

Incurable no more. Inaccessible no more

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How strangers across the globe are helping India fight the Thalassemia monster



Adding 10,000 new Thalassemic Major and an equal number of Thalassemia Intermedia children to the world, India is one of the countries worst affected by the disease. Despite being such a widespread disease, it is one of the lesser understood ones, surrounded by myths and misconceptions. For instance, people commonly believe that two Thalassemia carriers cannot have a healthy child. This is merely misconceptions. Truth is, there are medical solutions for 2 thalassemia carriers to have a healthy child. It is also commonly believed that Thalassemia is incurable, when in fact, the field of medicine has come up with a cure for this deadly disease.

Unfortunately, most of these children do not make it past their twenties and thirties. **In fact, there are over 1 Lakh children with Thalassemia being transfused every month. Unfortunately, most of them do not make it past the age of 20** due to lack of access to treatment. Financial constraints could be a great impediment to access in a country like ours with great economic inequality.

According to a research conducted at the Institute of Haematology & Transfusion Medicine located in Medical College, Kolkata, an average $18.5\% \pm 14.3$ of the total annual income is spent on the treatment for thalassemia in low-income families. Average man-days or school days lost for the patients was 29.87 ± 18.5 and 19.07 ± 12.7 for the accompanying persons. So far, a bone marrow transplant is the only known permanent cure for this deadly disease, though the treatment may cost anywhere between 10-15 Lakh and 30-45 Lakh. In some states like Tamil Nadu and Assam, the government provides financial aid to those suffering from this disease, but despite all help, the amount can easily go beyond the affordability of a common man.

Shayan Dey was diagnosed with Thalassemia Major when he was just 7-months-old. By the time he turned 4, he was

vomiting blood and having fits at night. Even with his limited means, Sayan's father could not afford to miss a single transfusion. With no matching donor in his family, the only life-saving treatment, a bone marrow transplant was estimated to cost 43 Lakh. The doctor helped the family set up an online fundraiser on Milaap. People from across the world showed their support and made Shayan's treatment possible. Today, Shayan is hail and hearty thanks to the generosity of over 2400 complete strangers who knew nothing about him before the fundraiser.

Bangalore, with a bunch of super-specialty hospitals, is a hub for people seeking quality healthcare solutions, especially those traveling from the far east and north, particularly from states like Tamil Nadu, Odisha, West Bengal, Andhra Pradesh, Maharashtra and even from Bangladesh. For them, the treatment costs are accompanied by additional expenses of travel, stay and even food.

Dr. Sunil Bhat, Head of Hematology, Oncology and Bone Marrow Transplantation at Mazumdar Shaw Cancer Center, Narayana Health City, Bangalore said, "*The cost of a Bone Marrow Transplant is still quite low in India in relation to west and approx 10-15% of cost in US or Europe. One would be lucky to find a matching donor in one's family, in which case the treatment would cost significantly lesser (10-12 lakhs). However, if there are no fully matched donors in the family, we have options of unrelated donors and half-matched donor transplants, the costs may go up to 40 Lakh or more. Crowdfunding should definitely be one of the options people explore for financing healthcare expenses. With the number of people online with the ability and willingness to help, platforms like Milaap open up a promising ray of hope for patients*"

Knowing how difficult it could be for his patients after spending most of their life earnings on transfusions, Dr. Bhat has been running digital fundraisers for his patients for the past 4 years on Milaap, South-Asia's largest platform for personal and medical needs. He has so far set up over 250 fundraisers, which have raised a total of more than 16 crores on Milaap.

Regarding this collaboration, Anoj Viswanathan, President and co-founder, Milaap, said, "It's heartening to see healthcare providers like Dr. Bhat going one step ahead to ensure people get the quality treatment and care they seek for their loved ones, irrespective of financial constraints. Milaap aims to connect those in need with those who can help, and it is amazing to see how so many patients are helped by complete strangers."

Unfortunately, the only way to prevent this deadly disease is by testing the carrier state before marrying or planning a child. On the bright side, the disease is no more incurable. The treatment available is highly specialized and intricate, but the results have been great so far, especially in the case of younger children. Milaap urges parents to not hesitate and open the doors of help to the world.

Milaap works with over 300 hospitals across the country to reach out to people like Shyan and his family, making the process of verification, data collection and even fund transfer hassle-free for those in need.

Setting up an online fundraiser is a process of less than 5 minutes and does not require a lot of technical know-how. Campaigns can be setup using Whatsapp, other instant messaging apps and even without typing, by recording their story in any of the 8 available Indian languages. It is then automatically transcribed to create text. All of these features open up online fundraising to anyone with a smartphone. Milaap has so far raised over 550 Crores for such causes from across India, over 80% of which is for medical and related needs.