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Donor search dilemma

2-year-old needs a bone marrow transplant – but the pool of possible matches is small

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The somber setting of a hospital room didn't dampen Tatiana Vaitai's spirits last week.

The 2-year-old cancer patient sat up in her room at UC Davis Medical Center in Sacramento, arms flailing as she showed off an ear-to-ear smile. Her fever had dropped and her appetite was hearty. She munched on sushi rolls and cheerfully watched Elmo DVDs.

Months of chemotherapy have staved off Tatiana's leukemia – she's in remission now – but the fight has left her body weak and vulnerable to illness.

"The hospital is our second home," said Tatiana's mother, Marian Vaitai.

Vaitai said doctors suspect the cancer may come back, and told her a bone marrow transplant is Tatiana's best option.

That will be a challenge, however, as the pool of possible donors for Tatiana is small. There are few Asian Pacific Islanders among the 7 million names on the national bone marrow registry.

The family will hold a bone marrow donor drive next Saturday to increase awareness within Sacramento's Pacific Islander community, interest that could lead to a donor match for Tatiana.

Doctors will continue different levels of chemotherapy to keep Tatiana in remission over the next three months. If a donor is not found by then, Vaitai said, doctors will reassess treatment options.

"That gives us three months to find a donor; that's the purpose for the drive," Vaitai said.

Chemotherapy eradicates cancer cells, but also kills healthy cells. The idea is to get healthy donor bone marrow to grow and thrive in Tatiana's body, instead of cancerous cells.

About a third of the time, patients can find a potential match among family members. In Tatiana's case, her mother, father and 6-year-old sister Daphne did not turn up as matches. The family turned to the national registry, but have not found potential matches, Vaitai said.

A good match is critical to a successful transplant.

Molecular tests match patients and donors. A good match means patient and donor share similar proteins on the surface of their cells. Proteins, or markers, are used by the body's immune system to identify foreign substances. If proteins are more similar, a patient's immune system is less likely to attack donor cells.

An "exact match" could promote donated cells to grow and thrive in a patient, said Dr. Patricia Kopko, Medical Director of BloodSource, a blood bank serving Northern California.

"Not only do you have to have all 10 proteins, you have to find them all in one donor," she said. Such a match is "most likely within her ethnic group."

Of Tongan descent, Tatiana will most likely find a potential donor within the Pacific Islander

community.

According to Kopko, race and ethnicity play a role because certain groups have more "variability" in the cell surface proteins. That variability makes it harder to find a perfect match.

A challenge to finding a donor for Tatiana is the sheer odds. In the national registry, there are only 8,700 Native Hawaiians or Pacific Islanders.

The real number may be even lower.

Kopko said it is heartbreaking for some families when a match is found, but the donor is no longer willing to donate marrow.

According to the National Marrow Donor Program, availability of donors ranges from 40 percent to 70 percent, and the follow-through among minority-group donors is below 50 percent.

Registered donors may decline for health, personal and emotional reasons, said Michelle Setterholm, director of scientific services for the National Marrow Donor Program.

In some cases cord blood can be an alternative, Setterholm said. Cord blood is umbilical cord blood extracted from the mother's placenta after she gives birth. Blood is tested, tissue-typed, and stored in cord blood banks. The national registry includes more than 70,000 cord blood units.

"These stem cells from an umbilical cord blood have more flexibility," Setterholm said. And mismatched markers do not have a negative impact on the outcome.

Vaitai said she's not yet talked to Tatiana's doctors about cord blood transplants. For now, the family is focused on the bone marrow donor drive and getting Asian Pacific Islanders to sign up as potential donors.

Vaitai is reaching out to Sacramento's Pacific Islander and Polynesian community through her church.

Jarvis Mahe, Bishop of the Liahona Tongan Ward Chapel, said the Pacific Islander community is "not informed" about the need for more bone marrow donors.

The Vaitai family and friends plan similar drives in Utah, Hawaii and Texas – other states with large Pacific Islander communities – to spread the search for a perfect match, Marian Vaitai said.

No one will be turned away, Vaitai said. The broader goal is getting more people, from all communities, to register as donors.

"It is not only to benefit Tatiana, but also benefits every child if more people join the registry," she said.

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