

**GOVERNMENT OF INDIA  
HEALTH AND FAMILY WELFARE  
LOK SABHA**

STARRED QUESTION NO:300

ANSWERED ON:30.08.2013

GENETIC DISORDERS .

Ahir Shri Hansraj Gangaram;Pathak Shri Harin

**Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:**

- (a) the estimated number of children suffering from genetic disorders like sickle cell anaemia, thalassemia, haemophilia and Lysosomal storage disorders (LSDs) in the country, State/UT-wise;
- (b) the diagnostic and healthcare facilities set up by the Government for the affordable treatment of such patients in the country, State/UT-wise;
- (c) the financial and technical assistance provided to the States/UTs to deal with the above genetic disorders during each of the last three years and the current year, State/UT-wise;
- (d) whether the Government has formulated/proposed any guidelines and action plan for prevention and control of children suffering from various genetic disorders; and
- (e) if so, the details thereof?

**Answer**

THE MINISTER OF HEALTH AND FAMILY WELFARE (SHRI GHULAM NABI AZAD)

(a)to (e): A statement is laid on the Table of the House.

STATEMENT REFERRED TO IN REPLY TO LOK SABHA STARRED QUESTION NO. 300 FOR 30TH AUGUST, 2013

(a) Data regarding children suffering from genetic disorders is not maintained centrally.

(b)to(e): Health being a State subject, diagnosis and management of this disease is done by the States.

However, Rashtriya Bal Swasthya Karyakrama (RBSK) recently launched under National Rural Health Mission (NRHM), provides early detection and treatment of children suffering from genetic disorders. Operational Guidelines have been issued under this scheme to all the States/UTs for Child Health screening and early intervention services. The diseases like sickle cell anaemia, Beta Thalassemia and other health conditions are covered under child health screening up to the age of 18 years. State Government can submit proposals in this regard in their respective Programme Implementation Plans (PIPs) for consideration of assistance under NRHM within their resource envelope.

The National Blood Transfusion Council under National AIDS Control Organisation (NACO) has issued guidelines to all States/UTs that patients suffering from haemophilia or sickle cell anaemia should be provided blood free of cost.

Diagnosis and treatment facilities for these diseases is also available in Central Government Hospitals like Lady Hardinge Medical College & Smt. Sucheta Kripalini Hospital, Safdarjung Hospital, Dr. Ram Manohar Lohia Hospital, New Delhi and Jawaharlal Institute of Post Graduate Medical Education and Research (JIPMER), Puducherry.

Ministry of Health & Family Welfare also give financial assistance for treatment of life threatening diseases at different hospitals under the Rashtriya Arogya Nidhi (RAN) and also the Health Minister's discretionary grant. The categories of treatment to be provided from RAN fund include Anti-haemophilic globulin, Blood and Blood products.