Sixteenth Loksabha

an>

Title: Need to formulate a National Policy on Thalassemia.

DR. SHRIKANT EKNATH SHINDE (KALYAN): India is facing a unique problems in the form of growing number of thalassemia major patients. Every year, at least 10,000 to 12,000 children are born as Thalassemia major patients. At present, the number of Thalassemia major Patients is about 3 lakh and the Thalassemia minor patients are about 12 crore, i.e. about 10% of lndia's population is Thalassemia minor.

The cost of treatment for Thalassemia major is huge, often breaking the financial backbone of the family. At least Rs one lakh is the cost of treatment per patient every year. Therefore, the total burden of this disease born out of genetic disorder is at least 50 thousand crore annually. A Developing country like India cannot afford this burden.

There is no permanent cure. A Thalassemia major Child doesn't live beyond a certain age. The average age of survival is 25 to 30 years. With advanced medicine, certain patients live upto 50 to 60 years. However, increased life means increased expenditure and continuing mental and physical stress.

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

The Thalassemia major Child is born out of the marriage of two thalassemia minor patients. Therefore, the only way to prevent the spread of Thalassemia major is to avoid the marriage of two thalassemia minor patients. However, at present the awareness about this issue is very low in India. Therefore, blood test for thalassemia minor is not conducted as routinely as blood tests for other diseases.

Therefore, it is imperative that the blood test for thalassemia minor be made compulsory before marriage. This cannot be left to the individual choice as it involves social health and economic issues. Therefore, I request the honorable Health Minister to formulate a National Policy on Thalassemia as well as make a law to make the blood test compulsory before marriage to ensure that that bride as well as groom are not Thalassemia minor patients.