

## In urban Ghaziabad only, around 61% of children between the ages of 6 to 59 months are anaemic

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India is one of the worst thalassaemia affected countries in the world with more than 4 crore carriers and over 1 lakh thalassaemia majors under blood transfusion every month. With the World Thalassaemia Day around the corner, the focus falls back on the efforts to contain the disease.

Over 1 lakh thalassaemia patients across the country die before they turn 20 due to lack of access to treatment. With preventive health not being the norm in India, people suffering from thalassaemia are unknowingly passing on this genetic disorder to their children. Every year more than 10,000 children with thalassaemia major are born in India.

While countries like Pakistan, Dubai, Abu Dhabi and Saudi Arabia have made carrier testing compulsory for relatives of thalassaemia patients long back, there has been no move to put in place prevention and control program at the national level in India.

“Thalassaemia is an inherited condition which is carried in the genes and passed on from parents to children. One of the major types of thalassaemia, Beta thalassaemia, happens when the gene that controls the production of a protein called beta globin becomes defective. The rising number of thalassaemic children is posing a threat to the public health of our country. Lack of awareness of the problem, failure in planning, no provisions for prevention and inadequate treatment leading to premature death among the affected children are the leading causes for the crisis”, says Dr. Sanjay Sharma, Consultant- Pediatrician, Columbia Asia Hospital, Ghaziabad.

The inherited blood disorder destroys the red blood cells extensively, leading to anaemia, in which the body does not produce enough normal healthy blood cells. Thalassaemia could be one of the important factors causing high anaemia rates in Ghaziabad. As per government data, around 61% of children between the age of 6 to 59 months are anaemic in urban Ghaziabad.

Children with mild thalassemia do not show any symptoms, and doctors may not suspect it until a routine blood test reveals anaemia. Only on further investigation and testing for iron-deficiency, is when Thalassemia is detected generally. The focus needs to be on early diagnosis, which gives the patient and family due time to contain the disease.

“Children who have mild thalassemia may feel tired or irritable, have pale skin, lips or nail beds. In more severe cases, they may also have heart palpitations, jaundice, enlarged liver or spleen, enlarged bones, mainly in the cheeks and forehead, and slowed growth which is caused by the late onset of puberty caused by anaemia. If children are not diagnosed and managed in time, thalassemia may play a part in other health problems such as heart diseases, infections and weakness, and brittle bones”, he says.

Thalassemia refers to a spectrum of genetic blood disorders characterized by the reduction in the synthesis or absence of haemoglobin in the body. The disease has wide-ranging effects on the human body like iron overload, bone deformities. Currently there is no cure for thalassemia and regular blood transfusion is the only measure to prolong life.

Most thalassemia major patients require blood transfusions every 2-4 weeks, depending on their consumption of the infused cells. Regular transfusions provide patients with the red blood cells needed to survive. However, once these red blood cells are broken down, the body is left with an excess of iron.

Suggesting some strategies for control, Dr. Sanjay Sharma says, “There is a need to educate health professionals, school and college students, pregnant women and the population at large about thalassemia. Establishing prenatal diagnosis facilities in different regions of the country and setting up a greater number of day care centers for managing existing thalassemia patients along with developing cost-effective facilities for stem cell transplantation across the country are certain infrastructure development strategies which can help in curbing the burden.”

Thalassemia poses a major physical and emotional health burden for many children and their family members, and just like other blood-disorders, there is still a certain level of stigma attached to it. Collective action can pave the way for a brighter future with regard to treatment and management in thalassaemic children. And, parents must remember that if they are diagnosed with the disease, it is not the end of the world, and there is hope left for them and their children.

Children suffering from this disease also require psychosocial support, including promotion of a clear understanding of the disease. Thalassemia support groups are also very important as they not only educate patients and their families about the disease, but also provide them with an opportunity to meet their peers and participate in social activities. Children should be allowed to get involved in normal activities with healthy peers to further their development and build their self-image.

The need for psychosocial support is even greater in India where treatment poses a financial burden as well. The need to shift the attention on psychosocial management aspects of thalassaemic by initiating intervention programs will help them in leading a healthy, creative and fulfilling life.

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