

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

UNSTARRED QUESTION NO:4568
ANSWERED ON:19.12.2014
DIAGNOSIS OF THALASSEMIA SICKLE CELL AND HAEMOPHILIA
Tharoor Dr. Shashi

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

- (a) the total number of children born with Thalassemia, Sickle Cell disease and Haemophilia over the last three years, State/ UT-wise;
- (b) the total number of Governmentrun pre-natal diagnostic centres in the country, State/UT-wise;
- (c) whether any assistance is offered to the States/UTs to establish diagnostic centres and provide for blood transfusion facilities for treatment;
- (d) if so, the funds allocated and utilised for the purpose during each of the last three years and the current year, State/UT-wise; and
- (e) the steps taken/proposed to be taken by the Government to spread awareness about such blood disorders in the country, particularly in the rural and tribal areas?

Answer

THE MINISTER OF HEALTH AND FAMILY WELFARE (SHRI JAGAT PRAKASH NADDA)

(a): As per information received from Indian Council Medical Research (ICMR), it is estimated that around 10,000 to 12,000 children with Thalassemia major and 5000 to 7000 children will sickle cell anemia are born each year in the country. However there is no state-wise central registry to give details on children born with Thalassemia, Sickle Cell disease and Haemophilia.

(b): As per information received from Indian Council Medical Research (ICMR), the government run prenatal Diagnosis Centres for Thalassemia and Sickle Cell Anemia are as following:-

- (i) National Institute of Immunohaematology, Mumbai.
- (ii) All India Institute of Medical Science (AIIMS), New Delhi.
- (iii) postgraduate Institute of Medical Education and Research (PGI), Chandigarh.
- (iv) Sanjay Gandhi Postgraduate Institute of Medical Science (SGPGI), Lucknow.
- (v) Kolkata Medical College, Kolkata.
- (vi) Nail Ratan Sircar (NRS) Medical College Kolkata.

New centres are being established at Indira Gandhi Medical College Nagpur, Regional Medical Research Centre- Jabalpur and Regional Medical Research Centre – Dibrugarh.

The Government run Prenatal Diagnosis centres for Hemophilia are at:-

- (i) National Institute of Immunohaematology , Mumbai
- (ii) PGI, Chandigarh

(c) to (e): Health being a State subject, diagnosis and management of this disease is done by the States. However under the National Health Mission, the Government Of India supplements the efforts of State governments in providing health care services, including for establishing blood transfusion services.

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

Ministry of Health and Family Welfare also gives financial assistance for treatment of life threatening diseases at different hospital

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.

The National Blood Transfusion Council under National Aids Control Organisation (NACO) has issued guidelines to all State/UTs administration that patients suffering from thalassemia, sickle cell and Haemophilia should be provided blood free of cost.

There is no separate vertical program for genetic blood disorders. The Rashtriya Bal Swasthya Karyakarama (RBSK) launched under the National Health Mission (NHM), provides early detection and treatment of children suffering from genetic disorders including sickle cell anaemia, Beta Thalassemia etc. up to the age of 18 years. State Governments can submit proposals for prevention, awareness generation and treatment for blood disorders in their respective Programme Implementation Plans (PIPs) for consideration of assistance under NHM within their resource envelope.