

Indians at Risk for Rare Blood Disorder Thalassemia

By **LISA TSERING**
India-West Staff Reporter

Indian Americans are at greater risk of contracting thalassemia than many other ethnic groups, according to a study by the Children's Hospital and Research Center Oakland in Oakland, Calif. To coincide with International Thalassemia Day May 8, the hospital is urging the community to get tested — and to seriously consider banking their infants' cord blood.

Gargi Pahuja, a thalassemia survivor who has devoted her professional and personal life to increasing awareness of the disease, says people from North India are especially at risk. "If you are Punjabi, or Gujarati, or Sindhi, you need to get tested," she said.

The rare and hereditary blood disorder can result in severe anemia. Children with thalassemia often require frequent blood transfusions and lifelong medical treatment.

Gargi Pahuja, a health care law attorney in New York, was diagnosed with thalassemia when she was 12 months old. "My parents were from India and they hadn't

heard of it," Pahuja told **India-West** in a phone interview. "They were shocked to find that they carried the trait."

Since thalassemia is so rare, some doctors are likely to confuse its symptoms, which include yellow skin, with jaundice. But thalassemia is a much more serious disease.

Thalassemia (also known as Mediterranean anemia) is an inherited blood disorder characterized by less hemoglobin and fewer red blood cells in the body than

normal. Since hemoglobin allows red blood cells to carry oxygen, a deficiency leads to anemia, marked by fatigue, pale appearance, shortness of breath and weakness.

Pahuja is 35 years old, and continues to get blood transfusions every two weeks.

"The fact that I'm 35 is an important milestone," she told **India-**

West. "My parents were told that I would die by the age of 15... my generation is the first to live into their 30s, 40s and 50s."

The cause of thalassemia is defects in the genes that make hemoglobin. The only way to contract thalassemia is to inherit one or more defective hemoglobin genes from your parents.

Infants in California are required to receive a test for thalassemia, but California is the only state to require the test, said Pahuja.

Bone marrow transplant is the established treatment to cure thalassemia. Umbilical cord blood stem cells donated by a sibling have been proven to cure 91 percent of cases, according to a 2007 Children's Hospital study of 40 children.

A Mayo Clinic statement said that most children with moderate to severe thalassemia show signs within the first two years of life. Prenatal testing is also available, at 11 weeks (chorionic villus sampling), 16 weeks (amniocentesis), and 18 weeks (fetal blood sampling).

"People need to be tested so that they can make informed decisions regarding family planning," said Pahuja.

The Children's Hospital study showed that in the United States, around two million people are carriers and that around 1,000 people have the full-blown disease. The hospital has one of the largest thalassemia centers on the West Coast, and currently treats around 300 patients.

In the U.S., there are more than 5,000 thalassemia cases, and those numbers are expected

to rise as the trait carrier population increases, said the study; in Alameda County alone, the Asian Indian population is more than 47,000 and has increased by 209 percent in the last decade, according to statistics provided by the



An Indian doctor checks on a thalassemia patient receiving blood at the Indian Red Cross Society's Ahmedabad District Branch May 7, 2009. Thalassemia is a genetic disease that disproportionately affects Indians, said a study by the Children's Hospital and Research Center Oakland in Oakland, Calif. (AFP/Getty Images)

Asian American Pacific Islander Health Forum.

According to Pahuja — who says she has devoted her professional and personal life to increasing awareness of thalassemia — people from North India are especially at risk. "If you are Punjabi, or Gujarati, or Sindhi, you need to get tested," she told **India-West**. Individuals who are past child-bearing age need not get tested, she added.

In India, as many as one in eight people are believed to be carriers of the thalassemia gene, and in India, it is expected that 1 million people will have the disease in the next 40 years. Babies born there are 80-90 percent likely to die of the disease, said the Children's Hospital spokesperson. But increasing awareness of the disease there has opened up a market

for blood cord banking; a recent Mumbai Mirror article states that there are now three private stem cell banks — one run by Reliance in Mumbai; the CryoCell stem bank in New Delhi; and Life Cell, run in collaboration with Cryo-Cell International, U.S.A., in Chennai.

In India, it costs around Rs. 70,000 (\$1,575) to preserve a newborn's cord blood for 20 years. Here in the United States, the average cost is around \$2,000.

For more information on thalassemia, call Children's Hospital Oakland Thalassemia Outreach at (510) 428-3885 or Cooley's Anemia Foundation at (800) 522-7222, or visit www.thalassemia.com, http://www.childrenshospitaloakland.org/healthcare/depts/hematology_services.asp or www.thalassemicsindia.org.

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