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

RAJYA SABHA
UNSTARRED QUESTION NO. 1075
TO BE ANSWERED ON 12.12.2023

LACK OF AWARENESS OF THALASSEMIA

1075. SHRI RYAGA KRISHNAIAH:

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

(a) the steps being taken to raise awareness about thalassemia and its prevalence in the country;
(b) whether there are any plans to introduce a national thalassemia screening program, similar to the one currently in place for sickle cell anaemia;
(c) if so, the details thereof and if not, the reasons therefor; and
(d) the steps being taken to promote research and development of new treatments and therapies for thalassemia?

ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH & FAMILY WELFARE
(PROF. S. P. SINGH BAGHEL)

(a) to (d): As per Indian Council of Medical Research (ICMR), New Delhi, an estimated 7,500 to 12,000 children with beta-thalassemia are born every year. Thalassemia is one of the inherited disorders of red blood cells that comes under the category of Haemoglobinopathies.

The primary responsibility of management of Thalassemia along with raising awareness lies with the respective State Governments. However, under National Health Mission (NHM), support is provided to States/UTs to strengthen their healthcare system including support for prevention and management of Thalassemia at public healthcare facilities, including for low-income patients, based on the proposals submitted by the States/UTs in their Programme Implementation Plans.

Under NHM, Comprehensive Guidelines on Prevention and Control of Hemoglobinopathies in India - Thalassemia & Sickle cell Disease and other variant Hemoglobins (2016) had been shared to assist the States/UTs for management of Haemoglobinopathies including Thalassemia. The Guidelines provide support for screening of hemoglobinopathies. Various

methods are prescribed which States can adopt as per requirement. The guidelines also detail the strategies for management of thalassemia disease. These include management of thalassemia major (Blood transfusion therapy with packed red blood cell, iron chelation for iron overload, monitoring and management of complication and psychological support etc.).

Ministry of Health & Family Welfare in association with Coal India limited (CIL), is implementing a scheme namely Thalassemia Bal Sewa Yojana (TBSY) wherein financial assistance up to Rs.10 lakh is provided to eligible patients for Bone Marrow Transplants (BMT) from CIL CSR funds. This scheme provides for BMT in 11 prominent hospitals spread across the country.

ICMR National Institute of Immunohaematology (NIIH) & National Institute of Research in Tribal Health (NIRTH) are involved in research related to Hemoglobinopathies including Thalassemia. ICMR-NIRTH has conducted various field based studies on the occurence of beta thalassemia in Tribal communities, has validated a point of care device (Gazelle) for the diagnosis of beta thalassemia and is involved in the diagnosis of beta thalassemia on referral cases from the hospitals.

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