

**GOVERNMENT OF INDIA
HEALTH AND FAMILY WELFARE
LOK SABHA**

UNSTARRED QUESTION NO:5670

ANSWERED ON:02.05.2000

GENETIC DISORDER

DHANI RAM SHANDIL;PUSHPDAN SHAMBHUDAN GADHAVI;SURESH RAMRAO JADHAV (PATIL)

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

(a) whether the Government propose to conduct a study to identify and curing the Thalassami genetic disorders prevalent in the rural areas specially among the tribal in the country;

(b) if so, the details thereof; and

(c) the steps proposed to be taken by the Government to provide free of cost treatment to the poors of the rural areas in this regard?

Answer

THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE (INDEPENDENT CHARGE)(SH SHANMUGAM)

(a) to (c) A Statement is laid on the Table of the House.

STATEMENT REFERRED TO IN REPLY TO PART (a) to (c) OF LOK SABHA QUESTION NO.5670 FOR 2.5.2000.

(a)&(b) Two multicentric studies have been initiated by Indian Council of Medical Research, one on Intervention programme for nutritional anaemia and hemoglobinopathies amongst some primitive tribal population of India and the other on 'Community control of thalassaemia syndromes, awareness screening, genetic counselling and prevention'. The letter has been approved as one of the major multicentric projects and is part of the 21 approved projects under Jal Vigyan Mission launched by the Prime Minister.

(c) The Department of Biotechnology has established 14 Genetic Diagnosis-cum-Counselling units in the country. These provide services to affected families for some of the common genetic disorders prevalent/ including Beta-thalassaemia. Government has given custom duty exemption on some imported items used for the management of this disease. Many thalassaemia societies are also offering chelator drug either free of cost or at reduced cost to the patients. Recently Govt. has created 'National Illness Fund' under which financial support is provided to the economically weaker groups to meet the cost of treatment of various diseases including thalassaemia.