

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

**RAJYA SABHA
UNSTARRED QUESTION No. 1087
TO BE ANSWERED ON 28th JULY 2026**

EXORBITANT COST OF TREATMENT OF RARE DISEASES

1087 # SMT. PHULO DEVI NETAM:

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

- (a) whether it is a fact that the cost of treatment for several rare diseases, including Spinal Muscular Atrophy, Amyotrophic Lateral Sclerosis/Motor Neuron Disease and Myasthenia Gravis in the country runs into crores of rupees per annum, which is completely beyond the reach of the common citizens;
- (b) the present status of the one-time financial assistance of ₹50 lakh provided to eligible patients under the 'National Policy for Rare Diseases' (NPRD) and the number of patients benefitted thereunder during the last two years; and
- (c) whether Government is considering complete exemption from customs duty and GST levied on life-saving drugs?

ANSWER

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

- (a) Spinal Muscular Atrophy (SMA) is identified as a Rare Disease under the National Policy for Rare Diseases (NPRD), 2021 which may involve high-cost therapies. However, Amyotrophic Lateral Sclerosis/Motor Neuron Disease and Myasthenia Gravis are not covered under this policy.
- (b) Under the NPRD, 2021, financial assistance of up to ₹50 lakhs is provided as per the extant guidelines for treatment of patients suffering from Rare Diseases identified under the policy. The fund is released based on the recommendation of the Rare Disease Committee at the designated Centers of Excellence (CoEs). More than 1700 patients have benefitted under this policy during the last two years.
- (c) The Government already provides complete exemption from Basic Customs Duty (BCD) and Integrated Goods and Services Tax (IGST) on drugs, medicines and Food for Special Medical Purposes (FSMP) for treatment of Rare Diseases identified under the policy, for personal use or use through the designated CoEs, subject to extant rules.
