

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

**RAJYA SABHA
UNSTARRED QUESTION NO. 1097
TO BE ANSWERED ON 29TH JULY 2025**

TREATMENT OF LSDs

1097. SHRI IMRAN PRATAPGARHI:

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

- (a) whether Government is aware that despite allocating over ₹205 crore between Financial Year 2022 and 2025, treatment uptake for Lysosomal Storage Disorders (LSDs) remains critically low, with less than 20 per cent of eligible patients receiving therapy;
- (b) the key reasons identified by the Ministry for the gap between funds disbursed and actual treatment provided;
- (c) the accountability mechanisms in place for underperforming Centres of Excellence (CoEs) that have received substantial funding yet continue to report high number of untreated patients; and
- (d) whether the Ministry proposes to conduct timely audits of these CoEs?

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

(a) to (d) 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 that facilitates financial assistance up to Rs. 50 lakhs per patient for treatment of 63 identified Rare Diseases categorised in 3 groups, including Lysosomal Storage Disorders (LSDs), in 13 designated Centers of Excellence (CoEs). Since Financial Year 2022-23, Rs. 290.62 (approx.) crore have been released under NPRD to the CoEs for treatment, purchase of consumables, purchase of equipments etc. The treatment has been given to all eligible patients suffering from identified rare diseases who have been recommended by the Rare Disease Committee (RDC) of the CoE based on clinical examination of the patient as per Rare Disease guidelines dated 11.08.2022. The CoEs are audited regularly through internal audit and CAG audit mechanism.
