

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

**RAJYA SABHA
UNSTARRED QUESTION No. 1401#
TO BE ANSWERED ON 11th MARCH, 2025**

TREATMENT OF RARE DISEASES

1401# DR. RADHA MOHAN DAS AGRAWAL:

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

- (a) whether Government had formulated any National Policy on Rare Diseases in the year 2021; and
- (b) if so, the provisions that have been made in it and to what extent they have been implemented?

ANSWER

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

(a) and (b) The Ministry of Health and Family Welfare introduced the National Policy for Rare Diseases (NPRD) in March 2021. The Central Government supports and encourages States in their efforts to screen and prevent rare diseases through the identification of Centers of Excellence (CoEs) under this policy. As per NPRD:

- Rare diseases are categorized into three groups, since 2021, 13 new diseases have been added to the list, bringing the total to 63 rare diseases currently covered by the policy.
- Five additional institutions/hospitals have been recognized as CoEs, increasing the total number of CoEs from 8 to 13.
- In alignment with the provisions of NPRD, 2021, financial support of up to Rs. 20 lakh was initially provided under the Rashtriya Arogya Nidhi (RAN) umbrella scheme. This financial assistance was increased to a maximum of Rs. 50 lakh for the treatment of patients with rare diseases at any CoE listed under NPRD, 2021, outside of the RAN umbrella scheme.
- CoEs have also been provided one time grant of Rs.5 crore for infrastructure strengthening.
- In accordance with NPRD, 2021, the Department of Health Research (DHR) has established the National Consortium for Research and Development on Therapeutics for Rare Diseases in India (NCRDTRD) to streamline research activities on rare diseases across the country.

- Ministry of Finance provides full exemption from Basic Customs Duty (BCD) and Integrated Goods and Services Tax (IGST) on Drugs, Medicines and Food for Special Medical Purposes (FSMP) imported for persons suffering from rare disease, if imported by an individual, for personal use or through CoEs, for treatment of rare disease.
