

Thalassaemia

Why in News?

Thalassaemia patients in **Maharashtra** are struggling due to a **shortage of life-saving iron chelation drugs** and the **unpleasant taste** of the available medicines.

 These drugs, like deferasirox, are crucial to remove excess iron from frequent blood transfusions, which can otherwise damage the heart, liver, and endocrine glands.

Key Points

- About: <u>Thalassemia</u> is a genetic blood disorder that lowers the body's ability to produce normal hemoglobin, resulting in fewer healthy <u>red blood cells</u> and <u>anemia</u>.
- Symptoms: Symptoms vary from growth delays, delayed puberty, and bone abnormalities in mild cases to poor appetite, jaundice, dark urine, and facial bone deformities in severe cases.
- Types:
 - Alpha Thalassemia: A person inherits four genes (two from each parent) that
 produce alpha globin protein chains. Alpha thalassemia occurs when one or more of
 these genes are defective.
 - Beta Thalassemia: A person inherits two beta-globin genes (one from each parent). Beta thalassemia develops if one or both genes are defective.
- Burden: India, often called the Thalassemia capital of the world, has an estimated 100,000-150,000 children living with the disease, while approximately 42 million Indians carry the Beta-Thalassemia trait.
- Treatment: Treatment involves regular blood transfusions to maintain healthy red blood cell levels, combined with iron chelation therapy to prevent iron overload.
 - In severe cases, a bone marrow or stem cell transplant can provide a potential cure.
- Initiatives for Eradication:
 - Under the <u>National Health Mission</u> (NHM), States and UTs receive support for thalassemia screening, treatment, and infrastructure development.
 - The government advises integrating thalassemia testing into the Reproductive and Child Health (RCH) program for early carrier detection and genetic counseling to reduce disease burden.
 - The National Program for Prevention and Control of Hemoglobinopathies (NPPCH) promotes awareness and provides counseling and testing services for affected individuals.
 - The <u>Thalassemia Bal Sewa Yojana</u> (TBSY) offers financial assistance for bone marrow transplants through Coal India Ltd.'s CSR in 17 empanelled hospitals nationwide.



Wirld Thalassemia Day



Definition

Thalassemia (thal-uh-SEE-me-uh) is an inherited blood disorder. It affects your body's ability to produce normal hemoglobin. If you have thalassemia, your body produces fewer healthy hemoglobin proteins, and your bone marrow produces fewer healthy red blood cells.

Statistics Around Thalassemia

1.4 out of every **10,000** live births throughout the world.



- · Alpha Thalassemia: Four genes are inherited, two from each parent, that make alpha globin protein chains. When one or more genes are defective, alpha thalassemia is developed.
- Beta Thalassemia: Two beta-globin genes, one from each parent are inherited. Your anemia symptoms and how severe your condition is depends on how many genes are defective and which part of the beta globin protein chain contains the defect.

Symptoms of Thalassemia

Asymptomatic

(no symptoms)

Mild to Moderate Symptoms

- Growth problems
- Delayed puberty
- Bone abnormalities, such as osteoporosis
- An enlarged spleen

Severe Symptoms

- Poor appetite.
- Pale or yellowish skin (jaundice).
- Urine that's dark or tea-colored.
- Irregular bone structure in your face.



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