

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

UNSTARRED QUESTION NO:2534
ANSWERED ON:25.07.2014
SICKLE CELL DISEASE
Ahir Shri Hansraj Gangaram

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

- (a) whether cases of sickle cell disease have been reported from various parts of the country;
- (b) if so, the details thereof during the last three years and the current year, State/ UT-wise;
- (c) the action plan drawn by the Government for early diagnosis, prevention and control of sickle cell disease in the country;
- (d) whether the National Human Rights Commission (NHRC) has made certain recommendations to the Government in this regard; and
- (e) if so, the details thereof and the follow up action taken/proposed to be taken by the Government thereon?

Answer

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

(a) & (b): Data regarding number of cases of sickle cell disease are not maintained centrally.

(c): Health being a State subject, diagnosis and management of this disease is done by the States. However, Rashtriya Bal Swasthya Karyakrama (RBSK) launched under National Rural Health Mission (NRHM), provides early detection and treatment of children suffering from genetic disorders including sickle cell disease.

Operational Guidelines have been issued under this scheme to all the States/UTs for Child Health screening and early intervention services. The diseases like sickle cell anaemia, Beta Thalassemia and other health conditions are covered under child health screening up to the age of 18 years. State Government can submit proposals in this regard in their respective Programme Implementation Plans (PIPs) for consideration of assistance under NRHM within their resource envelope.

The National Blood Transfusion Council under National AIDS Control Organisation (NACO) has issued guidelines to all States/UTs that patients suffering from sickle cell anaemia should be provided blood free of cost.

Diagnosis and treatment facilities for these diseases is also available in Central Government Hospitals like Lady Hardinge Medical College & Smt. Sucheta Kripalini Hospital, Safdarjung Hospital, Dr. Ram Manohar Lohia Hospital, New Delhi and Jawaharlal Institute of Post Graduate Medical Education and Research (JIPMER), Puducherry.

(d) & (e): The National Human Rights Commission (NHRC) recommended examination of the issue of inclusion of sickle cell disease in the schedule to the Rights of Persons with Disabilities (RPwD) Bill, 2012 introduced by Ministry of Social Justice & Empowerment.

The matter was examined in the Ministry of Health and Family Welfare and NHRC was informed that "Sickle Cell disease is a congenital blood disorder which usually causes anemia and other complications that may result into disability in some long standing cases. After they contract disability due to these diseases, they can be considered as persons with disability as the condition so warrants and they can be given the benefits under the Persons with Disability (Equal Opportunities, Protections of Rights and full Participation) Act of 1995 / RPWD Bill, 2012. However, these diseases per se cannot be included under disability without having disability caused by these diseases".