

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

**RAJYA SABHA
UNSTARRED QUESTION No. 3651
TO BE ANSWERED ON 24th MARCH 2026**

FINANCIAL ASSISTANCE UNDER NPRD

3651. SHRI TIRUCHI SIVA:

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

- (a) whether Government is aware that several rare disease patients suffering from chronic, progressive, and ultra-rare life-threatening conditions have exhausted one-time financial assistance of ₹50 lakh provided under the National Policy for Rare Diseases (NPRD);
- (b) whether Government acknowledges that interruption of treatment poses an immediate risk to life;
- (c) the details of unutilised funds under NPRD;
- (d) whether the Ministry plans to extend financial support for at least one additional year to such patients from the unspent allocation; and
- (e) the steps being taken to notify and implement such an extension?

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 and medical assistance of up to ₹50 lakhs for treatment of patients suffering from identified rare diseases in the designated Centers of Excellence (CoEs). Around 164 patients have exhausted the financial assistance provided under NPRD. Most of these patients suffer from Group III rare diseases, where the cost of treatment exceeds the financial assistance provided under NPRD.

(c) ₹83.14 cr. (approx.) are currently available with the CoEs for utilization on the recommendation of the dedicated Rare Disease Committees of the CoEs. Unutilized funds with the CoEs are carried over to next year for utilization.

(d) and (e) In regard to increasing the one-time assistance limit under the policy, the matter is sub judice before Hon'ble Supreme Court of India, wherein the Union of India has been directed to comply with the terms and conditions of the extant guidelines of the policy.
