

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

**LOK SABHA  
UNSTARRED QUESTION No. 1213  
TO BE ANSWERED ON 6<sup>th</sup> FEBRUARY 2026**

**NATIONAL POLICY FOR RARE DISEASES**

**1213. DR. BYREDDY SHABARI:**

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

- (a) the number of patients registered under Group 3(a) of the National Policy for Rare Diseases, 2021, disease-wise and State/UT-wise;
- (b) the number of such patients who have received financial assistance under the said policy in the country along with the amount disbursed to each patient;
- (c) the number of patients who have completed treatment, those who have exhausted the 50 lakh financial assistance cap and require continued or lifelong therapy and those who have died during treatment or while awaiting financial support, under the said policy;
- (d) whether the Government has reviewed the adequacy of the Rs. 50 lakh cap in light of recent directions of the Hon'ble Delhi High Court regarding the creation of a National Rare Diseases Fund with flexible financial ceilings and if so, the details thereof; and
- (e) the current status and expected timelines for establishing and operationalising the proposed National Rare Diseases Fund, along with the reasons for any delay, if any, in its establishment and operationalisation?

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

(a) to (c) 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 Government has framed the National Policy for Rare Diseases (NPRD), 2021. Under the policy, Financial support up to Rs. 50 lakhs per patient is provided under NPRD, 2021 for treatment of patients suffering from rare diseases including Group 3 diseases indentified under NPRD. The number of Centre of Excellences under the policy has been increased from 8 to 15 since its inception. Till date, More than 2800 Group 3 rare diseases patients have been registered under the NPRD. The patient of rare diseases are treated through the designated Centres of Excellence (CoEs) based on the recommendations of the dedicated Rare Disease Committee of the concerned Center of Excellence (CoE) within the extant guidelines. Advance funds are released to the CoEs as soon as a demand for money is raised by them in accordance with the extant General Financial Rules (GFR).

(d) & (e) Vide Order dated 04.10.2024, the Hon'ble High Court of Delhi issued various directions to the Government regarding adequacy of the Rs. 50 lakhs cap and National Rare Disease Fund. However, the same has been stayed by the Hon'ble Supreme Court vide its Order dated 09.12.2024. Therefore, the matter is sub judice in the Apex Court.

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