GOVERNMENT OF INDIA
HEALTH AND FAMILY WELFARE
LOK SABHA

STARRED QUESTION NO:210
ANSWERED ON:07.12.2012
GENETIC BLOOD DISORDERS
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Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

(a) whether a large number of children are suffering from various genetic blood disorders such as thalassemia and sickle cell disease in the country;

(b) if so, the details thereof indicating the estimated number of children reportedly suffering from them, State/UTwise;

(c) whether the Government has carried out any research in this regard;

(d) if so, the details and the outcome thereof; and

(e) the steps taken/proposed by the Government to address the issue?

Answer

THE MINISTER OF HEALTH AND FAMILY WELFARE (SHRI GHULAM NABI AZAD)

(a)to(e): A statement is laid on the Table of the House.

STATEMENT REFERRED TO IN REPLY TO LOK SABHA STARRED QUESTION NO.210 FOR 7TH DECEMBER, 2012

(a)&(b): The total number of children with genetic blood disorders like thalassemia and sickle cell anemia is not definitively known. However, estimates are that there are 1 lakh thalassemics and the same number of sickle cell disease patients in India and about 10,000 new thalassemia major cases and 5000-6000 new sickle cell patients are estimated to be born each year. The major density of thalassemia is in the states of West Bengal, Orissa, North Eastern States, Punjab, Gujarat, Maharashtra, Kerala and Karnataka. Sickle cell disease is common in all the tribal dominated states of Central India stretching from Gujarat and Maharashtra in West and Orissa in the East. In addition, there are pockets in the southern states of Kerala and Tamil Nadu. State-wise details of children suffering from these diseases are not maintained at central level.

(c)&(d):Extensive research has been carried out for the last 30 years by National Institute of Immunohaematology (NIIH), Mumbai. They include the following:

Mutation analysis has been carried out amongst patients from different parts of the country for thalassemia and sickle cell disease.

Technology has been developed for carrying out molecular diagnostics and prenatal diagnosis for these disorders.

Population screening and genetics counseling has been offered which has led to increased awareness in the community about the disorders.

A multicentric research on community control of thalassemia has been completed in 6 states of the country - Karnataka, West Bengal, Assam, Punjab, Maharashtra and Gujarat. In this study, screening programmes have been carried out among pregnant women as well as college students for thalassemia. Following the screening, genetics counseling, prenatal diagnosis and molecular characterization was carried out in affected families.

Another National Task Force (NTF) study was carried out to find the nutritional status and the prevalence of hemoglobinopathies amongst the primitive tribes from 4 different states i.e. Gujarat, Orissa, Maharashtra and Tamil Nadu. An important observation was the presence of anemia and the sickle cell gene in all tribal groups in these states.

The NTF studies involved genetic counseling, molecular analysis and prenatal diagnosis which was offered to prevent birth of children with thalassemia and sickle cell disease. The institute has also played an important role in imparting training to other centers in molecular diagnosis of thalassemia and other blood disorders.

(e) Health being a State subject, the identification and treatment services are provided by each State Government. However, the Ministry of Health and Family Welfare also provides financial assistance for treatment of life threatening diseases at different hospitals under the Rashtriya Arogya Nidhi (RAN) and also the Health Minister's discretionary grant. The National Blood Transfusion Council under National AIDS Control Organisation [NACO] has issued guidelines to all states/UTs that patients suffering from blood disorders

including haemophilia or sickle cell anemia; and all BPL patients suffering from any life-threatening diseases should be provided blood free of cost. The Indian Council of Medical Research is also supporting a multicentric study "Community control of Thalassemia: Establishment of molecular characterization of haemoglobinopathies and prenatal diagnosis of Thalassemia and Sickle cell disease". The study will lead to establishment of molecular technology for characterization of mutations in hemoglobinopathies as well as facilities for first and second trimester prenatal diagnosis at 5 regional centres in Maharashtra, Gujarat, Karnataka, West Bengal and Punjab.