

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

**LOK SABHA  
UNSTARRED QUESTION No. 451  
TO BE ANSWERED ON 3<sup>rd</sup> FEBRUARY, 2023**

**NATIONAL POLICY FOR RARE DISEASES, 2021**

**451. SHRIMATI SANGEETA KUMARI SINGH DEO:  
DR. JAYANTA KUMAR ROY:**

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

- (a) whether the Government proposes to constitute a national crowdfunding portal for persons living with rare/incurable diseases to crowd source the funds for their healthcare as stipulated in the National Policy for Rare Diseases, 2021 and if so, the details thereof;
- (b) the details of patients benefited from financial assistance for treatment of rare diseases so far;
- (c) whether the Government proposes to permit crowdfunding by PSUs under Corporate Social Responsibility scheme and if so, the details thereof;
- (d) whether such crowdfunding amount is exempted under Section 80G of the Income Tax Act for tax benefits; and
- (e) if so, the details thereof and if not, the reasons therefor?

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

(a) 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 (NPRD), 2021. The Digital Portal may be accessed through <https://rarediseases.nhp.gov.in/>.

(b) Financial assistance in respect of 120 patients has been released for treatment of patients suffering from rare diseases in accordance with the provisions of the NPRD, 2021.

(c) As per provisions envisaged under Guidelines and Procedures issued on 11.08.2022, Centres of Excellence (CoEs) have option to get financial assistance from other agencies/drugs

manufacturers/Corporate sector under Corporate Social Responsibility scheme by signing of Memorandum of Understanding (MoU) with them. 11 (Eleven) CoEs have been identified till date.

(d)&(e) Ministry of Health and Family Welfare has written to Department of Revenue for registration of Crowd Funding Portal for rare disease under Section 80G of the Income Tax Act.

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