GOVERNMENT OF INDIA
MINISTRY OF HEALTH AND FAMILY WELFARE
DEPARTMENT OF HEALTH RESEARCH

LOK SABHA
STARRED QUESTION NO. 425
TO BE ANSWERED ON THE 31ST MARCH, 2023

BURDEN OF GENETIC DISORDERS

***425. SHRIMATI POONAMBEN MAADAM:**

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

(a) whether the Government has analysed the burden of genetic disorders on health care system in the country and if so, the details thereof;

(b) the steps taken/proposed to be taken by the Government to address such 'inherited disorders' and if so, the details thereof;

(c) whether the Government has trained medical personnel in Government facilities for prenatal testing for genetic disorders; and

(d) if so, the number of Government hospitals equipped with such facility for mothers carrying high-risk genetic disorders?

ANSWER
THE MINISTER OF HEALTH AND FAMILY WELFARE
(DR MANSUKH MANDAVIYA)

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

STATEMENT REFERRED TO IN REPLY TO LOK SABHA
STARRED QUESTION NO. 425 FOR 31ST MARCH, 2023

(a) to (d) The Government has launched National Policy for Rare Diseases (NPRD), 2021 in March, 2021. The policy aims at lowering the incidence and prevalence of rare diseases based on an integrated and comprehensive preventive strategy encompassing awareness generation, screening and counselling programmes to prevent births of children with rare diseases, and within the constraints on resources and competing health care priorities, enable access to affordable health care to Patients of rare diseases. Financial assistance upto Rs. 50 lakhs is provided to the patients suffering from any category of rare diseases and getting treatment in any of the Centre of Excellence (CoEs) identified under NPRD, 2021. As per NPRD, 2021, eleven (11) CoEs have been identified for diagnosis, prevention and treatment of rare diseases.

Indian Council of Medical Research (ICMR) National Registry of Rare Diseases and Other Inherited Disorders (NRROID) initiated in November 2019 documents the hospital based data from patients seeking care for rare diseases. The registry at present contains the data of 9163 patients.

The Department of Biotechnology (DBT) started the Unique Methods of Management of Inherited Disorders (UMMID) Initiative in 2019, which has three components. Under the first component, 5 NIDAN (National Inherited Diseases Administration) Kendras (genetic testing laboratories) have been established at Government hospitals. Under the second component (outreach), prenatal and newborn screening is carried out at District Hospitals at 9 Aspirational Districts, coordinated by 7 premier research institutions of India. Under the third component, 6 training centers have been established for training of in-service Government doctors in genetic diagnostics and counseling. Also, PRaGeD mission is the first ever "Mission on Paediatric Rare Genetic Disorders (PraGeD), a countrywide screening programme in association with 20 other institutions to decode the unknown genetic mutations causing such diseases. DBT's autonomous institutions namely, National Institute of Biomedical Genomics (NIBMG), Kalyani, West Bengal and Centre for DNA Fingerprinting & Diagnostics (CDFD), Hyderabad, Telangana provide genetic testing services for Genetic Disorders.

Sickle cell disease (SCD) is a single gene disorder causing a debilitating systemic syndrome characterized by chronic anaemia, acute painful episodes, organ infarction and chronic organ damage and by a significant reduction in life expectancy. Under National Health Mission (NHM), Government of India supports the States for prevention and management of sickle cell disease as per their annual PIP proposals. The Ministry has also released technical operational guidelines for prevention and control of hemoglobinopathies in 2016 including sickle cell anaemia.

In the Union budget of FY 2023-24, it has been announced to launch a mission to eliminate sickle cell anaemia by 2047. The mission entails focus on awareness creation, universal screening of approximately seven crore people in the 0-40 years age group in affected tribal areas and counselling through collaborative efforts of central ministries and state governments.

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