Thalassemia in India

What is the issue?

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- World thalassemia day is on May 8.
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- As the number of thalassaemics grows in India, a prevention and control programme is nowhere in sight.
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- There is no national plan in our country for a disease with no cure, which is globally threatening.
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What is Thalassemia?

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- Thalassemia is a genetic blood disorder commonly characterised by the abnormal production of haemoglobin in the body.
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- The abnormality results in improper oxygen transport and destruction of red blood cells.
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- It has wide-ranging effects on the human body like iron overload, bone deformities and in severe cases can cause heart diseases.
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- The disease has no cure and people living with thalassemia require regular blood transfusions as an effective measure to prolong life.
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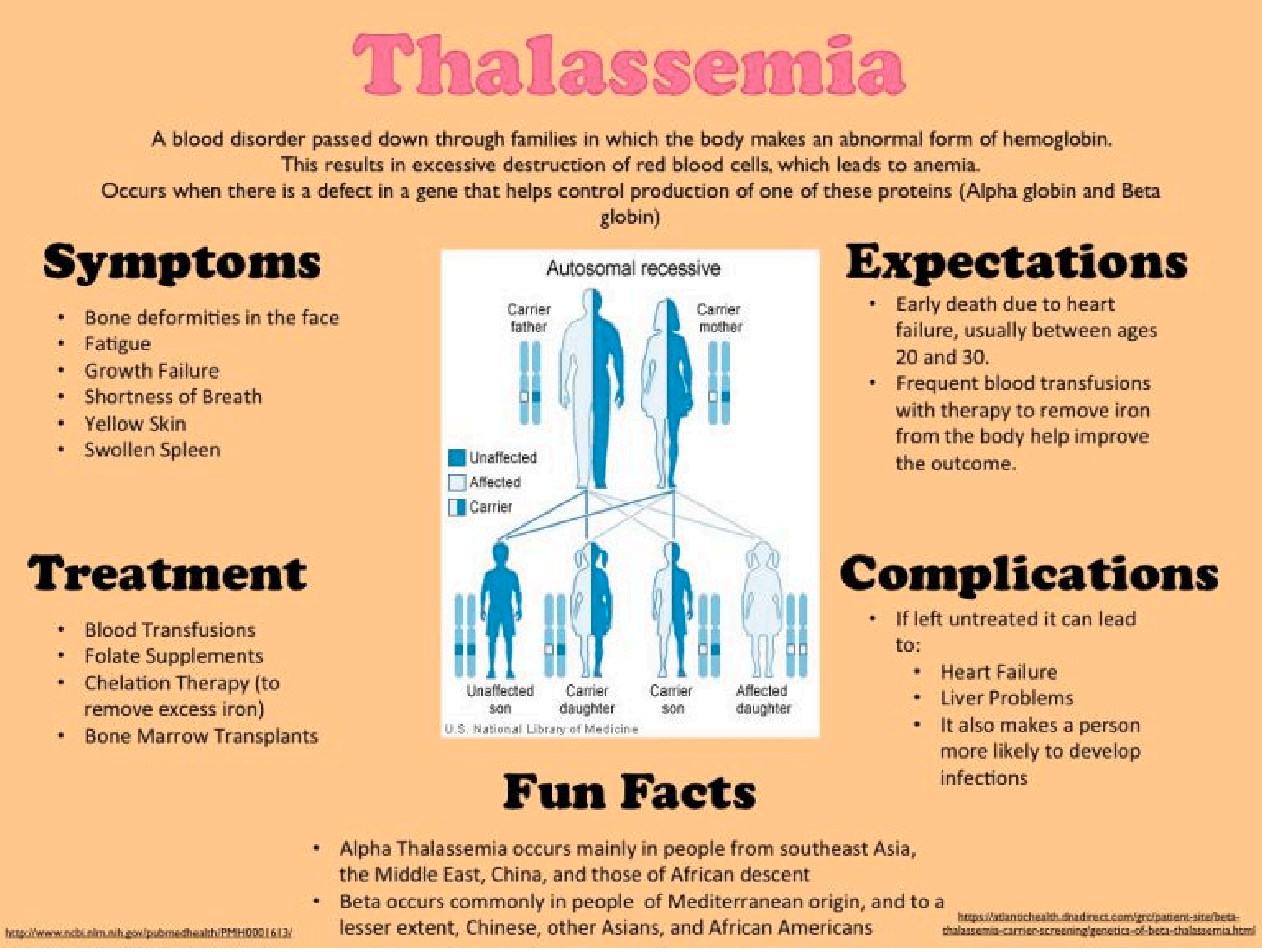

Thalassemia

A blood disorder passed down through families in which the body makes an abnormal form of hemoglobin.
This results in excessive destruction of red blood cells, which leads to anemia.
Occurs when there is a defect in a gene that helps control production of one of these proteins (Alpha globin and Beta globin)

Symptoms

- Bone deformities in the face
- Fatigue
- Growth Failure
- Shortness of Breath
- Yellow Skin
- Swollen Spleen

Expectations

- Early death due to heart failure, usually between ages 20 and 30.
- Frequent blood transfusions with therapy to remove iron from the body help improve the outcome.

Treatment

- Blood Transfusions
- Folate Supplements
- Chelation Therapy (to remove excess iron)
- Bone Marrow Transplants

Complications

- If left untreated it can lead to:
    - Heart Failure
    - Liver Problems
    - It also makes a person more likely to develop infections

Fun Facts

- Alpha Thalassemia occurs mainly in people from southeast Asia, the Middle East, China, and those of African descent
- Beta occurs commonly in people of Mediterranean origin, and to a lesser extent, Chinese, other Asians, and African Americans

http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001613/

https://atlantichealth.dnadirect.com/grc/patient-site/beta-thalassemia-carrier-screening/genetics-of-beta-thalassemia.html

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What is the position of the disease in India?

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- India is the thalassemia capital of the world with 40 million carriers and over 1, 00,000 patients.

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- There is no prevention and control programme at the national level.

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- With preventive health checks not being the norm in India, people suffering from thalassemia are unknowingly passing on this genetic disorder to their children.

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- Over 1, 00,000 patients across the country die before they turn 20 due to lack of access to treatment.

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- The Centre for Health Ecologies and Technology (CHET), framed first ever draft policy in India for rare diseases, it is submitted to the Karnataka

government in March 2016.
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What are the steps taken by other countries?

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- The neighbouring Pakistan, a Bill making carrier testing compulsory for relatives of thalassemia patients was passed in February.
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- A similar system is in place in Dubai, Abu Dhabi and Saudi Arabia.
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What is the way forward?

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- There is no known cure for thalassemia except bone marrow transplant (BMT) and most patients in India can neither afford it nor do they have relevant matches with siblings or others.
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- BMT can be done only for children up to the age of 10, after which it is a serious risk.
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- The treatment is so expensive in India government should take necessary step in this regard
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- The effort to provide patients better health care is largely spearheaded by the private sector and non-governmental organisations.
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- National policy on Thalassemia will help in not just creating awareness about the disease but also ensure treatment for all and strategies to prevent its spread.
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Source: The Hindu

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