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

LOK SABHA UNSTARRED QUESTION NO. 2328 TO BE ANSWERED ON 11TH MARCH, 2016

DOMESTIC MANUFACTURING OF HAEMOPHILIA, THALASSEMIA AND SICKLE CELL ANEMIA DRUGS

2328. DR. SHASHI THAROOR:

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

(a) whether the Indian Council of Medical Research (ICMR) has identified that there are 1 lakh thalassemia patients, 1 lakh sickle cell anemia patients and about 65,000 cases of haemophilia in the country;

(b) if so, whether the Government proposes to provide financial assistance for setting up prenatal counseling and early-intervention centres to prevent the transfer of genetic diseases and if so, the details thereof;

(c) if not, the reasons therefor;

(d) whether the Government consider to provide financial assistance to encourage domestic manufacturing of haemophilia drugs, as the current rate of the medicines is high, making inaccessible to patients and if so, the details thereof; and

(e) if not, the reasons therefor?

ANSWER THE MINISTER OF HEALTH AND FAMILY WELFARE (SHRI JAGAT PRAKASH NADDA)

(a): The number of people suffering from anaemia, thalassemia and haemophilia in the country, state/UT wise is not known in a definitive manner, as there is no central database for such conditions. It is roughly estimated that there may be total of about one lakh persons each with sickle cell anemia and with thalassemia and about 65,000 with haemophilia disease.

(b) & (c): Public Health is a state subject. However under National Health Mission, Government of India provides financial support to the States to strengthen their health care systems including system for handling blood disorders (Thalassemia, Haemophilia and Sickle Cell) based on the proposals submitted by the State/UT Governments in their Programme Implementation Plans. Considering the burden and the cost of management and for suitable control measures, a comprehensive guideline for Haemoglobinopathies (thalassemia, sickle cell anemia and other variant anemia) has been prepared by the Government of India and sent to the states to initiate the prevention and management of Haemoglobinopathies in their respective states. This also includes prenatal counseling and setting up of early intervention centres to prevent the transfer of the disease from parent to child.

(d) & (e): Bulk of the factor VII and IX for treatment of haemophilia is supplied through Government hospitals and the cost of such supplies is borne by the Government.

....