

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

**LOK SABHA
UNSTARRED QUESTION No. 838
TO BE ANSWERED ON 26th JULY, 2024**

INCREASING CENTRES OF EXCELLENCE (CoEs)

838. SHRI S JAGATHRATCHAKAN:

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

- (a) whether the Government is contemplating to frame a standard definition of rare diseases, increase budgetary outlays, dedicate funding for drug development and therapy, and increase the number of Centres of Excellence (CoEs) while also ensuring better coordination and responsible utilisation of funds;
- (b) if so, the details thereof; and
- (c) if not, the reasons therefor?

**ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY
WELFARE
(Smt. ANUPRIYA PATEL)**

(a) to (c) A disease that occurs infrequently is generally considered a rare disease, and it has been defined by different countries in terms of prevalence, either in absolute terms or in terms of prevalence per 10,000 populations. A country defines a rare disease most appropriate in the context of its own population, health care system and resources.

Ministry of Health & Family Welfare launched National Policy for Rare Diseases (NPRD) in March 2021 which aims at lowering the incidence and prevalence of rare diseases based on an integrated and comprehensive preventive strategy, constraints on resources and access to affordable health care to patients of rare diseases which are amenable to one-time treatment or relatively low cost therapy. Under NPRD, 2021, financial assistance upto Rs. 50 lakhs is provided to the patients suffering from any category of the Rare Diseases in any of the Centres of Excellence (CoEs) mentioned in NPRD, 2021. Financial allocation for last three year including the current financial year is as under:

(Rs. in lakhs)

Financial Year	Grant-in Aid General for Treatment			Grant for Creation of Capital Assets		
	Budget Estimate	Revised Estimate	Expenditure till date	Budget Estimate	Revised Estimate	Expenditure till date
2022-23	2500	3500	3499	-	-	-
2023-24	9284	7400	7400	5000	3500	3500
2024-25	8241	-	2420	2000	-	-

Research work of drug development and therapy is the core area of Department of Health Research (DHR) and Indian Council for Medical Research(ICMR). As per inputs/data obtained from ICMR, 19 projects on drug development are ongoing under the Call "Therapeutics for rare diseases" with the total budget of Rs.18,73,24,318/- for 3 years. First year grant of Rs. 7,87,69,547/- has already been released by ICMR to respective centres. Industry Collaboration for development of Therapeutics in rare diseases has also been initiated through an Expression of Interest (EoI).

Identification and inclusion of new Centres of Excellence(CoEs) under NPRD is an ongoing process based on the felt need of the Ministry of Health & Family Welfare/States/UTs and on meeting the eligibility criteria specified for inclusion of any Institute as CoE under NPRD. Initially 8 Centres of Excellence (CoEs) were identified, which are now increased to 12 with the addition of the 4 CoEs. The funds have been released to all the 12 CoEs to be kept at their disposal for utilisation of the same for treatment of rare disease patients and procurement of equipment etc.
