

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

**LOK SABHA
UNSTARRED QUESTION No. 1344
TO BE ANSWERED ON 6th FEBRUARY 2026**

**STATUS OF UTILIZATION OF FUNDS UNDER NATIONAL RARE DISEASE
POLICY, 2021**

†1344. SHRI OMPRAKASH BHUPALSINH ALIAS PAVAN RAJENIMBALKAR:

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

- (a) the details of the fund amount spent from the financial year 2021–22 to 2025–26, especially up to December 2025, under the National Rare Diseases Policy, 2021, year-wise;
- (b) whether the Government is aware that the pace of utilisation of funds allocated is low despite an increase in the number of rare disease patients registered in the country and if so, the details thereof and if not, the reasons therefor;
- (c) the number of centres of excellence that have not submitted utilisation certificates for the funds released earlier so far, which has led to a delay in release of further instalments, institution-wise; and
- (d) whether the Government has identified cases where the treatment of patients has been delayed or postponed due to the non-availability of funds in a timely manner and if so, the details thereof?

ANSWER

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

(a) to (d) 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. The amount of approximately Rs. 26400 Lakhs has been allocated to Centres of Excellences (CoEs) from financial year 2021-22 to till March, 2025 and approximately Rs. 6184 Lakhs is budgeted for Financial Year 2025-26. 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). Till date, Utilization Certificates of 11 CoEs are still awaited as per GFR rules. The Ministry reviews the funds utilization and other matters of rare diseases with CoEs periodically.
