

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

UNSTARRED QUESTION NO:1362
ANSWERED ON:18.07.2014
CASES OF PRIMARY IMMUNO DEFICIENCIES
Gaddigoudar Shri Parvatagouda Chandanagouda

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

- (a) whether a number of people, particularly children are suffering from primary immuno-deficiency disorders (PIDs) in the country;
- (b) if so, the details thereof, State/UTwise;
- (c) whether cases of PIDs often go undiagnosed/untreated because of the high cost of therapy in the country;
- (d) if so, the details thereof; and
- (e) the steps taken/proposed to be taken by the Government to bring down the cost of PIDs therapy/treatment and make it available at affordable cost in the country?

Answer

THE MINISTER OF HEALTH AND FAMILY WELFARE
(DR. HARSH VARDHAN)

(a) : Yes.

(b) : State/UT wise data is not maintained. ICMR's National Institute of Immunohematology(NIIM), Mumbai has been working over last 6 years in the field and a total of 315 cases have been diagnosed. Out of which approximately 70% are from western India (Gujarat and Maharashtra), 18% from South and 20% from north and eastern parts of India. The exact prevalence of this disorder is not known to document the magnitude of problem.

(c) & (d): Yes, cases of PID go on undiagnosed/untreated. Most children remain undiagnosed and succumb to recurrent infections. They remain undiagnosed for a long time due to lack of awareness amongst treating physicians. There are very few diagnostic facilities available in the Country.

Only two centres (National Institute of Immune hematology, NIIH (ICMR), Mumbai and PGIMER, Chandigarh are currently offering diagnostic facilities. The samples need to be transported or patients have to travel to these places to avail the facility, which are often difficult. The cost of Therapy is also high.

(e): ICMR has suggested that it is important to establish Regional Centre/Research Centres to initiate diagnosis and registry of children suffering with PID. Once the magnitude of problem is known preventive measures and cost effective/affordable solution for management of children suffering with PID may be implemented. ICMR is in the process of setting two Centres of Advanced Research at the Advanced Paediatrics Centre, Post Graduate Institute of Medical Education and Research (PGIMER), Chandigarh and National Institute of Immune Haematology (NIIH), Mumbai.