

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

**RAJYA SABHA  
UNSTARRED QUESTION No. 3461  
TO BE ANSWERED ON 01.04.2025**

**FINANCIAL ASSISTANCE FOR RARE DISEASE PATIENTS UNDER NPRD**

**3461. SHRI HARIS BEERAN:**

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

- (a) whether there is one-time financial assistance of ₹50 lakhs for rare disease patients under the National Policy for Rare Disease (NPRD);
- (b) if so, the details of total amount spent from 2021 to 28th February 2025 including number of patients, names of diseases and the centres of excellence through which the disbursements took place year wise; and
- (c) if so, whether the Ministry has made any request to State Governments for Implementation of Paragraph XI of NPRD in the context of generic production of patented medicine?

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

(a) and (b) Ministry of Health and Family Welfare has framed National Policy for Rare Diseases (NPRD), 2021. Health being a State subject, the primary responsibility of providing healthcare services is that of the State Governments. However, to mitigate the challenges posed by Rare Diseases in India, the policy provides financial assistance of up to Rs. 50 lakhs for treatment of Rare Diseases in the designated Centers of Excellence (CoEs). As on date, around 1000 patients have received financial assistance under NPRD for 63 identified Rare Diseases categorized in 3 Groups. Year-wise allocation of funds for treatment of Rare Disease patients in the CoEs is Rs. 35 Cr. for FY 2022-23, Rs. 74 Cr. for FY 2023-24 and Rs. 82.87 Cr. for FY 2024-25.

(c) In accordance with Paragraph XI of NPRD on promotion of local development and manufacture of drugs for rare diseases, Department of Pharmaceuticals provide financial incentives to selected manufacturers in various States for production of Rare Disease drugs under 'Production Linked Incentive' scheme for pharmaceuticals. Further, as reported by NITI Aayog, after initiation of indigenous manufacturing, 3 Rare Disease drugs have already been made available in the Indian market at reduced prices vis-a-vis imported drugs prices under the initiative of indigenization of selected Rare Disease drugs by NITI Aayog.

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