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

LOK SABHA UNSTARRED QUESTION NO. 1843 TO BE ANSWERED ON 29TH DECEMBER, 2017

NATIONAL POLICY ON THALASSAEMIA

1843. SHRI CHANDU LAL SAHU: SHRI ABHISHEK SINGH: SHRI DEVJI M. PATEL:

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

(a) whether the Government proposes to formulate a National Thalassaemia Policy;

(b) if so, the details thereof along with the number of patients suffering from Thalassaemia in the country;

(c) whether a large number of people die of the said disease due to lack of access to treatment which is highly expensive; and

(d) if so, the steps taken by the Government in this regard along with the funds allocated by the Government and facilities being made available for gene therapy in the hospitals?

ANSWER THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE (SMT. ANUPRIYA PATEL)

(a): Public Health is a state subject. However, Under the National Health Mission (NHM), the Ministry has prepared and issued comprehensive guideline for Haemoglobinopathies (Thalassemia, Sickle cell anemia and other variant anaemia) for prevention and management of Haemoglobinopathies.

(b): Exact data from India is not available. Estimated 10,000 to 12,000 children with -thalassemia are born every year. It is estimated that there are about 65,000-67,000 - thalassemia patients in our country (Colah et al. 2014).

(c): No published statistics regarding the annual deaths due to thalassemia is available.

(d) Public health and hospitals is a State subject. Government of India has not allocated any funds separately for gene therapy.

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