

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

**LOK SABHA  
UNSTARRED QUESTION. NO.2116  
TO BE ANSWERED ON 10<sup>TH</sup> DECEMBER 2021**

**TREATMENT OF RARE DISEASES**

**2116. DR. JAYANTA KUMAR ROY:  
SHRI BHOLA SINGH:  
SHRI VINOD KUMAR SONKAR:  
DR. SUKANTA MAJUMDAR:  
SHRIMATI SANGEETA KUMARI SINGH DEO:  
SHRI RAJA AMARESHWARA NAIK:**

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

- (a) whether the Government proposes to set up a digital platform for crowd funding for the treatment of rare diseases;**
- (b) if so, the details thereof and if not, the reasons therefore;**
- (c) whether the Government maintains any comprehensive data on prevalence of rare diseases and the associated morbidity/mortality, if so, the details thereof and if not, the reasons therefor;**
- (d) whether the Government has notified the National Policy for Treatment of Rare Diseases, if so, the details thereof; and**
- (e) the other steps being taken by the Government to provide financial assistance to poor patients of rare diseases?**

**ANSWER**

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

(a)&(b): The Department of Health and Family Welfare has launched a Digital Portal for Crowd funding and Voluntary donations for Patients of Rare Diseases in accordance with the mandate of the National Policy for Rare Diseases, 2021. The Digital Portal may be accessed through

**<https://rarediseases.nhp.gov.in/>**

(c): ICMR has initiated a National Registry wherein epidemiological data is being collected for rare diseases and other inherited disorders. Data of a total of 4001 rare diseases cases (Storage disorders, Small meta bone inborn error of metabolism, primary immune deficiency disorders, skeletal dysplasia, neuro muscular disorders, hemoglobinopathies and bleeding disorders) have been collected till 31<sup>st</sup> October, 2021.

(d): National Policy for Rare Diseases, 2021 (the Policy) has been finalized and put in public domain. The Policy can be accessed at website:- <https://main.mohfw.gov.in/documents/policy>

(e): On the basis of provisions envisaged under National Policy for Rare Diseases, 2021, with regard to providing financial assistance to the patients suffering from rare diseases, it is submitted that for the diseases/ disorders amenable to one time curative treatment (listed under Group -1), financial support will be provided under umbrella scheme of RAN i.e. an amount upto Rs. 20 lakh only for entitled beneficiaries shall be provided by the Central Government. The diseases requiring long term / lifelong treatment having relatively lower cost of treatment (listed under Group 2), the financial support is envisaged to be provided by the State Governments. The diseases for which definite treatment is available but involves very high cost and lifelong therapy (listed under Group 3), the policy provides assistance to the patients by creation of Digital Platform for inviting voluntary donations from individuals and corporate donors. Donors will have a choice to make donations to different Centres of Excellence (CoEs) and for the patients' treatment by these CoEs. Funds are to be utilized in a decentralised manner, i.e. every Centre of Excellence (CoE) will have its own Rare Disease Fund which is to be utilized with the approval of in charge concerned.