a cure. Each would have to find a person whose tissue type matched theirs in order to receive a transplant that could save their lives. Because tissue type is inherited, the best chance of matching is with a sibling, and about 30 percent of those who need a transplant will find a matching donor within their family. As an adoptee, this option wasn't available to Zak, and unfortunately Valerie was unable to find a match in her family despite having two siblings. Like the remaining 70 percent of patients eligible for treatment by transplant, they needed to search for an unrelated donor, and the next best chance of a perfect match was with someone of the same race or ethnicity.

Numbers game

Though Asian Americans are getting these diseases at the same rate as other

populations, when it comes to finding a donor, it's a basic problem of supply and demand. Currently Asian Americans account for less than 7 percent (about 349,000 people) of the more than 5 million people registered with the National Marrow Donor Program (NMDP), a non-profit organization that facilitates transplants for patients who do not have a donor in their family.

In the early '90s, the chance of Asians finding a donor on the registry was bleak. Only 28,203 Asian American volunteer donors were listed and a mere seven Asian Americans had received bone marrow or stem cell transplants by 1992, versus the almost 1,300 Caucasians who received transplants. Twelve years later, with more than 12 times the number of Asian American donors registered, the number of transplants for Asian Americans has increased to 529, but more donors could mean even more people who can potentially help someone overcome disease.

Just ask Joe Philipose. Of Indian heritage, Joe was in law school in 1997 when he heard about a bone marrow drive for a couple with a baby who needed a transplant. "It seemed like the kind of thing I should do," he recalls. A year after registering, he became a potential match for a boy with severe aplastic anemia. On some occasions, people on the registry have turned down the opportunity to donate when called upon. This can be devastating, especially when lives are at stake. But Joe wasn't backing out. "One of the big motivators [for me] was what if this was my child?" he remembers.

Besides the boy's age and illness, Joe knew nothing about who was receiving his marrow, which is typical protocol. No personal information is given to either the donor or patient until a year after the transplant. In 1999, after the NMDP-imposed confidentiality period ended, Joe had the opportunity to meet his "blood brother" Zak Rossbach and his father Gary

"...taking 10-15 minutes of your day to get tested could add 70 years onto a child's life who maybe won't make it through the year."

— Valerie Sun,
bone marrow recipient

QUICK FACTS:

- **To be a donor, you must be between 18-60 years old and in good general health.**
- **To be a donor and join the NMDP registry you must provide a small blood sample, which is used to determine your tissue type.**
- **There is no charge for minorities to join the registry.**
- **Once you've joined, your profile will be active until you turn 61, unless you ask to be removed before then.**
- **You won't be responsible for costs if you are asked to donate, though you will need to take time off from work.**
- **Donating takes about 90 minutes. A needle is inserted into the pelvic bone to extract the marrow.**
- **Bone marrow regenerates.**
- **Donating stem cells involves a series of shots over four to five days, followed by a procedure to stimulate the production and release of stem cells. Collecting the cells can take more than one visit. The actual process takes four to five hours.**

on a national television talk show. "We both thought it would raise awareness, and would really give the marrow donation program the exposure it deserved," says Joe. He adds that the experience was "phenomenal." "The look on Gary's face was all the thanks I could ask for."

she was told about a potential match, and she underwent a successful marrow transplant on September 8, 1999. The year following her treatment, she made contact with her donor, who happened to be Caucasian, and on the verge of the 5-year anniversary of her transplant.

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Ready to take action?

Contact one of the organizations below to get involved.

The National Marrow Donor Program:

(800) Marrow2,
www.marrow.org.

The Asian American Donor Program:

(800) 59-Donor,
www.aadp.org.

Asians for Miracle Marrow Matches (A3M):

(888) A3M-Hope,
www.asianmarrow.org.

Cammy Lee Leukemia Foundation Inc.:

(800) 77-Cammy,
www.cllf.org.

City of Hope:

(800) 826-Hope,
www.cityofhope.org.

Hawaii Bone Marrow Donor Registry:

(877) HI-Donor

South Asian Marrow Association of Recruiters Inc.:

(718) 592-0821,
www.samarinfo.org.

Now, Gary's happy to report that his son is entering high school, is doing great and loves to play soccer, but none of this would be possible if not for Joe. "It's the thing in my life I'm most proud of and I don't think it was that difficult to do," says Joe. "There's people dying and there's a way to save them. It seems as simple as that."

All you need is time

While Zak found his donor in a relatively short time, Valerie's search for a transplant was especially grueling. She was looking for a donor during a time when not only the total number of volunteers on the registry was just above 740,000 (versus the 5 million plus listed today), but Asians only made up 3.8 percent of that population. She knew that though it was not necessary for her donor to be of the same ethnic background to be a match, it was the best chance, and as a person of mixed race, her outlook was pretty grim. Her chances were "one in a million," she says.

She was on the registry for seven years, receiving numerous transfusions in order to make it into her teens. "That's the way I survived," she recalls, "getting blood transfusions and platelet transfusions every two to four weeks, from 8 a.m. to 5 p.m." It wasn't until the summer after her freshmen year in college that

Valerie will get to meet her donor in person at the end of summer.

Meanwhile, she continues to encourage others to join the registry. "The amount of pain and discomfort there might be [if you donate] is nothing compared to what a cancer patient goes through daily," she says, also stressing the fact that donating marrow is not like donating an organ. "The marrow grows back. There's pretty much no permanent risk to the donor and taking 10-15 minutes of your day to get tested could add 70 years onto a child's life who maybe won't make it through the year."

About 3,000 families browse the NMDP registry each day in search of a second chance. NMDP is connected to 22 other countries with donor registries, and through these cooperative agreements, NMDP can search more than 2.5 million additional potential donors on behalf of one of its patients. And though the number of Asian American volunteers has grown significantly in the last decade, people drop off the registry every day, for a variety of reasons, mostly due to outdated information or sometimes a change of heart. While NMDP and its affiliates are launching several initiatives to help retain donors as well as to educate and recruit Asian Americans to up their numbers, every new person who registers can make a difference. Could it be you? ❁