



What is Thalassemia?

Thalassemia is a genetic blood disorder that can be classified into two main types:

- Thalassemia Minor: carriers of the gene who typically show no symptoms.
- Thalassemia Major: carriers who demonstrate severe symptoms and require lifelong medical attention, including monthly blood transfusions and regular iron chelation treatments.

What is Thalassemia Major?

Thalassemia Major is characterised by the body's inability to produce enough healthy haemoglobin. Low haemoglobin levels hinder the necessary flow of oxygen through the body, inhibiting basic functions and potentially being fatal if untreated.

Patients with Thalassemia Major require lifelong treatment, including blood transfusions and medication, which can increase their risk of iron overload, weakened immunity, and cause other complications like diabetes. This is a huge emotional and financial strain on families of the patients.

While blood transfusions can extend survival, the only known cure is a bone marrow transplant (BMT), which is expensive and challenging to obtain.

Screening for Thalassemia

A simple blood test, called HPLC, is all that is needed to determine the carrier status of an unborn child. The test is available at most mainline laboratories. This test is especially important for individuals planning a family, as it can also diagnose other haemoglobin-related abnormalities like sickle cell haemoglobin and other rare disorders. Couples planning to have children should take a routine blood test to assess the risk of their child being born with Thalassemia Major.

3% of the Indian population is estimated to be carriers of Thalassemia Minor.

10k ANUALLY Children are born with Thalassemia Major in India, the largest number globally.



25%

probability that a child born to parents with Thalassemia Minor will have Thalassemia Major.

The MR Foundation for the Prevention of Thalassemia

Having experienced Thalassemia first-hand in our family, we understand the financial and emotional burdens that families with Thalassemia patients face.

After researching and supporting the work of other foundations, we realised that there is an opportunity to focus on the prevention of Thalassemia, particularly in India. Drawing on the experience of countries like Cyprus, Greece, and Italy, which have reduced Thalassemia incidence significantly, we identified the need to create awareness, particularly around the importance of testing including antenatal testing.

Our Objective

Our mission is to reduce the number of Thalassemia cases through sustained outreach and awareness. We are concentrating our efforts in Greater Mumbai and Maharashtra to establish successful proof points before expanding further. In the last year (2023-24) we have been embedding ourselves in the ecosystem to identify actionable steps toward this goal, including:

- Engaging with gynaecologists, including the Mumbai Obstetricians and Gynaecologists Society (MOGS) to encourage patients to test for Thalassemia Minor, especially when planning families.
- Exploring avenues of collaboration with government entities such as the Sickle Cell Initiative and the National Health Mission in Mumbai
- Leveraging digital and other media channels to emphasize the importance of HPLC testing.
- Understanding critical gaps in the regular medical care for Thalassemia major children as well as the support required for BMT in Maharashtra.

We look forward to your support and encouragement as we move ahead. We will keep you updated on our efforts and welcome your thoughts and advice. Please contact us at the details below:

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