

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

**LOK SABHA
UNSTARRED QUESTION No. 4193
TO BE ANSWERED ON 20th DECEMBER, 2024**

NATIONAL POLICY FOR RARE DISEASES

4193. DR. D PURANDESWARI :

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

- (a) the key features of the National Policy for Rare Diseases;
- (b) the data on total number of rare diseases that have been identified under the said policy and the support given to patients;
- (c) the budget allocated and utilized for the treatment of rare diseases during the last three years; and
- (d) the data on the number of patients who have benefitted under the National Policy for Rare Diseases particularly in Andhra Pradesh?

ANSWER

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

- (a) Ministry of Health & Family Welfare launched National Policy for Rare Diseases (NPRD) in March 2021. The key features of NPRD, 2021 are as under:
- The rare diseases have been identified and categorized into 3 groups as below:
 - Group 1:** Disorders amenable to one-time curative treatment.
 - Group 2:** Diseases requiring long term/lifelong treatment with relatively lower cost of treatment.
 - Group 3:-** Diseases for which definitive treatment is available but challenges are to make optimal patient selection for benefit, very high cost and lifelong therapy.
 - 12 (Twelve) Centres of Excellence (CoEs) have been identified so far, which are premier Government tertiary hospitals with facilities for diagnosis, prevention and treatment of rare diseases. List of Centres of Excellence (CoEs) is at **Annexure**.
 - In order to receive financial assistance for treatment of rare disease, the patient may approach nearby or any Centre of Excellence to get registered.
 - Ministry of Health and Family Welfare has obtained exemption from Department of Expenditure on Goods & Services Tax (GST) and Basic Customs Duty on drugs imported for Rare Diseases for individual use and through CoE.

- As envisaged in the policy, Department of Health Research has established the National Consortium for Research and Development on Therapeutics for Rare Diseases (NCRDTRD) for streamlining the research activities for rare diseases.

(b) Currently, 63 rare diseases are included under National Policy for Rare Diseases on recommendation of Central Technical Committee for Rare Diseases (CTCRD). Financial support of up to Rs. 50 lakhs per patient is provided for the treatment at the identified Centres of Excellence (CoEs) for Rare Diseases.

(c) Budget allocation made and utilized for the treatment of rare diseases during the last three years including the current financial year (till date) is as under:

(Rs. in lakhs)

Financial Year	Grant-in Aid General for Treatment		
	Budget Estimate	Revised Estimate	Expenditure till date
2022-23	2500	3500	3499
2023-24	9284	7400	7400
2024-25	8241	-	4337

(d) Since the launch of the policy, a total number of Eight Hundred and Seventy Six (876) patients have benefited under NPRD, 2021 across the country. State-wise data is not available as the financial assistance is extended to CoEs and not to State Governments as per the provisions of NPRD. The patients can approach any CoE across the country as per their convenience.

List of Centres of Excellence (CoEs)

1. All India Institute of Medical Sciences, New Delhi
2. Maulana Azad Medical College, New Delhi
3. Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow
4. Post Graduate Institute of Medical Education and Research, Chandigarh
5. Centre for DNA Fingerprinting & Diagnostics with Nizam's Institute of Medical Sciences, Hyderabad
6. King Edward Medical Hospital, Mumbai
7. Institute of Post-Graduate Medical Education and Research, Kolkata
8. Center for Human Genetics(CHG) with Indira Gandhi Hospital, Bengaluru
9. Institute of Child Health and Hospital for Children (ICH & HC), Chennai
10. All India Institute of Medical Sciences (AIIMS), Jodhpur
11. Sree Avittam Thirunal Hospital (SAT), Government Medical College, Thiruvananthapuram
12. All India Institute of Medical Sciences, Bhopal