

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

**LOK SABHA
UNSTARRED QUESTION NO. 4625
TO BE ANSWERED ON 28th MARCH 2025**

TIMELY INTERVENTION FOR RARE DISEASE PATIENTS

**4625. MS. PRANITI SUSHILKUMAR SHINDE:
SHRI VISHALDADA PRAKASHBAPU PATIL:**

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

- (a) whether many rare disease patients, especially children with Lysosomal Storage Disorders, require timely intervention; and
- (b) if so, the details thereof and the steps being taken by the government in this regard?

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

(a) and (b) Ministry of Health and Family Welfare has framed National Policy for Rare Diseases (NPRD), 2021. Under the policy, 63 disorders including Lysosomal Storage Disorders (LSDs) such as the Gaucher's, Pompe and Fabry diseases are categorized as Rare Diseases. 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, financial assistance up to Rs. 50 lakhs per patient is provided for treatment of Rare Diseases in the Centers of Excellence (CoEs) under NPRD, 2021. 13 Centers of Excellence (CoEs) have been identified, which are premier Government tertiary hospitals for diagnosis, prevention and treatment of rare diseases. The CoEs have also been provided with funds for infrastructure strengthening. Further, full exemption from Basic Customs Duty (BCD) and Integrated Goods and Services Tax (IGST) is provided on Drugs or Medicines imported for treatment of persons suffering from rare diseases, if imported by an individual, for personal use or through CoEs, for treatment of rare disease.
