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

RAJYA SABHA UNSTARRED QUESTION No. 897 TO BE ANSWERED ON 11th FEBRUARY 2025

ONE-TIME ASSISTANCE FOR TREATMENT UNDER NPRD

897. SHRI HARIS BEERAN:

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

- (a) whether ₹ 50 Lakhs one-time assistance for the treatment (one-time assistance) is provided under the National Policy for Rare Diseases (NPRD) of 2021, if so, the details thereof;
- (b) whether the Spinal Muscular Atrophy (SMA) patients are eligible for the ₹ 50 lakhs onetime assistance, if so, the details thereof;
- (c) the number of SMA patients applied for ₹ 50 lakhs assistance from 1st July 2021 to 31st December 2024; and
- (d) the number of SMA patients obtained the assistance and the amount disbursed for SMA patients during that period?

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

(a) to (d) Under National Policy for Rare Diseases (NPRD), 2021, financial assistance up to Rs. 50 lakhs is provided for treatment of patients suffering from any of the 63 identified rare diseases in 13 Centers of Excellence (CoEs). Spinal Muscular Atrophy (SMA) is categorized in Group 3 of Rare Diseases as per NPRD, 2021. As per provisions of NPRD, the financial assistance is provided based on the recommendation of the Institutional Rare Disease Committee of the CoEs. As per available data, 166 patients have received treatment under various schemes of Central and State Governments including NPRD.
