**What is Thalassemia?**

**Mission Thalassemia**

Thalassemia is a severe disorder of the blood. Affected persons can’t form proper *hemoglobin*, a chemical in the red blood cells (RBCs) that is responsible for carrying oxygen through the body.

Most patients are **children** as Thalassemia appears in the first months of life but also because it is a **deadly condition** when remaining untreated, living until adulthood is rather unusual then.

10,000 new children with the disorder are born every year – in India alone! There is no official survey or study examining the number of affected people but it is estimated that in southern India 8-11% of population are affected by the major form.

The red blood cells collapse due to an unstable hemoglobin structure, one suffers from ***anemia***, a low number of RBCs. This can only be treated with **blood transfusion** every three weeks.

Unfortunately the transfusion causes another major problem in Thalassemia patients – **iron overload**. It damages vital organs like liver, spleen and heart and can become a serious condition. The iron excess can be removed through giving medicines, so called ***chelation drugs****.*

🡪 **The only chance for Thalassemics to live is receiving regular blood transfusion and chelation drugs.**

**Thalassemia trait – what is it?**

Thalassemia is a genetic disease. That means it is passed on from parents to children through the DNA, the genetic information in every cell of our body. Genes encode our physical appearance – shape of our face, height etc. That information is available in two editions – one inherited from your father, one from your mother. Most of the time DNA exists in ‘packages’ called chromosomes, 46 altogether (23 maternal, 23 paternal). Someone suffering from thalassemia received two so called mutation, his or her genes are different from a healthy person’s ones. The part about hemoglobin is modified in a way that restricts the carriage of oxygen.

Only if both chromosomes encoding hemoglobin information are altered one has Thalassemia Major. Most parents of Thalassemic children are so called carriers – they have one healthy and one affected chromosome. Still having one faultless gene their red blood cells work rather sufficiently, most of the times the mutation is not observed. So the disorder is in one’s genes but doesn’t affect them, this is called Thalassemia Minor or Thalassemia trait.

**In case both parents are carriers the chance that their children have Thalassemia Major is 25%!**

Thalassemia being a genetic disease is developed once somebody inherited the mutated genes. No surgery or medication can prevent it. So to reduce the number of newborns with the disorder only screening for the carrier status and family planning (and genetic counseling) can prevent new Thalassemics.

All Indians belong to a high risk group for Thalassemia – be sure about it and get tested!

Pregnant women who know about their and their partner’s carrier status should consider prenatal tests which can reveal if the baby will have Thalassemia Major or not.

**What are the symptoms of Thalassemia?**

The disorder occurs in the first months of life. Children are weak, listless, apathetic.

* shortness of breath
* fatigue (tired, lethargic)
* a poor appetite
* jaundice
* dark urine
* a swollen abdomen
* irritability
* large number infections
* slow growth

***are signs of Thalassemia major in small children.***

***If the disease remains untreated Thalassemics will face***

* Severe anemia (low number of red blood cells)
* liver, spleen and heart enlargement
* delayed puberty
* bone fragility – they tend to break easily
* deformities of the facial bones
* heart failure
* premature death
* infertility

**Is there a cure for Thalassemia?**

Yes, **Bone Marrow Transplant** (BMT) provides healthy, new *stem cells* to the Thalassemia patient. RBCs are produced in the bone marrow so the patient can form well working ones after successful transplantation.

Unfortunately ***not many patients are in the condition*** to undergo this exhausting procedure, the risks must be avoided then. In general only children under 10 are considered when they have **a matching sibling as donor!** Their medical condition must be very good so continuous transfusion and chelation therapy in the past are necessary.

**🡪So the *supportive care* of transfusion and chelating is very important.**

**How to help Thalassemics**

* **Donate blood** regularly, only if one receives healthy red blood cells every 3 weeks the fatal causes of Thalassemia can be avoided.
* **Spread the word** – Thalassemia is a genetic disease and given from parents to children. ‘Healthy’ parents are carriers and have the disposition to pass the disorder on. This can be ***screened*** and Thalassemia prevented if carriers know about their status and plan accordingly!

As in India so many people (8-11%) are affected with Thalassemia many come from poor families.

*Nivethan Trust supports 70 families from Madurai financially to ensure the children get the treatment they need.*

**Please help us in providing support for**

* **Chelation drugs** which are very expensive. ***INR 6000*** are needed *per month!*
* **Travel expenses:** It is essential for the child’s well being to receive fresh blood through transfusion. Many families can’t afford the costs of going to a (sometimes quite distant) hospital to receive transfusion.

We assist them and provide funds for travel.

The amount required is ***INR 5000*** per month for the most needy families.

**Nivethan Trust**

Is a local nonprofit NGO from Madurai caring for those who need help in health and education issues. Mission Thalassemia is our main project .

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***Donations for Thalassemia patients please to:***

**Account name:** Nivethan Trust at SBI **Account number:** 30437489626 **IFSC Code:** SBIN0000253 D*onations exempted under 80G of the Income Tax Act,1961*