

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

**RAJYA SABHA
UNSTARRED QUESTION No. 590
TO BE ANSWERED ON 25th July, 2023**

IMPLEMENTATION OF NATIONAL RARE DISEASES POLICY 2021

**590. DR. AMEE YAJNIK:
DR. L. HANUMANTHAI AH:
SHRI SYED NASIR HUSSAIN:
SMT. RANJEET RANJAN:
SHRI PRAMOD TIWARI:**

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-wise;
- (b) whether Government has taken any action to implement the National Rare Diseases Policy 2021, if so, the details thereof and if not, the reasons therefor;
- (c) whether Government is aware that the Delhi High Court had recently constituted a committee for the same, if so, the details thereof; and
- (d) the steps taken by Government to ensure coordination among the Centres of Excellence mentioned in the National Rare Diseases Policy 2021?

**ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY
WELFARE
(DR. BHARATI PRAVIN PAWAR)**

(a) As per the data available with Indian Council of Medical Research (ICMR), 9,675 patients have been enrolled since November, 2019 on the portal of National Registry for Rare and Other Inherited Disorders (NRROID). State-wise details of patients enrolled are as below.

States/UTs	No. of rare disease patients enrolled
Delhi	2159
Chandigarh	671
Karnataka	2946
Assam	625
Tamil Nadu	781
Gujarat	555
Uttar Pradesh	566
Maharashtra	789
Puducherry	40
Telangana	543
TOTAL	9675

(b) The Government implemented 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. Eleven (11) Centres of Excellence (CoEs) have been identified, which are premier Government tertiary hospitals with facilities for diagnosis, prevention and treatment of rare diseases. Public Health is a State Subject, however, the Central Government encourages and supports the States in their endeavor towards screening and prevention of rare diseases through CoEs. The financial support for rare diseases patients has been increased from up to Rs. 20 lakhs to up to Rs. 50 lakhs per patient. 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.

(c) The Hon'ble High Court of Delhi had directed constitution of National Rare Diseases' Committee for procurement of therapies and drugs and creation of associated logistical framework for administration of treatment for patients with rare diseases; recommending necessary steps for the indigenization of therapies, medicines for rare diseases and identify the manner in which the same can be made accessible to the lakhs of patients who, as per the Policy, are suffering from rare diseases; undertake a periodic review of the Policy and recommend to the Ministry of Health and Family Welfare, broadly under the umbrella of policy, the changes needed in the Policy if the same is deemed necessary.

(d) As envisaged under the Policy, Consortium of Centres of Excellence (CoEs) was created with AIIMS 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 Chairpersonship 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.
