

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

**LOK SABHA
UNSTARRED QUESTION NO. 3284
TO BE ANSWERED ON 7TH AUGUST 2026**

UNUTILISED FUND UNDER NPRD 2021

3284. SHRI JOYANTA BASUMATARY:

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

- (a) whether the Government has taken a formal decision regarding unutilised funds under National Policy for Rare Diseases (NPRD) 2021 for the current and previous financial years, if so, the details thereof and if not, the reasons therefor;
- (b) whether these funds are proposed to be carried forward, reallocated or allowed to lapse, if so, the details thereof including the quantum of funds proposed to be carried forward, reallocated and allowed to lapse along with the reasons for each of the same and the rules governing such decisions;
- (c) whether the Government is likely to permit immediate utilisation of unspent funds to support patients who have exhausted the one-time assistance, if so, the details thereof and if not, the reasons therefor;
- (d) whether the Government accepts responsibility for the denial of treatment despite the availability of funds in this regard, if so, the details thereof; and
- (e) the time-bound measures being taken by the Government to ensure full utilisation of funds meant for life-saving care?

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

(a) to (d) The National Policy for Rare Diseases (NPRD), 2021 has utilized approximately 98.80% of the Revised Estimate (RE) for FY 2023-24, 97.60% for FY 2024-25 and 98.90% for FY 2025-26. In FY 2026-27, around 39.08% of the Budget Estimate (BE) has already been utilized as on date. The lumpsum funds released to the Centers of Excellence (CoEs) based on the recommendation of the dedicated Rare Disease Committee at each CoE after clinical examination of the patients on case-to-case basis are carried forward to the next year.

The matter of providing financial assistance above the ceiling of ₹50 lakhs under NPRD is sub judice before Hon'ble Supreme Court, wherein the Government has been directed to comply with the extant guidelines of the policy.

(e) Some of the measures taken by the Government to ensure full utilization of funds under NPRD are:

- The number of Rare Diseases identified under NPRD has increased from 51 to 63, enabling more patients to get benefit under the policy.
- The number of Centers of Excellence (CoEs) has doubled from 8 to 16 since the inception of the policy in 2021, thereby increasing geographical outreach and accessibility of treatment.
- The guidelines of the policy have been amended to enable the CoEs to outsource transplant facilities to fast track the treatment of patients suffering from Group 1 Rare Diseases.
