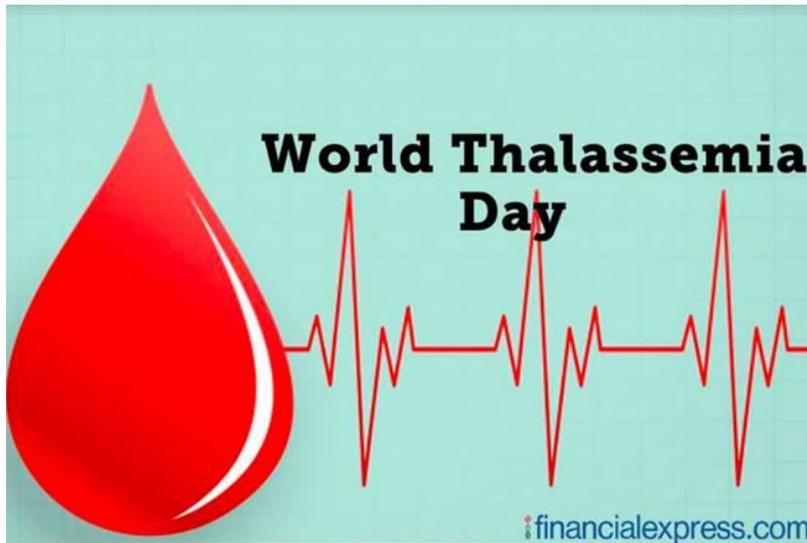


World Thalassemia Day: A collaborative approach towards prevention and management of Thalassemia is needed

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By Dr. K. Madan Gopal and Suryaprabha Sadasivan

World Thalassemia Day: Over the years, there has been endless conversations on the issue of chronic blood shortages in India. On any given day, social media and chat groups are buzzing with requests for blood donors across the country. While India has seen improvement in blood collection in the past few years from 9.8 million units in 2012-12 to 11.45 million units in 2017-18, we are still short of over 1.9 million units of blood.

What exactly is Thalassemia?

While the inconsistencies in the demand and supply of blood impacts many people across the country, one of the most vulnerable group are the thalassemic patients. Thalassemia comes from the Greek word Thalassa, which means 'sea', and the Latin word 'emia', which means blood as its earliest reported cases were first diagnosed in Mediterranean countries like Greece and Turkey. This genetic blood disorder requires

patients to be on lifelong regular blood transfusions, usually administered every two to five weeks. The lifelong struggles of these patients against this severe disease is almost unimaginable for a commoner. Not only does it cause physical and psychological stress on the patients and their families, it also involves a lot of financial stress owing to the treatment.

Thalassemia treatment in India

As per reports, in India, every year 10,000 children are being born with thalassemia which approximately accounts for 10% of the total world incidence of thalassemia-affected children and one in eight of thalassemia carriers live in India. Thalassemia treatment comprises blood transfusion and bone marrow transplant. While India has a high burden of blood disorders, very little is discussed and known about them.

Every year, 8th May is celebrated as the International Thalassemia Day with the objective of raising awareness about thalassemia. This year's theme is – The dawning of a new era for thalassemia: Time for a global effort to make novel therapies accessible and affordable to patients.

In an Indian context, there seems to be a long road ahead of us to find pathways to address the issues faced by thalassemic patients.

Better management of thalassemia is possible with regular and safe blood transfusions. In order to address the gaps of access to timely, adequate, and safe blood transfusion to these patients, it is crucial for India to strengthen the existing blood transfusion system (BTS). As rightly envisioned in NACO's Action Plan for Blood Safety 2007, it is important to create a partially centralization blood service through a hub-and-spoke model governed by a national blood policy and a legislative framework. This structural reform will help address the gaps in demand and supply of blood and blood products and reduce wastage of blood. Most importantly, consolidation of advanced testing and processing will result in economies of scale, cutting costs and managing quality through standardization. Adoption of the latest blood transfusion technology at the hubs will also enable consistency in the quality and safety of blood and blood product and timely access to it. In addition, there is a pressing need to increase awareness for voluntary blood donation in India to plug the demand -supply inconsistencies.

Can technology be a gamechanger?

As technological advancement is underway, besides blood transfusion and stem cell therapy, gene therapy has emerged as a treatment for Thalassemia, where they are trying to insert non-defective genes into the bone marrow. However, making these advanced treatment options accessible across the country might not be an easy feat and will require a collective approach among stakeholders.

On the preventive side, one of the strategies to control thalassemia is to increase public awareness. It is vital to educate and sensitize health professionals, students and pregnant women, and the population at large about the disorder, its causes, and ways to detect it. If you look at global examples, education and awareness building among students, youth and health workers yielded great success in prevention of thalassemia in the Mediterranean region. In addition, prenatal testing of fetus for Thalassemia is also becoming crucial to understanding possibilities of a child getting affected with Thalassemia. Thereby, providing the expecting parents with requisite information to make an informed choice on available courses of action.

A concerted effort towards prevention and management of Thalassemia is the need of the hour. It requires a collaborative approach between government, civil societies organizations, thalassemia patient societies and companies as a part of their corporate social to come together to strategize and implement measures required for a national control initiative.

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