

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

**LOK SABHA  
UNSTARRED QUESTION NO. 4623  
TO BE ANSWERED ON 20<sup>TH</sup> MARCH 2026**

**FINANCIAL ASSISTANCE UNDER NATIONAL POLICY FOR RARE DISEASES,  
2021**

**4623. SHRI G LAKSHMINARAYANA:**

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

- (a) the total number of patients sanctioned one-time financial assistance of up to Rs. 50 lakh under the National Policy for Rare Diseases, 2021 since its inception, year-wise and State-wise;
- (b) the number of beneficiaries who have exhausted the sanctioned assistance, year-wise along with the number of beneficiaries currently continuing treatment and those who have discontinued treatment due to lack of funds;
- (c) the total funds allocated, released and utilised under the said policy during the last five years, year-wise along with the amount remaining unutilised;
- (d) whether the Government maintains data on patients who are presently without treatment after exhausting the financial assistance and if so, the details thereof including age-wise and disease-wise;
- (e) whether representations have been received from patients seeking continuation of financial support for chronic and ultra-rare disease patients requiring lifelong therapy; and
- (f) the steps taken or proposed to be taken by the Government to ensure continuity of treatment for patients who have exhausted the one-time assistance limit under the National Policy for Rare Diseases, 2021?

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

- (a) 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 for treatment of Rare Diseases in the designated Centers of Excellence (CoEs). Rare Disease patients can get treatment in any of the 15 CoEs irrespective of States. The lists of total number of patients sanctioned financial assistance of up to Rs. 50 lakhs based on the recommendation of the dedicated Rare Disease Committees of the CoEs under NPRD, year wise and CoE wise is annexed.

(b) Around 1545 beneficiaries are currently continuing treatment under NPRD. The following table shows the number of patients whose treatment has been discontinued after exhaustion of the financial assistance provided to them under NPRD:

<b>S. No.</b>	<b>Year</b>	<b>No. of patients</b>
1.	2023	37
2.	2024	42
3.	2025	63
4.	2026	22

(c) The funds released to the CoEs under the policy for treatment of rare diseases, year-wise, are as follows:

(In Crores INR)

<b>S. No.</b>	<b>Financial Year</b>	<b>Funds released</b>
1.	2021-22	3.15
2.	2022-23	35.00
3.	2023-24	109.00
4.	2024-25	116.00

Unutilized funds with the CoEs are carried over to next year for utilization. As on date, Rs. 83.14 cr. is currently available with the CoEs for utilization.

(d) There are around 164 patients who have exhausted their financial assistance under NPRD. Most of these patients are suffering from Group III rare diseases, where the cost of treatment exceeds the financial assistance provided under NPRD.

(e) and (f) Representations have been received from patients seeking continuation of financial support for treatment of some rare diseases. In regard to ensuring continuity of treatment and increasing the one-time assistance limit under the policy, the matter is sub judice before Hon'ble Supreme Court of India in Petition for Special Leave to Appeal (C) No. 28777/2024, wherein Hon'ble Court has directed the Union of India to comply with the terms and conditions of the extant guidelines of the policy. Further, following measures have been taken to ensure the welfare of rare disease patients:

- Some Made-in-India drugs have become available at 1/10<sup>th</sup> of the price of the imported Reference Listed Drug (RLD) as NITI Aayog constituted a Committee for 'Drugs and Dosage Forms for Rare Diseases: Engagement with Manufacturers' to fast track indigenous development and marketing of identified orphan drugs by engaging with domestic manufacturers.
- The Ministry of Finance provides exemption from Basic Customs Duty (BCD) and Integrated Goods and Services Tax (IGST) on most of the drugs, medicines and Food for Special Medical Purposes (FSMP), subject to extant rules.
- The Department of Pharmaceuticals has initiated implementation of 'Production Linked Incentive' scheme for pharmaceuticals which provides financial incentives to the manufacturers selected for domestic manufacturing of various product categories, including rare disease medicines.

## Annexure

Centers of Excellence (CoEs)	Total no.of patients sanctioned one time financial assistance of upto Rs.50 Lakh under NPRD 2021				
	2022	2023	2024	2025	2026
All India Institute of Medical Sciences, New Delhi	19	37	176	107	28
Maulana Azad Medical College, Delhi	0	4	6	16	0
Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow	0	16	25	32	26
Post Graduate Institute of Medical Education and Research, Chandigarh	42	180	320	300	57
Centre for DNA Fingerprinting & Diagnostics with Nizam's Institute of Medical Sciences, Hyderabad	19	45	100	138	26
King Edward Medical Hospital, Mumbai	0	10	23	35	4
Institute of Post-Graduate Medical Education and Research, Kolkata	4	13	20	80	16
Center for Human Genetics (CHG) with Indira Gandhi Hospital, Bengaluru	44	118	157	170	173
Institute of Child Health and Hospital for Children (ICH & CH), Chennai	0	12	17	9	0
All India Institute of Medical Sciences (AIIMS), Jodhpur	0	0	6	43	18
Sree Avittam Thirunal Hospital (SAT), Government Medical College, Thiruvananthapuram	0	13	28	43	0
All India Institute of Medical Sciences, Bhopal	0	0	0	1	0
Regional Institute of Medical Sciences, Imphal (New CoE)	0	0	0	0	0
Assam Medical College and Hospital, Dibrugarh (New CoE)	0	0	0	0	0
All India Institute of Medical Sciences, Patna (New CoE)	0	0	0	0	0