

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

**LOK SABHA  
UNSTARRED QUESTION No. 2381  
TO BE ANSWERED ON 13<sup>th</sup> FEBRUARY 2026**

**TREATMENT OF SPINAL MUSCULAR ATROPHY**

**2381. DR. BYREDDY SHABARI:**

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

- (a) the number of Spinal Muscular Atrophy (SMA) cases reported in the country during the last five years, State-wise, including Andhra Pradesh;
- (b) whether the Government acknowledges that infants belonging to economically weaker families are unable to access SMA gene therapy due to its cost of about 16 crore per injection and if so, the details thereof;
- (c) whether the National Policy for Rare Diseases adequately covers ultra-expensive life-saving treatments required for infants suffering from SMA and if so, the details thereof;
- (d) whether the Government proposes to extend financial support, special approvals or negotiated pricing mechanisms for SMA gene therapy and if so, the details thereof; and
- (e) the steps taken or proposed to be taken by the Government to strengthen early diagnosis, newborn screening and genetic counselling for SMA across the country, including Andhra Pradesh?

**ANSWER**

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

- (a) 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 disease patients in India, the Government has framed the National Policy for Rare Diseases (NPRD), 2021. Under NPRD, more than 1125 Spinal Muscular Atrophy (SMA) patients have been registered since 2021 from across the country, including Andhra Pradesh.
- (b) As on date, 63 rare disease are identified under NPRD. Spinal Muscular Atrophy is categorized as Group-III rare disease with a prohibitive treatment cost. Some of the steps taken by the Government to support rare disease patients are as follows:
  - ◆ NPRD facilitates financial assistance of up to Rs. 50 lakhs for treatment of identified rare diseases through the designated Centers of Excellence (CoEs). As per NPRD guidelines, treatment and fund allocation to each patient is decided by the dedicated Rare Disease Committee in each CoE after clinical examination on case-to-case basis, irrespective of any income criteria.

- ◆ Exemption from Basic Customs Duty (BCD) and Integrated Goods & Services Tax (IGST) is extended to rare diseases' drugs, medicines and Food for Special Medical Purposes (FSMP), subject to the extant rules.
- ◆ For financial assistance of high-cost rare diseases, a “Digital Portal for Crowd Funding & Voluntary Donations for Patients of Rare Diseases” has also been launched to fill the funding gap between the Government assistance and the actual treatment cost.

(c) and (d) Vide Order dt. 04.10.2024 in W.P.(C) 5315/2020 & CM APPL. 19189/2020, 4237/2023, Hon'ble High Court of Delhi issued certain directions to the Government regarding adequacy of the Rs. 50 lakh cap for high-cost treatment of some rare diseases. However, that Order was stayed by the Hon'ble Supreme Court vide Order dt. 09.12.2024 in Petition for Special Leave to Appeal (C) No. 28777/2024, wherein the Court directed the Government to comply with the extant terms and conditions of NPRD. Therefore, the matter is sub judice in the Apex Court.

(e) The Government encourages and support the State Governments in implementation of a targeted preventive strategy through the CoEs. Some of the steps taken by the Government are as follows:

- ◆ Under NPRD, the CoEs are mandated to perform Antenatal Screening, Neonatal Screening (specified disorders), High-Risk Screening (Antenatal, newborns and children) etc. as methods of prevention and control of rare diseases.
- ◆ The CoEs are also given one-time financial support of up to Rs. 5 crore for procurement of equipment for strengthening patient care services for screening, diagnosis and prevention (prenatal diagnosis) of rare diseases.

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