A study on Thalassemia Awareness, Screening and Counselling among Young Adults of Delhi and NCR (India)

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Thalassemia Test needs to be done just once in a lifetime so Why Not Today?

A collaborative venture of

Department of Anthropology, University of Delhi

All India Institute of Medical Sciences (AIIMS) Delhi

Amity Institute of Anthropology, Amity University Noida

National Thalassemia Welfare Society

Thalassemia is an inherited blood disorder caused by mutations that reduce the synthesis of β-globin chains required for the formation of adult hemoglobin.

Severe β-thalassemia, also called β-thalassemia major, causes several health problems like delayed growth, bone problems, liver and gall bladder problems, and enlarged spleen. Survival depends upon lifelong blood transfusion. Repeated blood transfusion leads to iron overload, which if not treated adequately, damages vital organs liver & heart and can result in early death.

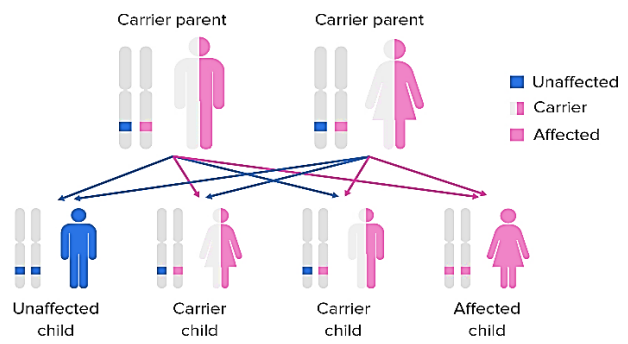
India has a huge burden of thalassemia and structural hemoglobin variants, but very few patients are optimally managed, and treatment is unaffordable for most families.

In India, every year 10,000 children are born with thalassemia major which approximately accounts for 10% of the total world incidence of thalassemia-affected children. Further, one in eight thalassemia carriers lives in India. The average prevalence of β-thalassemia carriers is 3-4% which translates to 50 million carriers in our multi-ethnic, culturally, and linguistically diverse population of 1.21 billion people.

Though β-thalassemia carriers live a normal life and do not have any health problems, if two thalassemia carriers get married, based on the probability, 25% of their children will have severe thalassemia, 25% will be healthy, and 50% will be carriers of thalassemia.

With this kind of scenario in India, prevention of β-thalassemia becomes the need of the hour. Control of thalassemia has been an issue due to lack of awareness, lack of genetic counselling, no proper screening or management, social stigma and cultural taboo around the disease, and inadequate planning for the prevention of the disease.

A simple blood test for thalassemia before marriage will let couples know if they are carriers or not and help them take informed decisions regarding their marriage and future pregnancies.



This diagram shows the inheritance pattern of beta thalassemia when both parents are carriers

Register for the Thalassemia Awareness Workshop cum Free Screening Camp.
To register, visit https://forms.gle/nQNoFQAPXHXBWEQB8; or scan
Our team will revert with the date and venue of the next workshop.

For further information on the study or the workshops, write to us at thalassemiaicmr@gmail.com.