

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

UNSTARRED QUESTION NO:366  
ANSWERED ON:26.07.2006  
RESEARCH ON THALASSAEMIA DISEASE  
Kripalani Shri Srichand;Narhire Smt. Kalpana Ramesh

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

- (a) whether the number of Thalassaemia patients is increasing in the country;
- (b) if so, the details thereof, State-wise during the last three years till date and the reasons therefor;
- (c) the steps taken/being taken by the Government to check the said disease;
- (d) whether the Government proposes to conduct any research on this disease; and
- (e) if so, the places where the research is proposed to be conducted?

**Answer**

THE MINISTER OF STATE IN THE MINISTRY OF HEALTH & FAMILY WELFARE (SMT. PANABAKA LAKSHMI)

(a): As reported by Indian Council of Medical Research, there is no central or state-wise registry to know the exact prevalence of the disease. However based on the data generated by various studies it is estimated that every year about 10000 children are born with the disease in the country.

(b): The detail of the Thalassaemia patients during each of the last three years (2003, 2004 & 2005) received from various states is annexed.

(c): There is no National Programme for Thalassaemia. However the patients are treated in the Health Care Delivery System at all levels.

(d)&(e): ICMR has been working in the area for the last two decades or so. A multi-centric study is now planned by the ICMR with the primary objective to establish molecular technology for characterization of mutations in haemoglobinopathies at regional centers, setting up pre natal diagnosis facility by chorionic villus sampling and DNA analysis, set up second trimester diagnosis by fetal blood analysis and to undertake a quality control programme to monitor uniformity and accuracy of diagnosis. The study will be carried out at five centers NRS Medical College, Kolkatta: Christian Medical College, Ludhiana: St. John's Medical College, Bangalore; Govt. Medical College, Nagpur; Valsad Raktadan Kendra, Valsad with IIH (ICMR) as coordinating Unit.