

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

**LOK SABHA
UNSTARRED QUESTION No. 3407
TO BE ANSWERED ON 7th AUGUST 2026**

FINANCIAL ASSISTANCE FOR RARE DISEASES

†3407. SHRI OMPRAKASH BHUPALSINH ALIAS PAVAN RAJENIMBALKAR:

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

- (a) the number of patients suffering from rare diseases covered under Group-3 (a) of the National Rare Disease Policy, 2021, who have exhausted the one-time lump sum financial assistance of up to Rs. 50 lakh, disease-wise and State/UT-wise;
- (b) whether the Government has made any assessment of the need for continuous financial support for such patients who require lifelong treatment and if so, the details thereof;
- (c) whether any proposal is under consideration by the Government to ensure continuity of treatment for high-risk patients who have exhausted one-time financial assistance available under the National Rare Disease Policy, 2021, if so, the details thereof; and
- (d) the steps taken by the Government to ensure uninterrupted treatment for such patients?

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

(a) As on date, around 155 patients suffering from Group 3(a) rare diseases have exhausted the financial assistance of ₹50 lakh provided under the NPRD. Centers of Excellence (CoEs)-wise details are annexed.

(b) and (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, the National Policy for Rare Diseases (NPRD), 2021 provides financial and medical assistance of up to ₹50 lakhs per patient for treatment of identified rare diseases at designated Centres of Excellence (CoEs). For financial assistance towards high-cost rare diseases, a “Digital Portal for Crowd Funding & Voluntary Donations for Patients of Rare Diseases” has been launched. Within the constraints on resources, it is pertinent to balance competing interests of public health for achieving optimal outcome from the resources allocated. In regard to continuity of treatment of such patients, the matter is sub judice before Hon’ble Supreme Court of India.

(d) Following steps have been taken by the Government to ensure uninterrupted treatment of rare disease patients:

- Full exemption from Basic Customs Duty (BCD) and Integrated Goods and Services Tax (IGST) on the Drugs, Medicines and Food for Special Medical Purposes (FSMP) imported for persons suffering from rare disease for personal use or use through CoEs.
- NITI Aayog's committee on "Drugs and Dosage Forms for Rare Diseases: Engagement with Manufacturers" fast tracks indigenous manufacturing of dosage forms (small molecules) for selected rare diseases. As a result, some drugs are available in the Indian market at 1/10th of the price of the imported Reference Listed Drug (RLD).
- Indian Council of Medical Research (ICMR)'s program for Indigenous Therapeutics for Rare Diseases takes forward the indigenous therapy for clinical development by funding the study sites directly, ultimately leading to affordability of the drugs in the country.

Annexure

The CoE-wise number of patients suffering from Group 3(a) rare diseases who have exhausted the financial assistance of ₹50 lakh provided under the NPRD:

S. No.	Centers of Excellence (CoE)	Number of Group 3 (a) patients who have exhausted the one-time financial assistance of ₹50 lakhs
1.	All India Institute of Medical Sciences, New Delhi	25
2.	Maulana Azad Medical College, New Delhi	4
3.	Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow	22
4.	Centre for DNA Fingerprinting & Diagnostics with Nizam's Institute of Medical Sciences, Hyderabad	10
5.	King Edward Medical Hospital, Mumbai	6
6.	Institute of Post-Graduate Medical Education and Research, Kolkata	26
7.	Center for Human Genetics(CHG) with Indira Gandhi Hospital, Bengaluru	32
8.	Institute of Child Health and Hospital for Children (ICH & CH), Chennai	15
9.	All India Institute of Medical Sciences (AIIMS), Jodhpur	6
10	Sree Avittam Thirunal Hospital (SAT), Government Medical College, Thiruvananthapuram	9
Total		155