

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

**LOK SABHA
UNSTARRED QUESTION No. 701
TO BE ANSWERED ON 29th NOVEMBER 2024**

NATIONAL POLICY FOR RARE DISEASES

701. SHRI ROBERT BRUCE C:

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

- (a) the number of patients suffering from rare diseases in the country;
- (b) whether all groups of rare disease patients were assured financial assistance of Rs. 50 lakhs for treatment in the National Policy for Rare Diseases and if so, the details thereof and if not, the reasons therefor;
- (c) the number of rare disease patients who have received assured financial assistance under the said Policy in the country; and
- (d) the steps taken/proposed to be taken by the Government to provide affordable healthcare for rare disease patients in the country?

ANSWER

**THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY
WELFARE**

(SHRI PRATAPRAO JADHAV)

- (a) As per data of National Registry for Rare Disease and Other Inherited Disorders (NRROID) portal maintained by Indian Council of Medical Research (ICMR), the total number of patients suffering from identified rare diseases in the country is 7414.
- (b) &(c) As per the National Policy for Rare Diseases (NPRD), 2021 and guidelines framed thereunder, the patients suffering from any of the 63 identified rare diseases covered in all three groups and registered with any of the 12 Centers of Excellence (CoEs) are provided financial assistance of up to Rs. 50 lakhs for treatment. The funds are released to the COEs based on the evaluation of the patients and recommendations of the Rare Disease Committee at CoE for treatment, Till date, a total of 876 patients have received treatment under the NPRD, 2021 through CoEs.
- (d) Following major steps are taken by the Government to provide affordable health care for rare disease patients in the country:

- i. National Policy for Rare Diseases (NPRD), 2021 provides financial assistance of up to Rs. 50 lakhs per patient for treatment of Rare Diseases in the Centers of Excellence (CoEs).
- ii. The Government has identified twelve Centers of Excellence (CoEs) that are premier government tertiary hospitals having facilities for diagnosis, prevention and treatment of rare diseases.
- iii. Full exemption from Basic Customs Duty (BCD) and Integrated Goods and Services Tax (IGST) is provided as per Department of Revenue's notifications dated 29.03.2023 and 26.07.2023 respectively on import of Drugs, Medicines and Food for Special Medical Purposes (FSMP) for treatment of patients suffering from identified Rare Diseases.
- iv. A Central Technical Committee for Rare Diseases (CTCRD) has been constituted under the chairpersonship of Director General of Health Services with technical experts to provide technical guidance on matters of rare diseases on case to case basis and to address matters related to NPRD, 2021 and its implementation.
- v. Department of Health Research has established the National Consortium for Research and Development on Therapeutics for Rare Diseases (NCRDTRD) for streamlining the research activities for rare diseases.
