



# Thalassemia Major<sup>1</sup>

**10,000 children every year are born with this disorder in India.  
How can you ensure that your family is not affected by it?**

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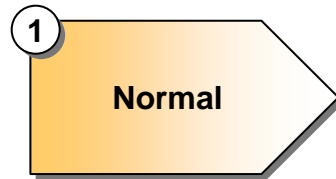


- What are the possible types of Thalassemia ?
- What is Thalassemia Major?
- What is the cause of Thalassemia Major?
- How is a child born with Thalassemia Major?
- How can you avoid having a child with Thalassemia Major if both parents are carriers?
- How can you find out whether you are a carrier?
- Who are we and how can you help us?

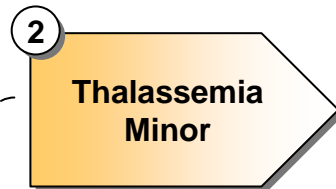


# What are the possible types of Thalassemia ?

*Each person can be either of the following three :*



- People who live a normal life and do not carry the gene for Thalassemia
- Majority of us belong to this group



- People who live normal lives but carry the gene for Thalassemia
- **Thalassemia minor is not a disease**
- Over 4 crore<sup>1</sup> Indians are Thalassemia minors and are living normal lives
- Many notable people are known to be Thalassemia minors
  - **Amitabh Bachchan, Amisha Patel, Pete Sampras, Zinedine Zidane** ([Wikipedia](#), [Times of India](#))



- People who have two copies of the abnormal gene and need medical care

There is also an intermediate condition called "Beta Thalassemia Intermedia" – a condition where children maintain Hb levels of 6 - 9 gm



## What is Thalassemia Major?

*Thalassemia Major is a serious blood disorder. People with the Thalassemia major have insufficient hemoglobin, the critical oxygen carrying component of blood*

- Patients with Thalassemia major need blood transfusions every 3-8 weeks to maintain hemoglobin levels and therefore are at risk of
  - Blood transfusion related infections like hepatitis C, hepatitis B and HIV
  - Iron overload with damage to the liver, heart, pancreas and endocrine glands
- With regular transfusion and removal of iron (chelation therapy), Thalassemics can live and grow into adulthood. If complications are avoided, they can enjoy a productive life
- Untreated Thalassemia Major eventually leads to death
- The only curative treatment is bone marrow transplant

**Thalassemia Major (& intermedia) needs medical attention. Thalassemia Minor is not a disease**



## What is the cause of Thalassemia?

*Thalassemia Major is a genetic condition and this means that it may be passed on to children by 'Thalassemia Minor' parents*

*Thalassemia Major cannot be contracted in any other way – through food, water, contact etc.*

- Over 10,000<sup>1</sup> Thalassemia Major patients are born in India every year
- Thalassemia major child is born when both parents are Thalassemia minors
- Most of the Thalassemia major patients are diagnosed between 6 months to 24 months of child birth
- Initial symptoms include paleness, failure to thrive and abdominal distension due to enlargement of liver and spleen.



# How is a child born with Thalassemia major ?

*This is completely dependent on the Thalassemia conditions of the parents*

Mother- Father	Normal Children	Thalassemia Minor Children	Thalassemia Major Children
Normal	100%	-	-
Mother or father- one is a Thalassemia minor	50%	50%	-
Mother and father both are Thalassemia Minors	25%	50%	<b>25%</b>

**% Chances**

The only way a child can be born with Thalassemia Major is if both parents are Thalassemia Minors

Even then there is a 25% chance that the child will be Thalassemia Major and a 75% chance that he or she will be normal or minor



