

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

**LOK SABHA
UNSTARRED QUESTION NO. 3155
TO BE ANSWERED ON 9TH AUGUST, 2024**

NATIONAL RARE DISEASE POLICY 2021

3155. SHRI GAURAV GOGOI

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

- (a) the number of patients suffering from various kinds of rare diseases in the country, State/UT-wise;
- (b) whether the Government has justification for the prolonged inaction in implementing the National Rare Diseases Policy 2021, if so, the details thereof;
- (c) whether the Delhi High Court had constituted a committee to oversee the implementation of the same in 2023, if so, the details thereof; and
- (d) whether the Government has taken any steps to ensure coordination among the Centres of Excellence mentioned under the National Rare Disease Policy 2021, if so, the details thereof?

ANSWER

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

(a) Indian Council of Medical Research (ICMR) maintains a portal of National Registry for Rare and Other Inherited Disorders (NRROID). The total number of patients enrolled with ICMR Registry since 2019 is 13,479. State/UT-wise number of rare disease patients enrolled in the registry is at **Annexure**.

(b) The Government launched the National Policy for Rare Diseases (NPRD) in March 2021 and further steps taken for implementing the policy are as under:

- Increased financial support for Rare Disease patients from upto Rs. 20 lakhs to upto Rs. 50 lakhs per patient in 2022.
- Financial assistance of Rs. 3.15 crore, Rs. 34.99 crore, Rs. 74.00 crore and Rs. 24.20 crore has been released to the CoEs in the financial years 2021-22, 2022-23, 2023-24 and 2024-25(till date) respectively for the treatment of rare disease patients. In addition, Rs. 35.00 crore has also been released to CoEs for procurement of equipment for strengthening patient care services.
- Constitution of Central Technical Committee for Rare Diseases (CTCRD) in 2021 for providing technical inputs on matters related to rare diseases.

- Identified and added 14 more Rare Diseases under NPRD, 2021 on the recommendation of CTCRD.
- Identified 4 more CoEs for Rare Diseases since 2021 in addition to 8 listed in the policy to increase accessibility for diagnosis and treatment of Rare Diseases on the recommendation of CTCRD.
- On the directions of the Hon'ble High Court of Delhi, a National Rare Diseases' Committee (NRDC) for implementing National Policy for Rare Diseases has also been constituted.
- National Consortium for Research and Therapeutics for Rare Diseases (NCRTRD) under Department of Health Research (DHR) constituted in 2021.
- 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.
- Launched Digital Portal for Crowd Funding & Voluntary Donations for Patients of Rare Diseases in 2022.

(c) On the directions of the Hon'ble High Court of Delhi, a National Rare Diseases' Committee for implementing National Policy for Rare Diseases has been constituted under the Chairmanship of Secretary, Department of Health Research(DHR) & Director General(ICMR) with 6 members including Joint Secretary(Rare Disease), MoHFW as a member. The mandate of the Committee is to take all steps needed for implementation of the National Rare Disease Policy, 2021 recommending necessary steps for the indigenization of therapies and medicines for rare diseases. Till date, 13 meetings of the Committee have been held.

(d) As envisaged under the Policy, Consortium of Centres of Excellence (CoEs) was created with All India Institute of Medical Sciences (AIIMS), New Delhi as a nodal CoE to synchronize prevention and treatment efforts for Rare Disease in the country and to coordinate with all the Centres of Excellence. A Central Technical Committee for Rare Diseases (CTCRD) under Directorate General of Health Services has been constituted under Chairmanship of Director General Health Services with technical experts. Its mandate is to provide technical guidance on matters of rare disease on case to case basis and to address matters related to the national rare disease policy and its implementation.

Annexure referred to in reply to part (a) of Lok Sabha Unstarred Q.No. 3155 to be answered on

9.8.2024

State/UT-wise number of rare disease patients enrolled in the ICMR Registry

S. No.	State	No. of Rare Disease Patients
1	Uttar Pradesh	1976
2	Maharashtra	1387
3	Karnataka	1275
4	Tamil Nadu	1201
5	Assam	898
6	Delhi	879
7	Andhra Pradesh	684
8	Telangana	661
9	West Bengal	642
10	Bihar	608
11	Gujarat	464
12	Punjab	460
13	Madhya Pradesh	440
14	Haryana	413
15	Jharkhand	251
16	Rajasthan	236
17	Kerala	234
18	Jammu Kashmir	130
19	Chandigarh	122
20	Himachal Pradesh	113
21	Odisha	112
22	Uttarakhand	80
23	Chhattisgarh	66
24	Goa	43
25	Tripura	26
26	Arunachal Pradesh	22
27	Manipur	13
28	Nagaland	10
29	Puducherry	8
30	Sikkim	7
31	Meghalaya	6
32	Ladakh	4
33	Andaman Nicobar	2
34	Lakshadweep	2
35	Mizoram	2
36	Dadra Nagar Haveli	1
37	Daman Diu	1
	Total	13,479