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

LOK SABHA
UNSTARRED QUESTION No. 3194
TO BE ANSWERED ON 13th DECEMBER 2024

GENETIC TESTING AND EARLY DETECTION

3194. DR. DHARAMVIRA GANDHI:

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

a. whether the Government is promoting prenatal and natal genetic testing as part of the strategy to manage rare diseases and if so, the details thereof;
b. the steps taken/proposed to be taken by the Government to make these tests accessible and affordable for all segments of the society;
c. the plans for integrating genetic testing with early diagnostics to prevent rare diseases and improve outcomes for affected individuals;
d. whether the Government is ensuring that such initiatives are being implemented across all regions of the country, particularly in rural and underserved areas; and
e. if so, the details thereof?

ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE
(SHRI PRATAPRAO JADHAV)

(a) to (e) As per the National Policy for Rare Diseases (NPRD), 2021, the Government is emphasizing on the strategies for early detection and prevention of rare diseases which include Primary Prevention i.e. preventing birth of an affected child and Secondary Prevention which focuses on avoiding the birth of affected fetus (Prenatal Screening and Prenatal Diagnosis), early detection of the disorders and appropriate medical intervention i.e. New-born Screening to ameliorate or minimize the manifestations. The Government has identified 12 Centres of Excellence (CoEs), which are premier Government tertiary hospitals with facilities for diagnosis, prevention and treatment of Rare Diseases. CoEs are responsible for Screening – Antenatal, Neonatal (specified disorders), High-risk Screening (Both Antenatal & in new-borns and children) and Prevention by Prenatal Screening & Diagnosis. The CoEs are also given one-time financial support up to a ceiling of Rs. 5 crores for procurement of equipment as per individual centre's need for strengthening patient care services for screening, diagnosis and prevention (Prenatal diagnosis) of Rare Diseases based on a gap analysis. Department of Biotechnology (DBT) has also set up Nidan Kendras under Unique Methods of Management and treatment of Inherited Disorders (UMMID) project for genetic testing and counseling services. Such initiatives are being implemented through CoEs across the country.

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