

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

**LOK SABHA
UNSTARRED QUESTION No. 3547
TO BE ANSWERED ON 21st MARCH 2025**

FINANCIAL SUPPORT FOR RARE DISEASES

3547. DR. PRABHA MALLIKARJUN:

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

- (a) whether the Government proposes to give financial support to rare diseases patients and if so, the details of patients provided financial assistance so far;
- (b) the measures taken/proposed to be taken by the Government to ensure that these patients, particularly those who have already benefited from initial funding, received uninterrupted and continued access to life sustaining therapies; and
- (c) the timeline fixed for addressing this funding gap and establishing sustainable solution for rare disease patients as they require lifelong treatment?

**ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY
WELFARE
(SHRI PRATAPRAO JADHAV)**

(a) to (c) Health is a State Subject, therefore the primary responsibility of providing healthcare services is that of the respective State Governments. However, the Ministry of Health and Family Welfare (MoHF&W) provides support in strengthening the overall health infrastructure and healthcare services in the country. In respect of Rare Diseases, Financial support up to Rs. 50 lakhs per patient is provided under National Policy for Rare Diseases (NPRD), 2021 for treatment of patients suffering from identified Rare Diseases through the designated Centers of Excellence (CoEs). To bridge the gap, the Government promotes crowd funding for which MoHF&W has launched a “Digital Portal for Crowd Funding & Voluntary Donations for Patients of Rare Diseases”.
