

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

**LOK SABHA
UNSTARRED QUESTION No. 3867
TO BE ANSWERED ON 25thMarch, 2022**

CROWDFUNDING FOR RARE DISEASES

3867. SHRI FEROZE VARUN GANDHI:

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

(a) the total number of patients registered on the Digital Portal for Crowdfunding and Voluntary donations for Patients of Rare Diseases;

(b) whether the total number of registration is very low when compared to the sizable number of people suffering from rare diseases, if so, the details thereof and the reasons therefor;

(c) the measures taken to create awareness about the said portal to ensure that patients and the families of those suffering from rare diseases avail the benefits;

(d) the total amount of donations that have been channelled to the portal along with the fund benefits accrued to the beneficiaries through this portal, case/amount-wise; and

(e) whether the accrued amount in the fund portal remains unutilized, if so, the details thereof and steps taken to channelize these fund for treatment?

ANSWER

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

(a) & (b) The total number of patients registered on the Digital Portal for Crowd funding and voluntary donations for patients of Rare Diseases is 253 till date. As per the National Policy for Rare Diseases, 2021, the rare diseases have been categorized into 3 groups and the digital platform is especially for Group 3 rare disease patients. Hence, the data available on the digital portal is of the Group 3 rare disease patients only.

(c) to (e) The National Policy for Rare Diseases (NPRD), 2021, which has the provisions for financial assistance through crowd funding to the patients suffering from the diseases for which definite treatment is available but involves very high cost and lifelong therapy (listed under Group 3), has already been in public domain since March 2021. 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 Policy. The Digital Portal may be accessed through <https://rarediseases.nhp.gov.in/>. The total amount of donations that have been channeled to the portal is Rs.1,18,016 (Rupees One Lakh Eighteen Thousand Sixteen Only) till date. The Donors have a choice to make donations to different Centres of Excellence (CoEs) and for the patients' treatment by these CoEs. The Centres of Excellence (CoEs) have their own Rare Disease Fund which is utilized with the approval of their competent authority.