

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

**LOK SABHA  
UNSTARRED QUESTION No. 4880  
TO BE ANSWERED ON 31<sup>st</sup> March, 2023**

**CASES OF RARE DISEASES**

**4880. SHRI VELUSAMY P.:  
SHRI P.V. MIDHUN REDDY:**

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

- (a) whether there is any estimate of the number of people suffering from rare diseases in the country during 2021-22 and if so, the details thereof;
- (b) whether it is a fact that the Government is relying on crowdfunding to provide financial support for those who need long-term, expensive treatments under the National Rare Disease Policy 2021;
- (c) if so, the details thereof regarding digital infrastructure available for voluntary individual contribution and corporate donors for crowdfunding and the mechanism of monitoring fund collection for the same; and
- (d) the details of the number of approved institutes for the treatment of rare diseases in the country, State/UT-wise including Tamil Nadu?

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

(a) 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. However, as per the data available with Indian Council of Medical Research (ICMR) National Registry for Rare and Other Inherited Disorders (NRROID), a total of 4579 patients suffering from rare diseases have been enrolled during 2021-22.

(b) & (c) The Government has launched National Policy for Rare Diseases (NPRD), 2021 for treatment of rare disease patients. Financial assistance upto Rs. 50 lakhs is provided to the patients suffering from any category of rare diseases and getting treatment in any of the Centre of Excellence

(CoEs) identified under NPRD, 2021. Department of Health & Family Welfare has launched a Digital Portal for Voluntary Donations for Patients of Rare Diseases in accordance with the mandate of the policy. The Digital Portal may be accessed through <https://rarediseases.nhp.gov.in/> . The information related to patients, diseases from which they are suffering, estimated cost of treatment and details of bank accounts of the Centres of Excellence (CoEs) is available on the portal. The Donors have a choice to make donations to different CoEs and for the patients' treatment by these CoEs. The CoEs have their own Rare Disease Fund which is utilized with the approval of their competent authority.

As per provisions envisaged under Guidelines and Procedures issued on 11.08.2022, CoEs have option to get financial assistance from other agencies/drugs manufacturers/Corporate sector under CSR (Corporate Social Responsibility) by signing of Memorandum of Understanding (MoU) with them.

(d) As per NPRD, 2021, eleven (11) CoEs have been identified for diagnosis, prevention and treatment of rare diseases. The details of the CoEs are given below:

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 Uttar Pradesh
4. Post Graduate Institute of Medical Education & Research, Chandigarh
5. Centre for DNA Fingerprinting and Diagnostics with Nizam's Institute of Medical Sciences, Hyderabad
6. King Edward Memorial Hospital, Mumbai, Maharashtra
7. Centre for Human Genetics with Indira Gandhi Institute of Child Health, Bangalore, Karnataka
8. Institute of Post-Graduate Medical Education and Research, Kolkata, West Bengal
9. All India Institute of Medical Sciences, Jodhpur, Rajasthan
10. Institute of Child Health & Hospital for Children, Chennai, Tamil Nadu
11. Sree Avittam Thirunal Hospital, Government Medical College, Thiruvananthapuram, Kerala.