

**GOVERNMENT OF INDIA
MINISTRY OF HEALTH AND FAMILY WELFARE
DEPARTMENT OF HEALTH AND FAMILY WELFARE**

**LOK SABHA
STARRED QUESTION NO. 266
TO BE ANSWERED ON THE 6TH DECEMBER, 2019
TREATMENT FOR RARE DISEASES**

***266. SHRI BALASHOWRY VALLABHANENI:**

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

- (a) the details of people suffering from Thalassemia, Hemophilia and Sick Cell Anaemia in the country, State/UT-wise;
- (b) whether diseases such as the above are considered to be of rarest of rare category and if so, the details thereof;
- (c) whether the Government provides free treatment and care to all those who are suffering from above diseases, if so, the details thereof and if not, the reasons therefor;
- (d) whether the Ministry has put income limit in providing free treatment to Hemophilia patients; and
- (e) if so, the reasons therefor and efforts being made by the Government to remove this income limit?

**ANSWER
THE MINISTER OF HEALTH AND FAMILY WELFARE
(DR. HARSH VARDHAN)**

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

**STATEMENT REFERRED TO IN REPLY TO LOK SABHA
STARRED QUESTION NO. 266* FOR 6TH DECEMBER, 2019**

(a) & (b) Data base of people suffering from Thalassemia, Sickle cell anemia and hemophilia State/UT wise is not maintained centrally. However as per the Information received from National Institute of Immunohematology -an Institute of Indian Council of Medical Research (ICMR), Haemoglobinopathies are the commonest single gene disorders. Overall the carrier rate of Beta -thalassemia is 1-17%, and of Sickle Cell Anemia is: 0–35%. It is estimated that every year 10,000 - 12,000 children are born with Beta - Thalassemia and more than 5000 with sickle cell disease.

Hemophilia, a hereditary bleeding disorder is prevalent amongst one in every 10,000 males. Considering the 1.3 billion population of India, the expected no. of Hemophilics patient would be 1.3 lakhs.

(c), (d)&(e) Public health and Hospitals being a state Subject, the primary responsibility of providing free treatment and care to the people suffering from above diseases lies with the respective State Governments. However, under National Health Mission (NHM), support is provided to the States/UTs to strengthen their health care systems including support for providing free blood, drugs for iron chelation, and Anti hemophilic factors, to patients suffering from Thalassemia, Hemophilia and Sickle Cell Anemia. The support is provided based on the proposals submitted by the State/UT Governments annually in their Programme Implementation Plans.

Ministry of Health & Family Welfare also give financial assistance to BPL patients for treatment of life threatening diseases at different hospitals under the Rashtriya Arogya Nidhi (RAN) and also the Health Minister's discretionary grant. The category of treatment support provided from RAN fund includes Bone Marrow Transplants for Thalassemia, Sickle cell diseases patients and corrective surgeries for Hemophilia.

Coal India Limited under its Corporate Social Responsibility (CSR) activity is supporting for Bone Marrow Transplants (BMT) of children of BPL families suffering from thalassemia.
