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

RAJYA SABHA
UNSTARRED QUESTION NO. 2658
TO BE ANSWERED ON 12TH AUGUST 2025

NON-PROVISION OF SUSTAINABLE SUPPORT FOR CHRONIC RARE DISEASE PATIENTS

2658. SMT. MAUSAM B NOOR:

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

(a) whether the Ministry is aware that over 50 patients, mostly children, have reportedly died while awaiting treatment despite being eligible and registered under the National Policy for Rare Diseases (NPRD), 2021;
(b) whether the Ministry acknowledges that ₹ 50 lakh one-time cap for funding under the National Policy for Rare Diseases (NPRD), 2021 is inadequate for patients requiring lifelong therapy for certain chronic, rare disease conditions; and
(c) if so, the steps being taken to move from a one-time disbursal model to a sustainable, long-term funding framework for Groups?

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

(a) to (c) Health being a State subject, the primary responsibility of providing healthcare services is that of the State Governments. However, to mitigate the challenges posed by rare diseases in India, Ministry of Health and Family Welfare has framed National Policy for Rare Diseases (NPRD), 2021 which facilitates financial assistance up to Rs. 50 lakhs per patient for treatment of 63 identified Rare Diseases in 14 designated Centers of Excellence (CoEs). The prescribed financial assistance has been given to all eligible patients who have been recommended by the Rare Disease Committee (RDC) of the CoE based on clinical examination of the patient and Guidelines dated 11.08.2022. To bridge the gap, the Government has launched a "Digital Portal for Crowd Funding & Voluntary Donations for Patients of Rare Diseases" which can be accessed through https://rarediseases.mohfw.gov.in/.

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