

# Life line

Sister's cord blood used to treat thalassaemia boy in India's first mixed stem cell transplant

BY RABI BANERJEE

**F**ive years of marriage and several complications later, the birth of their son Moinam in 2005 only increased Manisha and Ashim Pal's worries. Within a year, the Siliguri-based teacher couple's child was diagnosed with a complicated strain of thalassaemia.

Trouble began days before Moinam's first birthday. He turned pale and drowsy and couldn't breathe properly. He was rushed to a doctor who found him to be anaemic, with a haemoglobin (Hb) level of 8.6. The doctor prescribed iron syrup. A month later, the Hb levels plummeted further. This time, the doctor asked the Pals to go in for an electrophoresis test for thalassaemia.

Thalassaemia is a genetic disorder characterised by an imbalance in the amino acids that synthesise haemoglobin, the oxygen-carrying pigment in red blood cells. There are two types—alpha-thalassaemia (where the alpha chain of amino acids is affected), and beta- (affecting the beta chain). While the alpha- version affects those of Asian and African origin, the beta-strain traces its origin to the Mediterranean, from where it spread to Malaysia, Myanmar and Bengal. Moinam was diagnosed with e-beta thalassaemia, characterised by the presence of abnormal haemoglobin E.

A recent study suggests that cross-



TO BROTHER, WITH LOVE:  
Ashim Pal with daughter Ahoma

breeding with the northeastern tribes made the Bengalis vulnerable to e-beta thalassaemia. "The disease had reached the northeast centuries ago, through the invasion of Alexander the Great," says Dr Proshanto Chowdhury, medical director, CordLife, a cord blood banking network. "Had Alexander not invaded India, perhaps the Bengalis would not have carried the thalassaemia gene. The gene spread from here to even Sri Lanka during Ashoka's rule." He adds that alpha-thalassaemia spread from the middle east to the Sindh and Punjab areas.

Despite blood transfusions, haematologists in Kolkata told the Pals that Moinam's lifespan could not be prolonged beyond 10 years. "I could not even look at our son, who came to us after years of delay," says Manisha. "Was this the ultimate 'reward' God had in store for us? I had many sleepless nights. I even thought it would have been better to have remained childless than to have a baby with a deadly disease."

But the Pals weren't ready to give up on Moinam. "We brought him into the world," says Ashim. "It was up to us to give our last drop of blood to save his life."

The couple travelled to Vellore, from where they were directed to a haematologist in Delhi. At the All India Institute of Medical Sciences, doctors gave them a ray of hope—stem cell therapy, done with maximum accuracy.

Since the doctors told them it could be done in Kolkata, too, the couple returned home in 2006. Dr Ashish Mukherjee, director of Netaji Subhas Chandra Bose Cancer Research Institute gave them the answer: mixed stem cell transplant. The trouble was, it had never been done before in India.

"So we had no idea of the success rate," says Ashim. "But we had no choice." The procedure

would involve transplant of bone marrow or umbilical cord blood from Moinam's nearest of kin. "But bone marrow transplant alone could lead to graft versus host disease [GVHD], where stem cells produced by the transplanted bone marrow are rejected most of the time, by the recipient's body," says Chowdhury. "So, umbilical cord blood has to act as a catalyst and prevent rejection of stem cells due to GVHD. The best option was mixed transplant of bone marrow and umbilical cord blood, to produce stem cells." Umbilical cord blood alone could not produce the huge number of stem cells needed to cure Moinam, who was at an advanced stage of thalassaemia.

The Pals decided to have another baby. Their daughter, Ahoma, was born without complications, and her HLA (human leukocyte antigen) matched perfectly with Moinam's. Her cord blood was banked at CordLife. After her second birthday, Ahoma's bone marrow was removed and transplanted into Moinam, by Mukherjee, with Chowdhury's assistance, this April.

The Pals feel guilty that Ahoma has been deprived of her own umbilical cord blood, a boon which can help cure some deadly diseases. Cord blood can be stored for decades, but few parents are banking their baby's. Ahoma does not have an option if she comes down with a deadly disease later in life; her cord blood has already been used to save her brother.

Governments in Europe and the US are considering banning cord blood use on anyone apart from the owner of the cord, after children growing up and suing their parents for using their cord blood to save a sibling. In India, such a law is yet to be considered. "Since the parents are the custodians of children, we have taken their consent as final," says Chowdhury.



**GRATEFUL:** Manisha with son Moinam, who received Ahoma's stem cells

But Indian Medical Association members feel Ahoma is the owner of her cord blood, and not anyone else. "The donor of the cord blood is the newborn, the person at whose birth the cord blood is collected," says a member. "At least, that is what medical ethics is all about."

Worse, the Pals feel guilty at neglecting Ahoma. They have rented a flat in south Kolkata, close to Netaji Subhas Chandra Bose Cancer Research Institute. Moinam is now in a dust- and infection-proof environment, where he would have to stay for a few months. Ahoma is with relatives some 700km away. "I am sorry that I cannot even be affectionate towards my baby daughter, but what can I do?" asks Manisha.

The Pals say they will not differentiate between their son and their daughter. A blood test has confirmed that Ahoma is a carrier of thalassaemia and, hence, she does not have the disease. "I want to enrol both of them in good schools," says Ashim. "For me, my daughter is a blessing who saved our family from ruin." ●