

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

**LOK SABHA
UNSTARRED QUESTION NO. 4457
TO BE ANSWERED ON 20TH MARCH, 2020**

THALASSEMIA DISORDER

4457. SHRI CHHEDI PASWAN:

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

- (a) whether Thalassemia a genetic disorder is very common in India, if so, the details thereof and the strategy formulated by the Government for prevention of the disease;
- (b) the rules prescribed by the Government for Haploidentical Stem Cell Transplant to cure Thalassemia;
- (c) whether the private hospitals are complying with the said rules while treating Thalassemia patients, if so, the details thereof;
- (d) whether the Government has noted the incidents of death of two dozen children during the period 2016 to 2017, due to failure of the said procedure; and
- (e) if so, the details thereof and steps taken by the Government to curb such deaths?

**ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND
FAMILY WELFARE
(SHRI ASHWINI KUMAR CHOUBEY)**

(a) & (e): Thalassemia are one of the inherited disorders of red blood cells, comes under the category of Haemoglobinopathies, the other being the Sickle cell diseases.

Details of prevalence of Thalassemia in India are not known as no such database is maintained centrally. As per the information received from ICMR, New Delhi, an estimated 10,000 to 12,000 children with α -thalassemia are born every year and there are about 65,000-67,000 α -thalassemia patients in our country (Colah et al 2010, Colah et al, 2014).

Public Health and Hospitals being a state subject, the primary responsibility of management of Thalassemia including the preventive measures lies with the respective State Governments. However, under National Health Mission (NHM), support is being provided to States/UTs to strengthen their healthcare system including support for prevention and management of Thalassemia, 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 had been shared with States/UTs to initiate the prevention and management of Haemoglobinopathies in their respective States. This includes guidelines for prevention through carrier screening, genetic counselling and prenatal diagnosis and adequate therapy for those affected, helping them to lead better lives.

The Haploidentical transplant is a specialized procedure and cases of medical negligence related to haploidentical transplants are regulated under the Professional Conduct, Etiquette and Ethics: Regulations 2002 of Indian Medical Council.

As per the information received from Board of Governors in supersession of Medical Council of India (MCI), 10 complaints regarding the death of Thalassemia patients during and after transplant were received and an expert committee has been constituted by MCI to look into complaints. MoHFW will take appropriate action on receipt of the report from the MCI.