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

LOK SABHA
UNSTARRED QUESTION No. 827
TO BE ANSWERED ON 7th FEBRUARY 2025

FINANCIAL SUPPORT FOR TREATMENT OF RARE DISEASE PATIENTS

827. ADV GOWAAL KAGADA PADAVI:

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

(a) whether the Government has announced one-time financial support of Rs. 50 lakh for the treatment of all rare disease patients in the middle of year 2022, if so, the details thereof;

(b) whether approximately 40 patients from at least three Centres of Excellence (COEs) have exhausted this onetime funding support of Rs. 50 lakh and are currently awaiting further assistance particularly for chronic conditions like Lysosomal Storage Disorders, despite repeated pleas from patients and their families and if so, the details thereof;

(c) whether considering the urgency, the Government has taken any measures to ensure uninterrupted and continued access to life sustaining therapies to rare disease patients, if so, the details thereof; and

(d) whether the Government is considering for having an emergency funding mechanism to bridge the gap as a long-term decision is required in the current financial support mechanism for rare disease patients and if so, the details thereof?

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

(a) to (d) Since Health is a State Subject, the primary responsibility of providing of healthcare services in the State is that of the respective State Government. However, the Ministry of Health and Family Welfare (MoHF&W) provide supports in strengthening the overall health infrastructure and healthcare services in the country. In respect of Rare Diseases, Financial support upto Rs. 50 lakhs per patient is provided under National Policy for Rare Diseases (NPRD), 2021 for treatment of patients suffering from identified Rare Diseases including Lysosomal Storage Disorders, through the Centers of Excellence (CoEs) identified by MoHF&W. 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″.

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