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U.S. couple sets up bone marrow registry in India

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BANGALORE (Reuters) - Venture capitalist Tim Dutta spent a morning scraping the insides of employees' cheeks at one of India's biggest software firms as he tried to save other people from a disease that almost killed his wife.

Dutta aims to create the world's largest registry of South Asian bone marrow and stem cell donors after discovering the current shortage the hard way: his wife Pia developed leukemia in 2002 at the age of 27 and the couple struggled to find a matching donor to save her life.

"We were devastated," recalls 36-year-old Dutta, who was born in India but now lives in New Jersey in the United States.

"When we first started, there was no where to go to, no one to turn to. A match was not on our cards anytime soon, as there are so few South Asians registered as donors."

The cancer was attacking Pia's bone marrow and interfering with her body's production of blood cells.

Doctors told Pia the best chance of survival would be to receive a transplant from a donor to replace her diseased bone marrow with healthy blood stem cells -- the cells that can develop into different types of mature blood cells.

But a successful transplant requires the cells come from a donor with a genetically identical or similar tissue type.

The best donors are usually among the patient's immediate family, but in Pia's case a match could not be found. After that, patients are most likely to find a match within their ethnicity.

So the couple looked at the 10 million potential donors signed up to America's main bone marrow registry, the National Marrow Donor Program (NMDP), and its partner registries around the world. But the news was disappointing.

"About half of the patients searching for a match cannot find a suitable donor," explained Dr. Jeffrey W. Chell, NMDP's chief executive officer, in an e-mail.

He said that South Asians are particularly under-represented on donor registries, making it difficult for cancer patients of South Asian origin to find donors.

"Some parts of the world such as Europe and Australasia have well-developed donor registries," he explained. "Other areas like Africa and South Asia would benefit from more donor registries."

Bone marrow campaigners say it is difficult to raise awareness in India as communities are fragmented by language barriers -- more than a dozen different languages are spoken -- as well as at least half a dozen religions, from Buddhism to Islam, with varying views on medical intervention.

DEFEAT NOT ACCEPTABLE

With the bad news from the NMDP, the Duttas had blown what Tim says was their 1 in 20 million chance of finding a match. Tim was told to enjoy whatever time he had left with Pia.

"That was not acceptable," said Tim. "So we took matters into our own hands."

The couple set up a charity called Matchpia (www.matchpia.org) in 2004, which collaborated with the NMDP and started organizing drives to encourage donors to sign up all over the United States to find Pia and others a match.

They finally found one for Pia in late 2004 and she underwent the transplant surgery. There are risks and possible complications -- including the body's sometimes fatal rejection of the transplant -- but Pia is now doing fine.

"One would never know she is a cancer survivor," said Tim.

The couple have continued campaigning, and have now added close to 34,000 donors to the registry through the Matchpia project.

They are now widening their scope, setting up the United South Asian Donor Registry in India in October 2006 -- the first functional registry of its kind in the country, says Dutta.

They are spending more than $12 million on the project, with funding coming from their own pocket, friends, family, and corporate sponsors, including drug company Abbott Laboratories Inc. and a New York-based company, Histogenetics.

LOW PUBLIC HEALTH PRIORITY

There is no reliable data on the number of cancer patients who require stem cell transplants in India.

Experts give varying figures ranging anywhere from 2,000 to 30,000 a year, which makes setting up such a registry a low public health priority in a nation of over a billion people.

Dutta has already recruited over 5,000 potential donors in recruitment drives at companies in six Indian cities. In keeping with standard medical practice, they are all unpaid volunteers.

Should someone on the list match a patient, the donor undergoes health checks and is offered counseling before deciding whether to go ahead with the donation.

The donating process is only a little more intimidating than a simple blood donation, requiring a number of hormone injections over several days before stem cells are extracted from the bloodstream through a needle.

"Saving a life means a lot," said Indrajit Aich at a recent recruitment drive in the southern city of Bangalore, as Dutta prepared to swab the inside of his cheek.

"That was the basic motivation for me."