## How can you avoid having a baby with Thalassemia Major?

*By following a simple two step process*

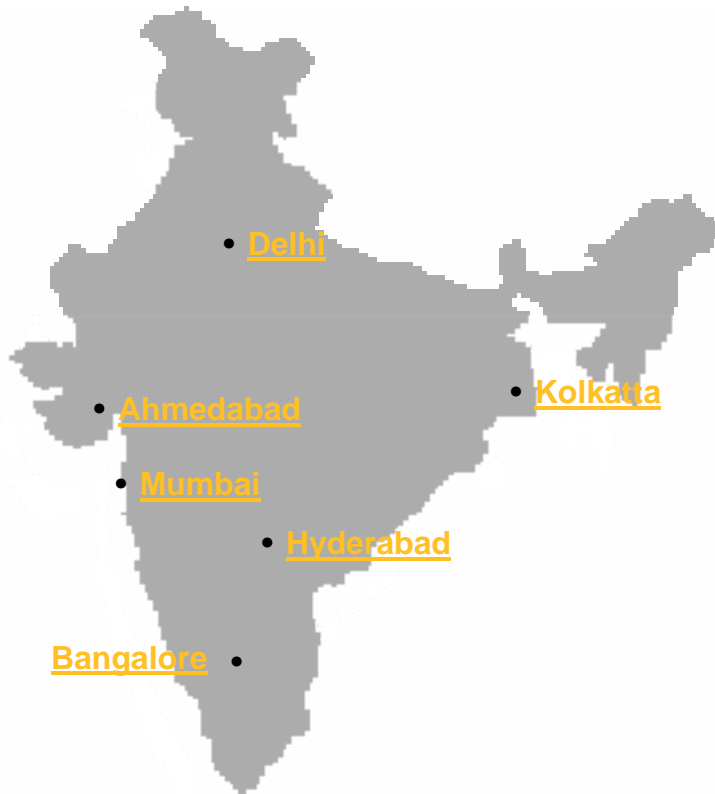
- 1 Get yourself and your partner tested to determine whether you are a carrier of Thalassemia gene
- 2 If both you and your partner are Thalassemia minors, consult your doctor before planning a pregnancy



# How can you find out whether you are a carrier?

*There are various credible testing centers across the country. Click on the city of your residence for details on testing centers in your city*

## Testing Centers



## Test Details

Indicative Test : Complete blood count test

- Simple blood test – available at most hospitals and costs only Rs. 200 /-
- Most employees go through a CBC during pre-employment check-ups. Check with your hospital if there were indications of thal trait

Confirmatory Tests : Hb HPLC or Hb Electrophoresis for Hb A2 estimation

- If CBC shows Thalassemia trait, visit your nearest testing center for a confirmatory test
- The test costs ~ Rs. 600 /-



- Each person can be one of the three – normal, Thalassemia minor or Thalassemia major
  - Thalassemia major is a serious condition while minors have no symptoms and can lead a normal life
- Thalassemia is a genetic disease and is transmitted from parents to their children:  
Thalassemia major is usually detected between 6 months to 24 months of child birth
- A Child can be Thalassemia Major only if both the parents are Thalassemia minors. Then too, there is only a 25% chance that the child will be Thalassemia Major
- This brings us to the simple two step process of not having a baby with Thalassemia major:
  - Determine your and your partner's Thalassemia condition through a simple blood test
  - If both of you are Thalassemia minors, then contact your doctor before planning pregnancy

**This message is endorsed by :**

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# Who are we and how can you help us?

*Foundation for Blood Ailments aims at preventive care of blood ailments, providing support to affected patients and their families.*

*It was started in 2007 by people whose friends and families were affected by blood diseases*

You can help us in the following way:

- Be a volunteer : Sign-up now
  - Help us spread awareness
  - Help us in getting sponsorships
  - And much more
- Donate blood : You can donate blood every 3 months
- Be a sponsor : Tax benefits on all donations
  - Sponsor on our website and mailers sent by us
  - Sponsor a Thalassemia testing drive
  - Sponsor a Thalassemia patient

Read more about us at our website

[www.fbaindia.org](http://www.fbaindia.org). Feel free to reach out to us if you have any questions:

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**Get yourself tested for Thalassemia**

**Please forward this presentation to all your friends & colleagues**

**Please include a CBC test as a part of the pre-employment test**

**Get your current employees tested for Thalassemia – group testing is not expensive**