

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

**LOK SABHA
STARRED QUESTION NO. 345
TO BE ANSWERED ON THE 19TH MARCH, 2021
SCHEME FOR THALASSEMIA PATIENTS**

***345. SHRI KAUSHAL KISHORE:
SHRIMATI MANEKA SANJAY GANDHI:**

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

- (a) the details of Thalassemia patients in the country and the number, out of them, being children under the age of 12, State/UT-wise and particularly in Udaipur district, Rajasthan;
- (b) whether the Government has drafted any scheme for Thalassemia patients and if so, the details thereof;
- (c) the measures being taken by the Government to assist low income Thalassemia patients who cannot afford the treatment;
- (d) whether the Government proposes to regulate or reduce prices of expensive Thalassemia drugs or medicines; and
- (e) if so, the details thereof?

**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.345* FOR 19TH MARCH, 2021**

(a) Thalassaemia is one of the inherited disorders of red blood cells. As per the information received from ICMR, Thalassaemia is the commonest genetic disorder in India. The prevalence of α -Thalassaemia carrier varies from 1 to 17% in different population groups with an overall prevalence of 3-4%. It is estimated that almost 8,000 to 10,000 children are born with Thalassaemia every year¹. Details of patients suffering from Thalassaemia, State/UT wise are not maintained centrally. As per the Information received from state of Rajasthan, there are 296 registered patients of Thalassaemia in Udaipur district and out of them, 256 are under the age of 12.

(b) & (c) Public Health and Hospitals being a state Subject, the primary responsibility of management of Thalassaemia including initiation of schemes for thalassaemia patients 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 Thalassaemia 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 - Thalassaemia & Sickle cell Disease and other variant Hemoglobins* (2016) had been shared with States/UTs to assist the States for management of Haemoglobinopathies including Thalassaemia. This includes guidelines for prevention and management of Thalassaemia affected children. Support is provided to States under NHM for blood transfusion therapy with packed red blood cells (pRBCs) and Iron chelation.

Under NHM, 1,074 blood banks and 1,699 blood storages have been made operational, which provide blood services including packed red blood cells, free of cost including for Thalassaemic patients. Further, 171 Integrated centers for Hemoglobinopathies & Haemophilia (ICHH) Centres have been established in District Hospitals in high prevalence areas of the country to provide treatment.

(d) & (e) The National Pharmaceutical Pricing Authority (NPPA) has the mandate to fix the ceiling price of scheduled medicines specified in the first schedule of the Drugs (Prices Control) Order, 2013 (DPCO) in accordance with the provisions of the DPCO. All manufacturers of scheduled medicines (branded or generic) have to sell their products within the ceiling price (plus applicable Goods and Service Tax) fixed by the NPPA. A manufacturer is at liberty to fix the maximum retail price of a non-scheduled formulation (branded or generic) launched by it. However, as per the DPCO, NPPA

monitors that the manufacturers of non-scheduled formulations do not increase the maximum retail price of such formulations by more than 10% per annum.

As per the guidelines, the three drugs used for Iron Chelation towards management of Thalassemia are Desferrioxamine, Deferiprone and Deferasirox. The medicine - Desferrioxamine powder for injection 500 mg is a scheduled formulation under DPCO 2013 and its ceiling price has been fixed. The detail of price notification is available on the website of the NPPA i.e. www.nppaindia@nic.in

Further, under NHM, States/UTs are supported for provision of three Iron-chelation drugs viz Desferrioxamine, Deferiprone and Deferasirox at Public Health Facilities.

¹ *Reference: R. Colah, A.Gorakshakar, Anita Nadkarni, et al Regional heterogeneity of thalassaemia mutations in the multi ethnic India population. Blood, Cells and Molecular Disease (2009) 242(3):241*
